



PAEDIATRICS

A NATIONAL MODEL OF CARE FOR PAEDIATRIC HEALTHCARE SERVICES IN IRELAND

CHAPTER 44: PAEDIATRIC SPECIALIST REHABILITATION



Féidhmeannacht na Seirbhíse Sláinte
Health Service Executive

Clinical Strategy and Programmes Division



**ROYAL
COLLEGE OF
PHYSICIANS
OF IRELAND**

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44.1 INTRODUCTION

Paediatric specialist rehabilitation (PSR) represents the coordinated integration of medical, social, educational and vocational services to enhance a child's functioning and societal participation. While it is acknowledged that children present with rehabilitative needs arising from a wide spectrum of illness/injury, this chapter focuses specifically on specialist rehabilitation services after acquired neurological injury, limb absence and complex trauma or illness.

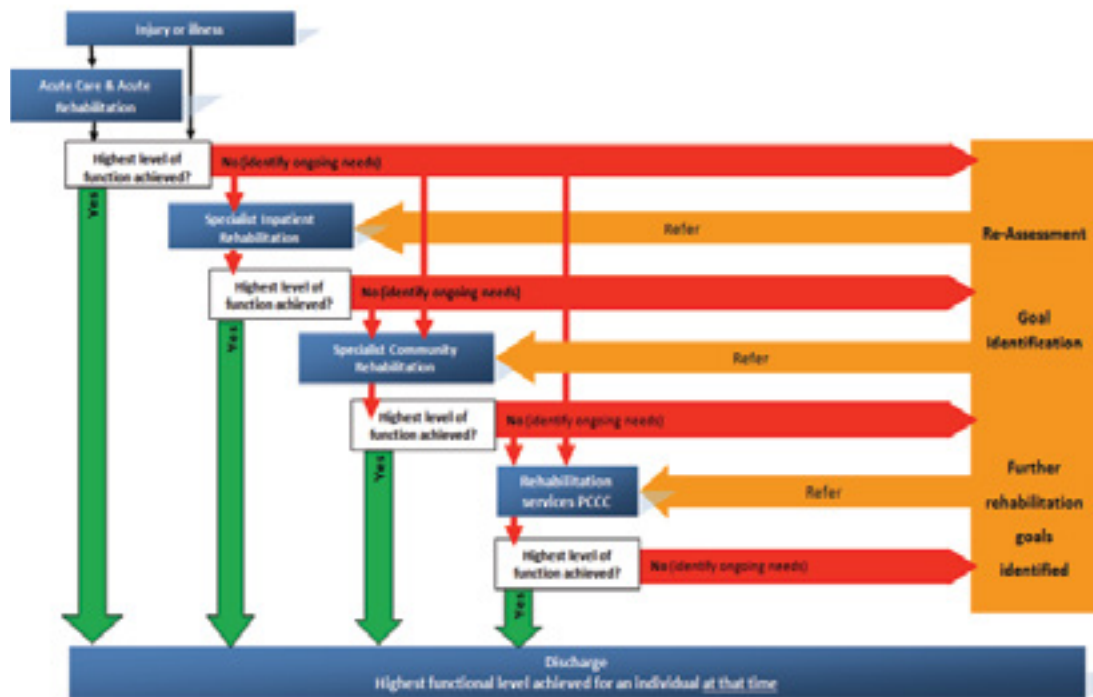


Figure 44.1 Adapted from the Victorian Paediatric Rehabilitation Service Model of Care (2012)

Ideally, PSR services are delivered by interdisciplinary teams (IDT) across the continuum of care to ensure coordinated referral and discharge pathways with community providers, and to ensure that children with long-term needs receive expert follow-up particularly around critical points of transition (State of Victoria Department of Health, 2012). The model of care described in this chapter is based on the principles of the Victorian Paediatric Rehabilitation Service (VPRS):

- To provide each child with the most appropriate care
- To support a child/adolescent-centred and family-focused model of care
- To encourage and support continuity of care
- To encourage appropriate transition from inpatient and ambulatory settings and optimise community reintegration

Policy and Drivers for Change

This chapter takes note of the following key policy documents:

Name	Relevance
National Policy and Strategy for the Provision of Neuro-rehabilitation Services in Ireland 2011-2015 (DoHC, HSE 2011) ¹	Growth and development are recognised as key factors in identifying objectives and success in children's neuro-rehabilitation; emphasis is placed on maximising function with reference to developmental milestones
Rehabilitation Medicine Programme Model of Care (HSE, RCPI 2015)	Sets out a strategic framework for specialist rehabilitation services for adults, with many concepts transferable to paediatrics including: (i) levels of specialism (ii) clinical rehabilitation networks and (iii) access, quality and outcome measures
Progressing Disability Services for Children and Young People Programme (Health Service Executive, 2010)	Suite of reports accessible online at www.hse.ie/progressingdisabilityservices/ : <ol style="list-style-type: none"> 1. Report of the Reference Group on Multidisciplinary Services for Children aged 5 to 18 years, December 2009 2. Outcomes for Children and their families 2013 3. Framework for Collaborative Working between Education and Health Professionals 2013 4. Report on the Findings of Consultation on draft Outcomes Statements 2013
WHO Convention on the Rights of Persons with Disabilities (WHO 2006)	Priority should be given by signatory states to ensure access to appropriate, timely, affordable and high quality interventions for those who need them. Although Ireland is one of the 82 signatories to the Convention it has not yet formally acknowledged the optional protocol, nor has it ratified the Convention

Table 44.1 Relevant Policy Documents

¹ Cited as the 2011 Neuro Rehabilitation Strategy in the remainder of this chapter

Demographic Information

There is no national data available in relation to incidence or prevalence rates for children presenting with acquired neurological injury and complex trauma or illness. However there is some limited data on numbers of children presenting to tertiary centres with ABI, SCI and limb absence.

Acquired Brain Injury (ABI), which includes injury from traumatic and non-traumatic causes, is a leading cause of disability worldwide. Figures from the UK suggest an incidence rate of approximately 450 per 100,000 for all childhood head injury based on Emergency Department (ED) attendances, of which 40-50 per 100,000 (10%) will sustain a moderate to severe brain injury with temporary or lasting neurological sequelae (Yates et al., 2006). These figures do not include children who sustain an ABI from non-traumatic origins, such as strokes and brain tumours, and children who do not present to ED.

Children with ABI often have lifelong and changing needs. There is an increasing awareness of the potential long-term cognitive and psycho-social effects of mild TBI and concussion injuries. However, rates are unknown and mild injuries are often undiagnosed or unreported.

Extrapolating from international childhood SCI epidemiological figures one could expect an annual incidence of four and a prevalence rate of 25 in Ireland. The tertiary centre² receives referrals on almost all children who have sustained significant spinal injuries in Ireland and provides services to 40 children at any one time.

The number of children who present and continue to attend the tertiary centre for rehabilitation and prosthetic provision is in line with international incidence rates for congenital paediatric limb absence of seven in 10,000 live births (Michael et al., 2015). Reliable data concerning prevalence of traumatic amputation in childhood is unavailable.

² National Rehabilitation Hospital (NRH) Paediatric Family-Centred Rehabilitation Programme

44.2 CURRENT NATIONAL SERVICE PROVISION

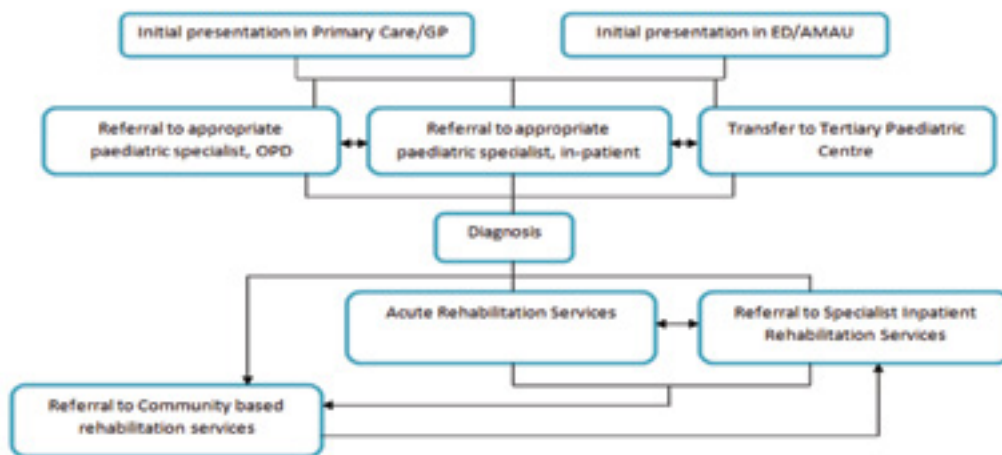


Figure 44.2 Patient Pathways

Figure 44.2 presents a range of potential pathways for children presenting with rehabilitative needs after serious illness or injury.

44.2.1 Tertiary Services for Paediatric Specialist Rehabilitation

There is at present no defined acute rehabilitation facility in tertiary paediatric hospitals in Ireland. The Paediatric Programme at the NRH is the tertiary service for provision of post-acute complex specialist rehabilitation for patients with disability resulting from acquired neurological injury and limb absence. Referrals are received from all acute paediatric hospitals and neurosurgical units across Ireland for admission to a 5-day in-patient unit or to out-patient programmes incorporating many of the services listed in Appendix 1.

Emergency departments (EDs) refer some 14-18 year olds presenting with concussion with persisting cognitive and/or behavioural sequelae. Referrals are also accepted directly from general practitioners. There are some joint pathways between the adult and paediatric clinical teams in the tertiary centre with regard to management of care and transition to adult specialist rehabilitation services.

Demand on the service has greatly increased in recent years with a higher number of referrals in addition to an increase in the complexity and acuity of those referrals. Demand now outweighs capacity by a factor of four to one.

	2011	2012	2013	2014	Cumulative case load
SCI (spinal cord injury)	4	4	4	16	40
ABI (acquired brain injury)	32	35	35	43	210
POLAR (limb absence, congenital and acquired)	4	1	1	1	50 (shared with adult service)

Table 44.2 NRH Paediatric Referral Numbers 2011 – 2014

44.2.2 Shared Care

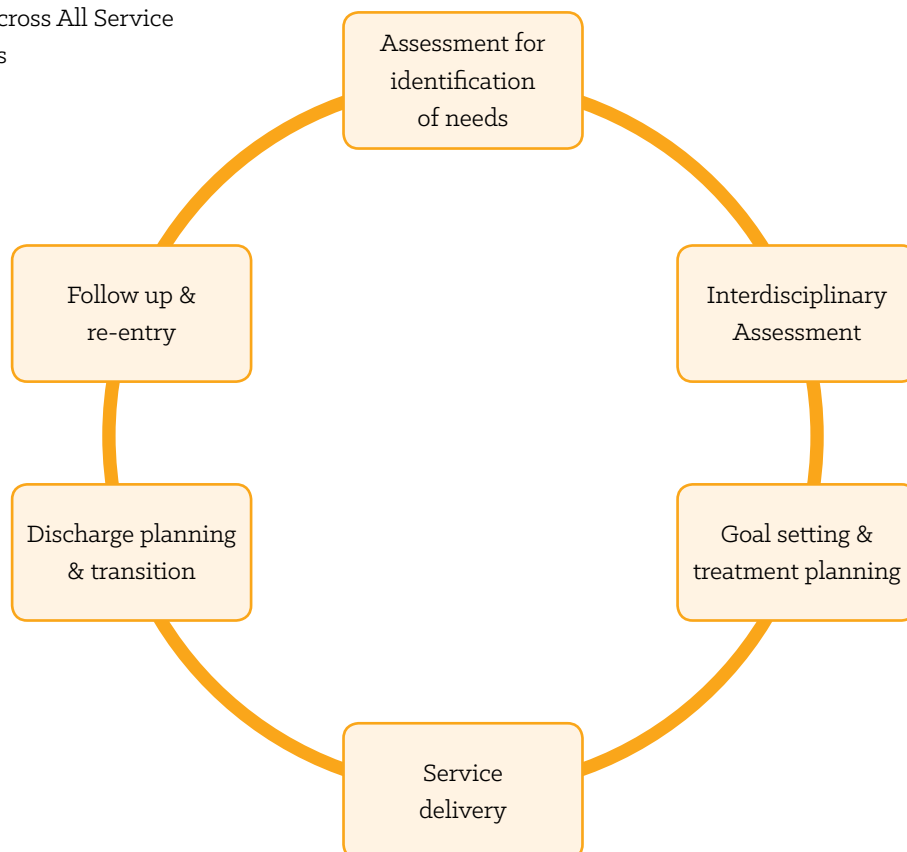
There are already many examples of shared care in place for this patient group outlined in the 2011 Neuro Rehabilitation Strategy document. Implementation of Progressing Disability across Ireland is starting to support collaborative working between specialist rehabilitation services and community services to develop care pathways to ensure continuity of care.

Some children with ABI present with complex lifelong and changing needs, and require ongoing access to specialist services that are not available in the community. As an example, paediatric neuropsychology, which is central to mapping a child’s changing cognitive and learning needs after ABI, can only be accessed in acute hospitals and the tertiary specialist rehabilitation centre.

44.3 PROPOSED MODEL OF CARE

44.3.1 Rehabilitation Without Walls

Figure 44.3 Rehabilitation Process
Applicable Across All Service
Delivery Sites



In June 2014, the development board of the new children's hospital, the National Rehabilitation Hospital and the National Clinical Programmes for Paediatrics and Rehabilitation reached a consensus decision that the NRH would continue to host the national centre for post-acute paediatric specialist rehabilitation. The new children's hospital will host an 8-bedded³ acute rehabilitation unit on site.

Patients need different levels of expertise and specialisation at different stages in their rehabilitation journey. This three-tier model which outlines levels of complexity of need forms the basis for the provision of specialist rehabilitation services in the UK and Ireland (HSE CSPD, RCPI 2015) and is adapted below for PSR. Although service-users may require support from different services as they progress, the transition between services should be facilitated by information-sharing to ensure seamless delivery of care.

A comprehensive PSR service comprises the following key elements:

1. Acute rehabilitation carried out alongside or immediately after active medical or surgical investigation and treatment
2. Tertiary specialist rehabilitation when possible with re-entry as needed
3. Long term management delivered by the Community Disability Team, as the initial point of contact or after tertiary centre treatment.

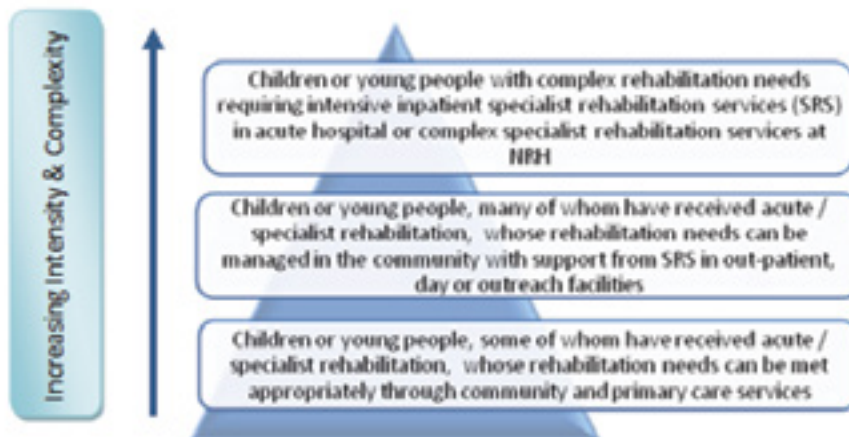


Figure 44.4 Levels of Rehabilitative Care in PSR

Core rehabilitation principles should include:

- Early referral for specialist rehabilitation assessment (within 48 hours)
- Shared care between medical specialist groups
- Initiation of acute rehabilitation after initial resuscitation and definitive medical/surgical interventions
- Appropriate levels of clinical input to provide complex, high intensity intervention in line with well-validated international staffing ratios
- Interdisciplinary, inter-professional model of working delivered by teams of specialist clinicians trained in acute rehabilitative care

³ Proposed number at time of writing mid-2015

44.3.2 Acute Rehabilitation

Timely acute rehabilitation exploits plasticity and reduces the potential for complications (Gutenbrunner et al., 2007). There is grade A evidence that acute rehabilitation leads to reduced length of stay (LOS) in hospital and improved outcomes (Turner-Stokes, 2008). Acute rehabilitation should be available to children admitted to hospital with severe injury or illness that may result in disability. Paediatric rehabilitation services can be delivered in acute hospital settings using a range of models outlined in table 44.3.

Model	Activity	Clinical Advantages	Challenges
Rehabilitation beds in acute paediatric hospitals	Transfer of children to rehabilitation beds within the acute paediatric hospital	<ul style="list-style-type: none"> • Early exposure to RM clinical activity and • rehabilitation principles • RM clinicians integrated into acute hospital governance systems 	<ul style="list-style-type: none"> • Early access to acute beds maintained only if post-acute bed capacity is sufficient and well-managed
Mobile rehabilitation medicine (RM) team within the paediatric hospital	RM team working solely within the acute paediatric hospital visiting patients	<ul style="list-style-type: none"> • Possible to consult on larger numbers of patients with a wider range of conditions • Effective liaison between team and acute clinicians 	<ul style="list-style-type: none"> • Reduced clinical control for RM team • No RM team available out of hours
RM consults to acute wards in paediatric hospitals	RM physician from stand-alone RM centre reviews children in acute beds	<ul style="list-style-type: none"> • Larger numbers of patients with a wider range of conditions reviewed 	<ul style="list-style-type: none"> • Reduced clinical control for RM team • RM physician not on site

Table 44.3 Adapted from BSRM / RCP Medical Rehabilitation in 2011 and Beyond

44.3.3 Tertiary Specialist Rehabilitation

CARF⁴ standards for post-acute paediatric specialist rehabilitation provide a benchmark for excellence in service provision. The NRH Paediatric Programme is accredited by CARF and its services are listed in appendix 1. A RAG analysis⁵ of national tertiary services is presented in Appendix 2.

44.3.4 Community Disability Services

As Progressing Disability is rolled out across Ireland it is expected that specialist tertiary rehabilitation services⁶ will work collaboratively with community services to develop care pathways to support the continuum of care.

Community rehabilitation teams, whose development will be strongly supported by the implementation of the 2011 Neuro Rehabilitation Strategy, will deliver multidisciplinary, goal based therapy of moderate intensity. The focus of these services is and will be to maintain functional ability and support participation in society and everyday activities through reiterative intervention as needed.

⁴ Commission for Accreditation of Rehabilitation Facilities www.carf.org (accessed 14th July 2015)

⁵ 'Red, Amber, Green' project management tool in appendix 2, page 14

⁶ Acute beds in the New Children's Hospital and post-acute unit in the NRH

43.3.5 Service Delivery Components for PSR Services

The main features of an ideal PSR service are summarised below. The service should be supported by an electronic clinical rehabilitation management system which enables secure and timely transfer of clinical information between all stakeholders and across agencies.

Access / referral / assessment / outreach

- Timely referral management
- Telephone advice available during the five day working week from the specialist interdisciplinary team to acute care facilities, community services, and children and families already receiving PSR services
- Timely assessment of the child or young person before their admission to the PSR service
- Joint assessments with staff from other health agencies at specialist or outreach clinics and community interdisciplinary team (IDT) meetings

In-patient treatment

- Timely goal-setting by a full IDT involving parents and taking note of patient-focussed clinical outcomes and national process outcomes
- High-quality discharge planning initiated during pre-admission assessment, involving close liaison with other specialist and community rehabilitation services, and development of formal shared care arrangements across the three levels of service delivery

Out-patient, follow-up and transition

- Monitoring of long-term conditions using appropriate assessment measures delivered at out-patient clinics, telephone consultations and shared care arrangements
- Community or centre-based outpatient therapy to prevent hospitalisation and/or reduce length of stay
- Transition clinics and IDT meetings with adult specialist rehabilitation services

Education and support

- Services work with family to assist them in making informed decisions about their child's services and supports. The strengths and needs of all family members are considered.

44.4 REQUIREMENTS FOR SUCCESSFUL IMPLEMENTATION

44.4.1 Infrastructure for Specialist Services

Dedicated wards: Acute: at least 8 beds in NCH Post-acute: 8 in-patient & 2 day-care beds in new NRH	Communal dining & leisure areas for patients	Quiet room for interviews
IDT out-patient consultation rooms	Play space	Office space for staff
Extensive therapy space	Multisensory space	Parent accommodation
Hospital School	Meeting room	Access to hydrotherapy
Telemedicine facilities	Information management systems	

Table 44.4 Infrastructure Requirements for Delivery of Specialist Rehabilitation Services

44.4.2 Human Resources

The table below outlines recommended team resources for (i) an 8-bed acute rehabilitation facility in the new children's hospital and (ii) 7-day inpatient, out-patient and outreach services at the NRH. By way of comparison current staffing levels for the existing 5-day in-patient tertiary unit are presented.

Professional title	Acute (new children's hospital) Min 8 beds	Tertiary centre	
		Current WTE 5-day service	Recommended WTE 7-day service + outreach + outpatients
Consultant Paediatrician with expertise in Paediatric Neurodisability	1.0	0.17	1.0
Paediatric Orthopaedic Surgeon	On-site	None	0.2
Paediatric Urology	On-site access	None – access to Adult Urologist	0.2
SpR / Reg / SHO (NCHD)	1 SpR and shared SHOs	0.13	1.0
Paediatric Nurses (ward and day cases)	12.0	7.0	10
Healthcare Assistant	4.0	2.0	3.0
Liaison coordinator (nurse/HSCP)	1.0	1.0	2.0
Programme Manager		0.7	1.0
Speech & Language Therapist	1.0	1.0	3.0
Physiotherapist	2.0	1.0	4.0
Hydro- and Sports therapists		0.1	0.5
Occupational Therapist	2.0	1.0	4.0
Therapy Assistants	2.0	0.5	2.0
Clinical Neuropsychologist	1.0	0.6	3.0
Assistant Psychologist	On-site access	0.1	0.5
Medical Social Worker (case manager)	1.0	0.8	4.0
Music Therapist	1.0	0.3	2.0
Programme Administration	0.5	1.0	1.0
Prosthetist/orthotics/splinting	On-site access	0.2	0.5
Dietitian	1.0	0.1	0.5
Pharmacy	On-site access	0.1	0.25
Play Therapist	On-site access	0	1.0

Table 44.5 Clinical Staffing for Paediatric Specialist Rehabilitation Services

⁷To be included in the MSW role

44.4.3 Education and Training for Specialist Rehabilitation Teams

- All clinical staff must maintain their competency in paediatric care, child development and management of chronic conditions in childhood. Specific staff grade and senior grade competencies in these areas in addition to assessment and interventions for children with ABI, SCI and limb absence are a requirement.
- Competency-based education in these areas should be delivered through a combination of internal (senior neurological paediatric clinicians) and external education. A clinical supervision structure should be in place.
- Clinical caseloads should be supported in line with international recommendations to ensure delivery of services within staff capacity and the required intensity to deliver goal-orientated rehabilitation (for example BSRM guidelines 1:5 for PT/OT/SLT).
- PSR team members should have competencies in rehabilitation of complex neurological conditions such as acquired brain injury and spinal cord injury.
- Post-graduate education in the field of paediatric neurological rehabilitation (such as that available in the UK) is desirable and should be supported.
- Posts for advanced practice clinicians and clinical specialists in paediatric neurological rehabilitation should be developed.
- Rotation of clinicians between acute and post-acute rehabilitation should be developed in order to increase education and competency across the continuum of care and create pathways between services.
- Specific cases can present invaluable opportunities for joint education and learning between clinicians in regional and tertiary services.

44.5 PROGRAMME METRICS AND EVALUATION

The PSR service aims to improve (a) the quality of care delivered to children referred to the service (b) access to specialist services and (c) value.

These aims are presented below in smaller, more measurable, objectives:

Quality

1. Improve safety and quality through agreement of pathways that reflect best practice in paediatric specialist rehabilitation
2. Improve liaison with community colleagues as part of the tertiary centre's obligation to support delivery of expert, needs-based care in the child's local environment
3. Improve patient experience
4. Achieve desired clinical outcomes in line with international outcome measurement and targets (CARF)

Access

1. Develop improved referral processes to ensure children are seen in the right place, by the right person at the right time
2. Identify resource gaps in paediatric specialist rehabilitation that will directly impact on ability to achieve national standards with respect to waiting times

Value

1. Reduced length of stay in the acute hospital
2. Improved management of the child's ongoing needs in out-patient and community services to avoid unnecessary hospital admission

Table 44.6 PSR Service Objectives

44.6 KEY RECOMMENDATIONS

- Each child will receive person-centred and family-focused appropriate care
- Children will receive different levels of expertise and specialisation at different stages in their rehabilitation journey:
 - Acute rehabilitation will be carried out alongside or immediately after active medical or surgical treatment (acute rehabilitation facility new children's hospital)
 - Tertiary specialist rehabilitation will continue to be provided in the NRH
 - Community rehabilitation teams will deliver intermittent, multidisciplinary, goal based therapy of moderate intensity.
- Quality of care, access to specialist services and value will be measured and monitored

44.7 ABBREVIATIONS AND ACRONYMS

ABI	Acquired Brain Injury
BSRM	British Society of Rehabilitation Medicine
CARF	Commission for Accreditation of Rehabilitation Facilities
CSPD	Clinical Strategy and Programme Directorate
EAT	Electronic Assistive Technology
ED	Emergency Department
HSCP	Health and Social Care Professional
HSE	Health Service Executive
IDT	Interdisciplinary Team
LOS	Length of Stay
NCHD	Non-Consultant Hospital Doctor
NRH	National Rehabilitation Hospital
OT	Occupational Therapy
PT	Physiotherapy
PRS	Paediatric Specialist Rehabilitation
PSR	Paediatric Specialist Rehabilitation
RAG	Red, Amber, Green
RCP	Royal College of Physicians
RCPI	Royal College of Physicians of Ireland
RM	Rehabilitation Medicine
SCI	Spinal Cord Injury
SHO	Senior House Officer
SLT	Speech and Language Therapy
SpR	Specialist Registrar
UK	United Kingdom
VPRS	Victorian Paediatric Rehabilitation Service
WTE	Whole Time Equivalent

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44.9 APPENDICES

Appendix 1: NRH Paediatric Programme services

Inpatient	The NRH Paeds Programme has been funded and staffed solely as a 5-day in-patient programme (8 beds - 6 inpatient beds and 2 day places), with minimal change in staffing or resources since 1972. Patients are assessed and treatment goals are set in collaboration with the child/young person and their family taking into consideration the complexity of their needs. Regular reviews and family meetings are scheduled with social workers acting as the key workers.	
Outpatient department (OPD)	Four interdisciplinary (IDT) specialist spinal cord injury (SCI) clinics, held jointly with the adult SCI consultant, offer annual review to all children with SCI. The NRH Paeds Programme provides in-reach to the adult POLAR team in respect of children with limb loss. Interdisciplinary out-patient review is provided to children with ABI on request only due to resource deficits, although best practice recommends they should be reviewed at key stages in their development and/or as required.	
NRH Paediatric Outreach	This outreach service is a partnership model that sits at the interface between tertiary services and local providers and is offered to children with a range of highly complex physical, cognitive and behavioural needs at pre-admission or discharge. It facilitates return to home and school through visits to acute hospitals, regional outreach clinics, home and phone advice to local disability services. Some services are provided to each child until they are no longer required or until the patient is transferred to adult or local community services if the relevant expertise is available.	
Other available NRH facilities	<ul style="list-style-type: none"> -Electronic Assistive Technology (EAT) Clinic -Driving assessment service -Paediatric vocational assessment -Real life / contextual rehabilitation -Recreational Therapy -Sexuality and disability service -Specialist splinting service -Specialist wheelchair / seating assessment -Sports and Exercise Therapy -Therapeutic Garden 	<ul style="list-style-type: none"> -Adapted kitchen -Dietetics -Discharge planning -HSE Dentist -Hydrotherapy -Orthoptist -Pharmacy -Radiology -Woodwork

Appendix 2: RAG Analysis

Paediatric Specialist Rehabilitation Service best practice standards (limited information from acute hospital sites)	<p style="text-align: center;">Current Status in Ireland</p> <p style="text-align: center;"> ■ Significant Deficiency ■ Partial compliance ■ Standard achieved </p>
Entry to service	
Pre-admission assessment of patients referred for specialist rehabilitation in a timely manner depending on client needs	All patients referred are assessed from a waiting list to identify needs by the Consultant, Liaison Nurse and IDT members.
Telephone advice from the specialist Interdisciplinary Team (IDT) for both acute care facilities and community-based teams and services	The liaison nurse is the primary point of contact for external agents; available Mon - Fri, 9-5 only. Direct contact with the team is arranged as required.
Out-patient assessment of new patients referred for specialist rehabilitation	IDT out-patient assessment of new referrals occurs but with long waiting times
Community or centre-based outpatient therapy for patients whose needs can be met on this basis to prevent hospitalisation or reduce length of stay	The service has capacity to treat in-patients and day patients. Limited out-patient services are available.
Within the service	
Management by a co-ordinated IDT team consisting of appropriate medical, nursing and HSCP staff	See staffing composition in table 4.2; recommended WTE provision will allow optimal service delivery
Each family is the constant in the child's life and experts on the child's abilities and needs.	The NRH Paediatric Programme has gained international accreditation as a family-centred service.
Involvement of patients and parents in setting realistic and achievable meaningful goals	All children, and their families, participate in a comprehensive interdisciplinary assessment. Patient / family engagement is key requirement for CARF accreditation.
In-patient assessment and treatment of patients requiring intensive neurorehabilitation	Long waiting times for admission, in some cases more than 9 months
Access to therapies at a level appropriate to the child's needs in a suitable environment with family-friendly facilities	Following initial assessment, the intensity and range of services required are agreed and detailed in the treatment proposal.
Access to education and socialisation opportunities	The school is currently on site but will not transfer to the new hospital.
Psychological support for children, siblings and their families	Dedicated clinical neuropsychology service in addition to family supports available through medical social work.
Access to child and adolescent psychiatric services where appropriate	None available on site – NCH or NRH
Detailed planning for discharge from in-patient setting initiated on admission; timely discharge	High demand for home care packages and community rehabilitation often delays discharge despite timely assessments
Continuing care and liaison with community services	

Joint in-patient and outreach assessments and clinics and IDT meetings in the community	Some shared clinics with adult services are facilitated on-site. Clinics with other service providers are limited by lack of specialist paediatric and adult resources.
Monitoring of the condition throughout childhood and adolescence Capacity for re-assessment and further treatment if required	Children with SCI engage in a structured annual review programme; Post-discharge ABI patients receive outreach and outpatient crisis management only; capacity for home and school visits is limited
Excellent communication with community health, educational and social care services	Engagement is not systematic and is delivered on request only
Specialist outreach advice and support of patients requiring high level neuro- rehabilitation support within the community	NRH outreach supports community teams in managing the complex rehabilitation needs of some children. Capacity to deliver this is severely limited.
Provision of specialist advice and support to community professionals, other relevant agencies and educational facilities	Engagement is not systematic and delivered on request only
Transition clinics and IDT meetings with adult neuro-rehabilitation services.	Children with SCI transition to adult services through a series of joint clinics. Similar pathways need to be identified for children with ABI and other conditions