



PAEDIATRIC FAMILY-CENTRED REHABILITATION PROGRAMME

SCOPE OF SERVICE

Introduction

The **Paediatric Family-Centred Rehabilitation (PAEDS) Programme** established in 1972 is the tertiary service for provision of post-acute complex specialist rehabilitation for children and young people with disability resulting from acquired neurological injury and limb absence. Our goal is to maximize each child/young person's abilities and minimize the effects of their impairments.

The PAEDS Programme offers inpatient beds, day places and outpatient rehabilitation services. In effect, the PAEDS Programme encapsulates the specialist rehabilitation services of the three adult programmes at the NRH, delivering these to children and young people up to the age of 18 who require a complex specialised interdisciplinary rehabilitation intervention. It is a Comprehensive Integrated Inpatient Rehabilitation Programme (CIIRP) accredited by The Commission for Accreditation of Rehabilitation Facilities (CARF) and meets international best practice standards. The PAEDS Inpatient Programme has 6 beds that provide 24 hours, five-day-a-week (Monday – Friday) rehabilitation and nursing care with weekend leave at home.

The Day Programme accommodates 2 patients who can access the NRH on a daily basis for either a full rehabilitation programme similar to the In-patient or for previous patients returning for a review of their rehabilitation needs in the context of their natural growth and development.

Under the direction of the PAEDS Programme Manager and the Medical Director, the programme in conjunction with the persons served and their families/carers, provides individualised, goal-directed rehabilitation designed to lessen the impact of impairment and to assist children with neurological conditions to achieve their potential in terms of functional independence, social/ peer participation and community reintegration.

Continuum of Care – “Rehabilitation without Walls” approach

The continuum of care for children and young people with rehabilitation needs encompasses the in-patient, day-patient and out-patient phases with linkages to community service providers and follow-up care. The PAEDS’s vision of a “rehabilitation without walls” approach has led to a more child and family-centred and

Date Effective: 01/11/2007

Reviewed Version Date: 11/05/, Date: 01/05/, Date: 23/07/2013, draft revision 18/11/2014, Reviewed

Version Date: 25/04/2017

integrated approach. The PAEDS Programme provides for fluid movement between the services based on assessment of individual clinical need and social circumstances.

The PAEDS Programme has developed the continuum of care based on the national context within which we operate which includes fragmented community services, on ongoing national reconfiguration of community based disability services for children and plans for a new national children's hospital.

PAEDS Pre-admission services include the following:

- NRH Consultant Assessment/advice at acute care setting/other agency
- NRH Paediatric Liaison Nursing Assessment/advice
- Team Assessment/advice at acute care setting - *when appropriate*
- Consultant led pre-admission Assessment
- Non Consultant led Pre-admission Assessment - done by the team - *when appropriate*
- Pre-admission visits to unit for patients and families – mainly involving the social work and nursing services.

PAEDS Rehabilitation Interventions:

A key goal of Ireland's National Clinical Programme for Paediatrics, is to prevent unnecessary Hospital admissions for children. In line with this goal and to maximise the resources available, the PAEDS programme operates its services within a variety of "sub programmes" as follows:

1. **Full Rehab Programme (P1)** – children who are in for their main rehabilitation programme, whether in a bed or a day case slot. The programme is divided into 3 phases - Assessment phase leading to goal setting (2 weeks), the rehabilitation treatment phase (time set at goal setting) and the discharge/ outreach phase. The full programme meets CIIRP standards.
2. **The Assessment Programme (P2)** – for children who require a 2 week assessment with a particular goal e.g. to have a cognitive assessment which leads to support to the school. The child may be an in-patient or day patient.
3. **Specialist Programme (P3)** – children who are attending a group programme or summer camp e.g. Paeds Polar Day for peers support, secondary school transition program, carer education, support and information updates.
4. **OPD treatment Slots (P4)** – children who attending treatment slots with 2 or less therapies for up to 4 sessions e.g. children who need a few sessions on homework strategies or gait work following an SCI OPD clinic.

Children are "admitted" to one of these programmes and these categories are reflected in the waiting list management systems.

Outreach - There is a limited amount of outreach services integrated into the continuum of care as follows:

- Pre- admission outreach by the Paediatric Liaison Nurse and/or NRH Consultants
- Pre -admission outreach by the IDT in cases where the complexity of the child's condition indicates this approach e.g. visiting and advising on the care of a ventilated child with an SCI
- Outreach on P1/P2 children occurs during the programme

Date Effective: 01/11/2007

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- Outreach by the Paediatric Nursing Staff at 6 weeks post discharge by telephone to check in with the family
- Outreach by the IDT team following OPD treatment or reviews including liaison by phone, teleconference, case conferences etc with parents, community services, schools and other relevant agencies

In addition the PAEDS Programme has the following OPD Services:

Clinics

- ABI Review Clinics (established in 2016) – an IDT non consultant led clinic
- SCI Review Clinics jointly maintained – an IDT Consultant led clinic in conjunction with the Director of the NRH SCSC Programme.
- In-reach services are provided to children with limb absence attending the POLAR OPD clinics

OPD Treatment Slots

- There is a limited capacity for children to attend 2-4 OPD treatment slots with the team to enhance a particular skill or to review equipment etc

Rehabilitation Setting

The National Rehabilitation Hospital (NRH) is a publicly financed, voluntary, and free-standing, in patients, day places and outpatient rehabilitation hospital located in South Dublin suburb of Dun Laoghaire.

The PAEDS Programme occupies two areas in the hospital:

The ward (St. Agnes's): The ward situated on the 3rd floor of the hospital provides the accommodation where children/young people sleep and take their main meals. It has 4 beds in an open ward area and 2 separate enclosed cubicles. Depending on need children and young people may have some interventions with nursing and e.g. OT on the ward involving personal care skills. Children/young people and parents vacate the ward to attend therapy sessions at 9:00 – 9:30 and following lunch at 13:30 unless they are unwell and/or require more rest.

The PAEDS Day Unit (PDU): The PDU on the ground floor acts as a hub area from which therapeutic rehabilitation sessions and school attendance usually take place between 09.30 – 12.30 and 13.30 - 17.00. Young people, their family/carers and nursing staff are based in the Paediatric Day Unit close to the school and most therapy areas (the paediatric gym, multi-sensory room, OT kitchen, woodwork room, sports hall and hydrotherapy pool). The Day Unit itself comprises 2 play and relaxation rooms, a nursing office, a toilet/personal care room and an outdoor playground. The PAEDS team has access to another room adjacent for parts of the week for Music Therapy. Paediatric Neuropsychology Services are delivered on the second floor of the hospital in the Psychology Department.

Efforts are made to ensure that children and young people are treated and cared for in as protected and child and young person friendly environment as possible taking into account the age and design of the hospital building.

Date Effective: 01/11/2007

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The NRH also has its own Policy and Procedures for the Protection of Children in the hospital based on *Children First: National Guidance for the Protection and Welfare of Children, 2011*.

Feedback from the children and young people, their parents and carers regarding the services offered by the PAEDS Programme is encouraged by staff and through the use of suggestion boxes and questionnaires. The Programme Manager also facilitates periodic focus groups with patients attending the service at that time and there is a part parent rep on the NRH Patient Forum.

Data is collected routinely and Key Performance Indicators (KPIs) identified and monitored to demonstrate the accessibility, efficiency and effectiveness of the services provided.

The management of the single Health Care Record for each child/young person is managed in line with the National Hospitals Office standards.

Hours of Service

The PAEDS programme offers 8 therapeutic places: 6 in-patient beds and 2 days-patient places available over 5 days – Monday to Friday. Children and young people under-going full rehabilitation programme receive, on average, a minimum of two hours of direct service per day, Monday to Friday (as the child comes towards the end of their d/c the focus will be with linking with community therapists, preparation for discharge, etc). Weekends are typically spent at home for the child/young person to rest, spend time with family and to continue/practise individually devised home programmes of rehabilitation activities.

One parent/carer for each child/young person in-patient is offered free accommodation either in the hospital grounds during the week or in a local Bed and Breakfast establishment in order that the child/young person is supported emotionally during their course of rehabilitation.

Objectives of the Programme

- To achieve the maximum rehabilitation potential of each child/young person – physically, emotionally, socially and cognitively.
- To positively involve the children/young people and their families/carers in the rehabilitation process.
- To effectively support the successful reintegration of the child/young person into his/her home, school and the wider community.
- To help and support the child/young person and his/her family to adjust to loss, changed self- image and abilities as a consequence of their illness/injury.
- To liaise and advocate with Health, Therapeutic and Education Authorities in the young person's local communities re: their ongoing rehabilitation needs.
- To provide rehabilitation training, education and information in an accessible manner to the young person, the family/carers to enable them to advocate and care for their child and their needs.

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- To provide rehabilitation training, education and information to Teachers/Special Needs Assistants and Personal Assistants and other service providers in relation to service users, order to support the successful transition of the child/young person to their home and community.
- To provide rehabilitation training, education and information to Community Services Staff, Teachers/educators, Disability Managers and other service providers in relation to Paediatric Neurological Rehabilitation and to act as a resource where possible.

Referrals to the PAEDS Programme

Referrals are received from across Ireland: major referring hospitals are Children's University Hospital, Temple Street, Our Lady's Children's Hospital, Crumlin, The National Children's Hospital, Tallaght, Beaumont and Cork University Hospital neurosurgical units. Referrals are also accepted directly from general practitioners (GP), Network Disability Teams and other agencies.

Referrals are logged on the Patient Administration System (PAS) when received and are triaged by the Consultant Paediatrician and the Paediatric Liaison Nurse. If a referral is incomplete, referrers are contacted and asked to complete the Minimum Data Set form. In some cases the initial referral documentation may indicate the need for a risk assessment or further information from families/carers, schools, local therapeutic service providers and this will also be requested or set up at this stage to ensure appropriate and timely admissions.

If the referral is outside the Scope of Service, the Consultant writes back to the referrer explaining this information and suggesting a more relevant service if possible. In the case of Beaumont and other hospitals where adult NRH Consultants are visiting, a pre-admission assessment may be carried out and recommendations made to the PAEDS team. The Paediatric specialist liaison nurse will also be involved in many cases and can advise both the referring and the neuro-rehabilitation team on suitability and readiness for rehabilitation.

If a referral is considered suitable the child/young person is listed for the inpatient waiting list or for a pre-admission assessment of needs (MDT) or an outpatient (OPD) assessment.

Admission Criteria

To be admitted to the Paediatric Family-Centred Rehabilitation Programme the patient must:

- Be under 18 years of age.
- Be medically stable.
- Have the potential to benefit from an interdisciplinary rehabilitation process.
- Have medical, nursing and interdisciplinary therapy needs requiring the services of the specialised Interdisciplinary Paediatric Rehabilitation team.

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- Be accepted under the care of the National Rehabilitation Hospital (NRH) Paediatric Medical Consultant.

The PAEDS Programme at the NRH accepts referrals for patients with the following diagnoses:

- Acquired Brain Injury of traumatic (RTA, falls, assaults, sports injuries) and non- traumatic origin (tumour/AVM/aneurysm/ infection)
- Acquired Spinal Cord Dysfunction of traumatic (falls, ballistic injury) and non-traumatic origin (Transverse Myelitis/ tumour/Guillian Barré Syndrome)
- Acquired and congenital limb absence with prosthetic intervention
- Other acquired neurological conditions requiring specialist rehabilitation

Excluded are:

- The PAEDS team is proficient in caring for those who are respiratory compromised including those with tracheostomy however cannot accommodate patients who are ventilator dependent.
- In situations where the appropriateness of admission is unclear the child/young person may be seen by the Consultant Paediatrician and members of the Interdisciplinary Team for a pre-admission assessment as an outpatient/day patient.

PAEDS In-patient and Day-patient Service

Children/young people and their parents are invited to visit the NRH prior to admission to familiarise themselves with the service and to meet with the Liaison Nurse and the Medical Social Worker. In complex situations a member of the PAEDS team (usually the Paediatric Liaison Nurse), may be able to visit the child/young person in his/her acute care setting to gather and share information to facilitate the transition to the NRH.

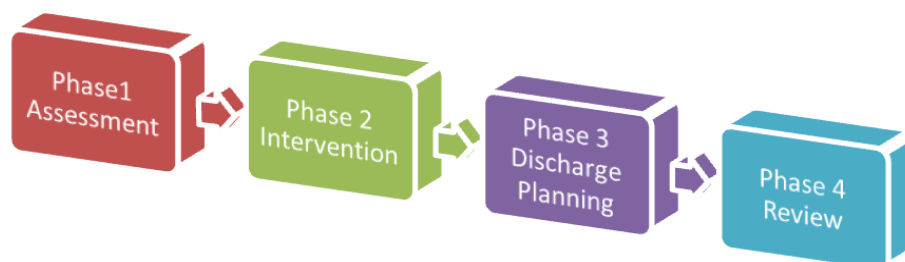
Once listed for admission, families are sent pre-admission information about the service. Parents are given an information book on the NRH and the PAEDS Service before admission as well as a leaflet on the Phases of Rehab. The Social Worker also gives a talk to parents/families on "Your child's Journey through Rehabilitation" once the child has been admitted to the service. As weekend leave is part of the programme, formal feedback via the weekend leave form is requested from parents/carers by nursing staff on the child's return. The philosophy of 24 hour rehabilitation is highlighted and encouraged by all team members and emphasised through links with the Children in Hospital Ireland play staff who volunteer in the evenings.

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Phases of Rehabilitation

The Rehabilitation Programme is divided into four key phases.



The **Assessment Phase** takes place during the first 2 weeks of admission depending on the child's needs. The aim of this phase is to identify if and how the child will benefit from the NRH Rehabilitation Programme. Interdisciplinary (IDT) Goal planning takes place at this point followed by goal feedback to the family which is generally managed by the Social Work staff.

The **Intervention Phase** usually 4-8 weeks, depending on the child's individual needs. The child/family will be in active treatment and encouraged to continue the programme during weekend leave. A family meeting with the team is organised during this phase and parents/carers are actively encouraged to be part of the team, attend therapy sessions and educated on the condition itself and the philosophy of 24 hour rehab. Progress towards goals is reviewed weekly and new goals formulated or goals reviewed as necessary.

The **Discharge Planning Phase** (approximately 2 weeks) at the NRH is focused on preparing the child and family to return home, to education and to life in the local community as much as possible. Discharge arrangements become more of a focus during this phase. During this phase, the child may attend less therapy sessions while the team liaise with community colleagues, schools and services and prepare the IDT Discharge report and home programmes. Disability Services and/or SNA staff might attend the NRH for training or handover.

The **Review Phase**: When a child leaves the NRH they will be offered one or more of the following options in terms of Review:

- An appointment for follow-up or review at a Paediatric Non-Consultant Led ABI Clinic or at a Paediatric Spinal Cord Injury Multidisciplinary Clinic
- Contact with the Paediatric Liaison Nurse
- A review appointment with 1 or 2 therapists only
- A set time frame for a Neuropsychological Review
- A set time frame full team review
- A review 2 week Assessment Programme at a future date
- A review on request by the community team now managing the child's care
- If appropriate, the child may be ready for discharge from the service or transfer to the NRH adult services

Services Provided For the Person Served

Admission to the PAEDS Programme is based on the assessment of rehabilitation needs and on meeting the programme's admission criteria.

Our Interdisciplinary team offers an integrated approach to assessment and rehabilitation. We combine medical/nursing care, therapy, education, play and family support to facilitate children and young people to regain skills and maximise their ability to participate in family, education and community life.

For children/young people who are ready to benefit from rehabilitation interventions at the NRH but are medically unable to commence spending weekends at home then arrangements may be made for them to return to their familiar acute paediatric hospital service at weekends for a period. Alternatively e.g. a local paediatric hospital setting near to their family home may be asked to accommodate the child/young person at weekends so that they may be able to participate in short trips home during the day or have more visits from family and friends.

Primary/initial interdisciplinary assessments of rehabilitation needs are generally carried out by the PAEDS programme team via a two week admission and this will then guide the decision as to whether a period of individual, goal focused rehabilitation is appropriate. Shorter or longer assessment periods may be arranged depending on the needs of individual patients.

The intensive interdisciplinary assessments and rehabilitation interventions, can be offered on an in-patient or day- patient basis, Monday to Friday

As children and young people may experience difficulties as a consequence of their illness/injury at later developmental milestones the PAEDS Programme may provide a follow-up/review rehabilitation service if further specialised assessment/advice is needed. These services can be provided on an in-patient, day place or limited outpatient and outreach basis.

Interdisciplinary assessments carried out by the PAEDS Team address the rehabilitation needs of each child/young person taking into account their age, stage of development, their family circumstances and cultural background.

The initial and ongoing/review assessments are carried out by personnel with the paediatric competencies necessary to evaluate and facilitate the achievement of predicted outcomes in the following areas as appropriate:

- Behaviour
- Cognition
- Communication
- Functional abilities
- Medical
- Pain management
- Physical
- Psychological
- Recreation and leisure
- Social
- Community
- Education/vocational
- Emotional
- Family
- Sexual

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Services offered to meet identified needs could include:

- Activities of daily living (ADL) assessment and training
- Adaptive equipment assessment and training
- Art Therapy and classes
- Aquatic Therapy
- Assessment and advocacy for community state education services
- Assistive technology assessment and training
- Bowel and bladder training
- Counselling in relation to:
 - Child/young person/family changed expectations
 - Bereavement/grief/coping
- Community services and school liaison/transition/reintegration
- Clinical neuropsychological assessment
- Dental services
- Driving and community transport assessment and education
- Dysphagia assessment and management
- Entitlements/benefits counselling, advocacy and guidance
- Horticultural Therapy
- Independent living skills assessment and training
- Medical assessment and management
- Environmental modifications
- Normal growth and development information/education.
- Mobility assessment and training
- Nutrition counselling and management
- Orthotics and splinting assessment and training
- Pastoral and spiritual support
- Patient and family advocacy and support
- Patient and family education, training and counselling
- Pharmaceutical care, management and training
- Play and leisure assessment, counselling and guidance
- Prevention education/information related to recurrence of the impairment, injury or illness
- Risks and complications information and education related to impairment
- Fitness and sports assessment and guidance
- Relaxation and stress management for patient and family
- Reproduction information and counselling
- Respiratory therapy
- Safety awareness and training
- Seating assessment and training
- Sexuality counselling
- Socialisation
- Spasticity management
- Speech/Language and communication assessment and training
- Substance abuse/smoking cessation training and support
- Transition to appropriate adult services
- Vocational assessment and counselling

Other services available on-site include:

- Orthoptic Service
- Discharge Liaison Occupational Therapists (Dublin Area only)
- Osteoporosis assessment/DXA scan

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- Urology

Off-site Services:

Other Paediatric sub-specialist services are available via referral to the tertiary children's hospitals. Dr. Susan Finn, NRH Consultant Paediatrician also works at Our Lady's Children's Hospital, Crumlin.

Other services:

Members of the PAEDS Interdisciplinary team develop and deliver education/information presentations for interested groups and organisations on a variety of aspects of Paediatric rehabilitation. The team also host educational events for professionals and carers including training seminars on Paediatric ABI and Paediatric Spinal Cord Injury. Members of the team offer placement and lectures to third level students and are encouraged to present research findings at International Conferences.

Patient Mix

As the national rehabilitation service the PAEDS Programme caters for children and young people who may vary in relation to age and levels of ability/disability. There may be occasions when services are being provided simultaneously to:

- A young child with communication and learning difficulties following meningitis,
- A young teenager with memory, concentration and behaviour difficulties following a brain injury sustained in a car accident,
- A child with a spinal injury sustained in a fall unable to mobilise independently, and
- A young person requiring training in the use of a new prosthetic limb.

Assisting children, young people and their families to cope with and co-exist with the differing needs of all is a priority for staff.

Services provided for Families, Carers and Support Systems of Person Served

Family-centred care is the cornerstone of the PAEDS Programme. It places children and families at the centre of the service by advocating for the needs of service users, protecting their rights, respecting their diversity, values and preferences, and actively involving them in the provision of care. Young people and their families are involved in goal setting, education about their condition and self-management, where appropriate. The PAEDS team offer parental education and opportunities for family peer support. Siblings are encouraged to attend the unit and participate in therapy sessions, and each family has a medical social worker as their case co-ordinator. Siblings may be offered counselling sessions in their own right or referred to local services near their home and the NRH has a range of information leaflets available for child relatives. The team place a particular emphasis on working with the family as a whole.

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Many services are available within the PAEDS Programme to meet the needs of the family/support system including:

- Family advocacy and support
- Family education, training on the Rehabilitation Journey and all relevant aspects of the neurological condition and the child's needs
- Crisis/ and Adjustment Counselling
- Relaxation and stress management for patient and family
- Safety awareness and training
- Pastoral and spiritual guidance services
- Family/ support system education, training and counselling
- Entitlements/benefits, information/guidance on relevant services, and advocacy to source these services
- Information about community/peer supports, accommodation and assistive technology resources
- Transition planning – a new transition to adult services for children with ABI is at the planning stage and a Transition Information Event for all Paediatric patients at NRH is being offered from 2017

Discharge Criteria

Potential challenges/difficulties regarding discharge issues will be identified during the pre-admission process and planning for a constructive timely discharge will be commenced at the point of admission.

To be discharged from the PAEDS Programme, one or more of the following conditions must be met:

- The child/young person will have achieved their identified rehabilitation goals and received maximum possible benefit from their inpatient programme.
- The child/young person has improved to the projected functional level that will allow discharge to a specified environment.
- The child/young person's ongoing rehabilitation needs can be appropriately met in an alternative environment such as local community based paediatric services
- The child/young person has experienced a major intervening surgical, medical or psychiatric problem that precludes benefit from a continued intensive rehabilitation programme.
- The child/young person and/or their family/carers no longer willingly agree to cooperate/participate in the rehabilitation process.
- The young patient has reached 18 years of age and is appropriate for referral/transition to adult services.
- Children/young people will be refer to Paediatric Palliative Care Services, should this be required.
- If a child/young person becomes too unwell for management with his/her rehab programme, he/she will be refer back to the primary carer.

Discharge Outcomes and Environments

It is always the aim of the PAEDS Programme to discharge children and young people to their chosen/family home environment and local mainstream education settings. Where this is not possible the team will cooperate with the young person and their family together with community services to identify and achieve the most appropriate and desired setting. When necessary, and possible, children/young people may remain in the NRH after their rehabilitation goals have been achieved for a period to prevent distress or admission to inappropriate interim placement. In these circumstances the admission will be recognised by the NRH senior management as a "delayed discharge" and representations made to relevant funding authorities to release necessary financial/support services.

The PAEDS Staffing for the Programme

The full continuum of care for the PAEDS programme is currently managed by one IDT team with support from ancillary services.

The people who routinely work closely with the child/young person and their family/carers during rehabilitation are:

- Consultant Paediatrician (limited time at the NRH)
- Non Consultant Hospital Doctors (NCHDs)
- Paediatric Liaison Nurse
- Clinical Nurse Manager (CNMII)
- Registered Nursing Staff
- Health Care Assistants (HCA)
- Speech and Language Therapists (SLT)
- Physiotherapists (Physio – PT)
- Occupational Therapists (OT)
- Clinical Neuropsychologists
- Medical Social Workers (MSW)
- Music Therapist
- Programme Administrator
- Children in Hospital Ireland – Play Volunteers*

The members of the team serving each individual child/young person will be determined by their individual assessment, an individualised goal planning process, the predicted outcomes and the strategies utilised to achieve the outcomes predicted.

The PAEDS team in relation to the wider hospital is modest in size; the senior permanent members of the team are experienced and skilled in providing rehabilitation therapeutic services to children and young people. All team members, including the staff grade therapists who rotate between the NRH programmes, are assessed annually as to their abilities, skills and competencies.

Depending on the reason for the child or young person to be engaged in rehabilitation at the NRH e.g. an acquired brain injury, spinal injury or limb absence - members of the team could include:

- The Medical Consultant in Rehabilitation Medicine & Limb Absence
- The Medical Consultant in Rehabilitation Medicine and Spinal Injury
- Orthotist

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- Prosthetist
- Dietitian
 - Dentist
 - Dysphagia Therapist
 - Pastoral Care Worker
- Pharmacist
- Podiatrist/Chiropodist
- Exercise Physiotherapist
- Aquatic Physiotherapist

Throughout the year the PAEDS service will also have students, trainees and assistants on education/training placements.

Children in Hospital Ireland Play People

Children in Hospital Ireland have volunteers specially trained in working with children in a hospital environment and the NRH has a number of "Play People" as part of the programme.

The main focus of these volunteers is to play with the child, give them a break from the difficult regimes they may have to go through and allow parents some down time. Since much of paediatric rehabilitation is done through play however, there are opportunities to enhance the child's programme through this service.

A manual of suggested activities for the Children in Hospital Volunteers which can enhance or reinforce the child's programme and their ability to join in play has been developed by the team. A child may enjoy co-ordination exercises through a computer game or the play may be more successful if the volunteer is aware that the child is better with one activity at a time.

The weekly goals on the back of the child's timetable are a means of communicating with the Play People and the team also meets with this group approximately once a year.

School Education on-site for the PAEDS service

The Department of Education and Science provide term time schooling onsite for all children and young people - 4* – 18years (i.e. those children having reached the age of 4 years on or before 1st September of the school year in question) attending the NRH as day patients and inpatients. The school is integral to the young person's rehabilitation process.

Staff in the school

- Principal/Special Duties Teacher
- Special Needs Assistants x 2
- School Secretary (7 hours per week)

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

During the major school holidays the NRH endeavours to source play creative arts and craft activities for patients.

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PAEDS Out-patient treatment and clinic Service

The OPD review of children seen by the NRH PAEDS Programme are considered an important element of the rehabilitation programme, as the rehabilitation needs of children/young people can change as they grow and develop. Reviews should be planned with due consideration of the capacity of treating team, but also with consideration of the fact that the child/young person for review has been deemed to have needs which can be appropriately met in a community environment (reference discharge criteria of programme).

Paediatric review appointments can be for one of the following:

1. Paediatric/Spinal Injury Consultant Led Spinal Cord Injury Multidisciplinary Clinics. These clinics continue to prove an effective and efficient forum to manage children and young people with a spinal injury comprehensively. All children attending the NRH with ongoing SCI needs are offered review through these clinics.
2. Paediatric Non-Consultant Led ABI clinics. International best practice indicates that children with ABI should be reviewed at key stages in their development and/or as required. Children with ABI can appear less complex initially and then become more complex as times passes. Cognitive, social and behavioural issues are known to increase over time. This clinic aims to provide review services for children with ABI most of whom have attended the NRH CIIRP programme.
3. Single discipline clinical appointments e.g. where the SLT would like to review an assistive technology device

The type of review appointment scheduled will be determined by the individual child/families needs. The decision as to most appropriate review service the child/young person may need is based on:

- a) IDT discharge report recommendations
- b) Pre-review questionnaire circulated in advance of review (see appendix 1)
- c) Diagnosis

When a child/young person leaves the NRH after their main rehabilitation they will be offered an initial review by the programme. This can be a follow-up contact with the Paediatric Liaison Nurse, an appointment at a Paediatric Review Clinic or if appropriate, the child may be ready for discharge from the service or transfer to the NRH Adult services. After this, additional reviews will be by referral from GP/Consultant/family. Ongoing review may also be recommended by the paediatric team if the child/young person is identified as needing to avail of specialised rehabilitation assessment/therapeutic services at regular intervals throughout their childhood to benefit from the identified pathways/treatment guidelines for brain injury, spinal injury, and limb absence.

The primary objective of the Review is to encourage and assess the durability/sustainability of outcomes achieved following inpatient admission and/or rehabilitation intervention. Out-patient review appointments can also provide tertiary advice and onward referrals.

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The PAEDS Programme Out-patient Review should include review of the following domains:

- Medical status (including details of any re-hospitalisations)
- Functional status including durability of outcomes following in-patient admission.
- Psychological needs
- Family coping and adaptation
- Equipment status
- Participation status (including initiation, socialisation, leisure pursuits, transportation)
- Educational status
- Community living status
- Transition planning
- Longer term life planning

Outpatient appointments/clinics may be scheduled with the Consultant Paediatrician and/or members of the Interdisciplinary Team to address specific rehabilitation needs of children and young people.

Children seen at OPD/Outreach clinics and services are discussed with the whole team as part of the case conference process.

A review is not considered an appropriate setting for treatment interventions. It is a reassessment of functional status post discharge. A child may be referred to another aspect of the PAEDS service if further intervention is required

Criteria for availing of review services:

- Have been previously assessed and received rehabilitation services by the NRH PAEDS interdisciplinary team.
- Emerging rehabilitation needs of the young person cannot/are anticipate not being able to be met by community services because of their complex nature.
- Child/young person is assessed, by the interdisciplinary team, as needing to avail of specialised rehabilitation assessment/therapeutic services at regular intervals throughout their childhood to benefit from the identified pathways/treatment guidelines for brain injury, spinal injury, and limb absence.
- If there are developments as a result of a change in the neurological condition, non attendance at school, child/family distress which need to be addressed by the specialist team

Information gained through a review will be shared with the child/young person, their family/carers and relevant community services. Referral to services necessary to meet the emerging/continuing needs of the child/young person will be made and when appropriate referral/transition to adult services will be made.

Outcomes of reviews:

Date Effective: 01/11/2007

Reviewed Version Date: 11/05/, Date: 01/05/, Date: 23/07/2013, draft revision 18/11/2014, Reviewed

Version Date: 25/04/2017

The outcome of the review can be one of the following:

1. Further review at a future date
2. Referral or re-referral to community based services
3. OPD treatment slots for limited, targeted treatment
4. Referral to the 2 week review programme (P2)
5. Referral for a further period of intensive rehabilitation (P1)
6. Transition to NRH adult services
7. Discharge if the child is no longer in need of the PAEDS service

OPD Treatment Slots:

The programme has a limited number of OPD treatment slots for children who would benefit from 2-4 slots of intervention by the specialist team. This might include work on homework techniques or social skills, review of AFO etc

PAEDS in-patient/Day patient intervention

A decision to refer a child reviewed in OPD by Paediatric Team to an NRH based should be based on the following:

- If the child's specific needs cannot be met in the community
- Significant rehabilitative potential is seen by clinician with clear/specific achievable goals identified for the proposed intervention
- The child is placed back on the main waiting list and managed through this process

When any issues of concern are raised in the OPD Review, Consultant will make appropriate referrals for an appropriate intervention, be the hospital or community based services.

Information gained through a review will be shared with the child/young person, their family/carers and relevant community services. Referral to services necessary to meet the emerging/continuing needs of the child/young person will be made and when appropriate referral/transition to adult services will be made.

Criteria for referral/transition to NRH Adult Services

- Be 18, or approaching 18 years of age.
- Be in need of continuing specialised complex rehabilitation services as provided by the specialty NRH adult programmes.
- Be between 16 and 18 years of age and be living an adult lifestyle that would be in conflict with the needs of other patients of the PAEDS programme

OPD/Review Outreach

Outreach activity also occurs at the outpatient stage of the PAEDS programme

The team seek pre-clinic reports from medical services and schools in relation to progress at home and in the community and may liaise with community staff by phone or teleconference before the clinic appointment where appropriate.

Date Effective: 01/11/2007

Reviewed Version Date: 11/05/, Date: 01/05/, Date: 23/07/2013, draft revision 18/11/2014, Reviewed Version Date: 25/04/2017

Community and school staff is welcome to the NRH for clinics/treatment slots if they are available and it is of benefit to the child.

There will also be follow up outreach work after OPD clinics to discuss the outcome of the review, update treatment plans and arrange for further review as required.

The long term vision for NRH outreach is that the PAEDS team would provide specialist reviews in a regional area, possibly linked to the proposed regional rehabilitation units.

Costs

The National Rehabilitation Hospital is a publicly financed, voluntary, CARF accredited, freestanding in-patient, day and outpatient rehabilitation hospital located in Dun Laoghaire, County Dublin.

The PAEDS service is part of the NRH and therefore there are no fees for the delivery of patient services. There may be costs involved in the provision of some equipment and services for the child/ young person's return to the community and where appropriate the family will be helped to apply for funding for any such expenses via an application e.g. for a Medical Card or Domiciliary Care Allowance.

The NRH is also able to receive costs, through court settlements, for the treatment of patients injured as a result of a road traffic accident.