



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.

The Paeds Programme offers inpatient beds, day places and limited 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. Although it is modest in size, the challenges of the Programme for the experienced Paediatric Team are broad and exacting.

The Paeds Programme has 10 beds between inpatient and day places. It operates as a 5-day (Monday – Friday) service. Children and young people are admitted for either a full rehabilitation programme or for previous patients returning for a review of their rehabilitation needs in the context of their natural growth and development.

The Out-patient service (OPD) offers review clinics and a limited capacity for treatment service. This work is done by the current team. The establishment of a separate paediatric outpatient team to develop and implement fully its outpatient, outreach and community services remains a top priority.

The Paeds Programme also offers a limited Outreach service. The Outreach activity can occur at any stage of the rehabilitation journey.

Our goal is to maximize each child/young person's abilities and minimize the effects of their impairments.

Rehabilitation Setting

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

As the NRH provides rehabilitation to all ages of patients the Paeds Programme is organised to provide services in family friendly areas. The Paeds Programme operates in an enclosed fully integrated unit known as “Daisy Unit” with an outdoor playground adapted to the needs of the children and young people receiving rehabilitation treatment.

- Daisy Unit is comprised of eight single en suite rooms to accommodation for each patient and one parent, music therapy room, multisensory room & bathroom, therapy gym, individual therapy rooms and administration offices and meeting rooms. Other rooms provided are a family room, teenagers den and a dining/recreation room.

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

The NRH also has its own Policy and Procedures for the Protection of Children in the hospital.

Feedback from the children and young people, their parents and carers regarding the services offered by the Paeds Programme is encouraged by staff and using suggestion boxes and questionnaires or at the Parents 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.

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' vision of a "rehabilitation without walls" approach has led to a more child and family-centred and integrated approach. The Paeds Programme provides for fluid movement between the services based on assessment of individual clinical need and social circumstances.

Hours of Service

The Paeds programme offers 8 therapeutic places between in-patient beds and day-patient places available over 5 days – Monday to Friday. Based on their individual rehabilitation needs, children and young people under-going a full rehabilitation programme receive an average of two hours of direct service per day, Monday to Friday. 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.

To support and sustain patients in the Paeds Programme a pull-out bed is provided for one parent staying in each room with their child/young person 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.
- To provide rehabilitation training, education and information to Teachers/Special Needs Assistants and Personal Assistants and other service providers to support the successful transition of the child/young person to their home and community.

Exclusion Criteria

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 a day patient.

Children and young people are excluded from the Paeds Programme where other needs (medical/psychiatric/behavioural/drug & substance misuse) predominate over the potential to benefit from specialised paediatric rehabilitation care and the cognitive, physical and psycho-social needs of the patient. In these cases, recommendations may be made to the referring party regarding other more appropriate services at the time.

The Programme is proficient in caring for those who have respiratory compromise including those with tracheostomy however cannot accommodate paediatric patients who are ventilator dependent.

Admission Criteria

To be admitted to the Paeds Programme the patient must:

- Be under 18 years of age.
- Be medically stable.
- Have the potential to benefit from an interdisciplinary rehabilitation programme.
- Have medical, nursing, and interdisciplinary therapy needs requiring the services of the specialised Interdisciplinary Paediatric Rehabilitation team.
- 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/Guillain Barré Syndrome)
- Acquired and congenital limb absence with prosthetic intervention
- Other acquired neurological conditions requiring specialist rehabilitation

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 referred 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 referred back to the primary carer.

Referrals to the Paeds Programme

Referrals are received from across Ireland: major referring hospitals are Children's Health Ireland (CHI) at Crumlin, Tallaght and Temple Street, Beaumont, and Cork University Hospital neurosurgical units. Referrals are also accepted directly from general practitioners (GP).

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 refers back to the referrer explaining this information and suggesting a more relevant service if such service is known to us.

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.

Services Provided for the Person Served

Admission to the 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 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.

Initial interdisciplinary assessments of rehabilitation needs are generally carried out by the Paeds programme team at the beginning of an admission and this will then guide the decision as to whether a period of individual, goal focused rehabilitation is appropriate.

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 in-put/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

Services offered to meet identified needs could include:

- Activities of daily living (ADL) assessment and training
- Adaptive equipment assessment and training
- 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
- Entitlements/ benefits counselling, advocacy and guidance
- Aqua 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:

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

Off-site Services

All other Paediatric sub-specialist services are available via referral to the tertiary children's hospitals.

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.

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 key worker. The team place a particular emphasis on working with the family as a whole.

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

- Entitlements/benefits counselling, advocacy, and guidance
- Family advocacy and support
- Family education, training, and 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
- Information about community support, advocacy, accommodation, and assistive technology resources.

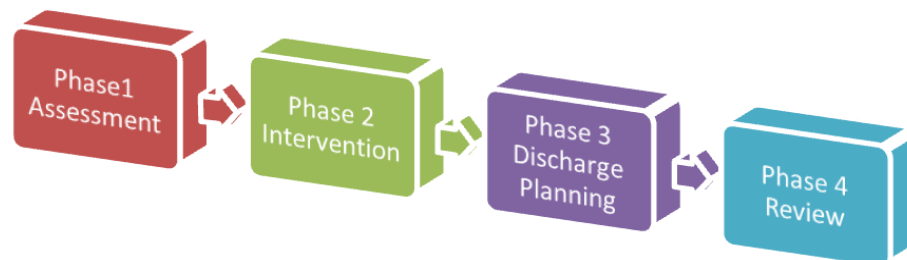
The Paeds In-patient and Day-patient Service

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.

Phases of Rehabilitation

The Rehabilitation Programme is divided into four key phases.



The **Assessment Phase** takes place during the initial admission (usually the first two weeks) 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.

The **Discharge Planning Phase** (usually the last 2 weeks of admission) 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 their 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 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 review 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

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 “Family’s Journey through Rehab”. 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.

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 NRH strives to deliver goal orientated rehabilitation for all patients who require our service. However, it is recognised that in some instances active rehabilitation is not the appropriate or suitable approach for the patient and / or their family. In such cases, the NRH will liaise with all relevant parties to ensure the best possible outcome for all. For instance, in the case of palliative care, when medically indicated and in full agreement with the patient and/or their family, the NRH will refer back to the acute hospital to support the transition to such services.

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.

The Paeds Staffing for the Programme

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

- Consultant Paediatrician
- 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
- Dietitian
- 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 skills, knowledge, 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
- Prosthetist
- Dentist
- Dysphagia Therapist
- Pastoral Care Worker
- Pharmacist
- Podiatrist/Chiropodist
- Sports Therapist
- Aquatic physiotherapist

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

Links with the 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 focus on the Play People is to engage in play activities 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. There is a book of suggested activities on the ward for the Children in Hospital Volunteers which can enhance or reinforce the child's programme and their ability to join in play. For example, 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 to 18 years (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. The school is integral to the young person's rehabilitation process. 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.

Out-patient & Review services

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:

- Paediatric 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)
- Paediatric Consultant Led ABI clinics (The sharing of a single limited resource, impacts on the availability and intensity of services for patients). 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.
- Single discipline clinical appointment

The type of review appointment scheduled will be determined by the individual child/family's 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

Children attending the service will be offered an initial review by the programme. 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 assess the durability/sustainability of outcomes achieved following inpatient admission.

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
- Equipment status
- Participation status (including initiation, socialisation, leisure pursuits, transportation)
- Educational status
- Community living status
- Life-long care plans

Out-patient review appointments are primarily driven by the need to assess durability of outcomes and provide tertiary advice and onward referrals.

A review is not considered an appropriate setting for treatment interventions. It is a reassessment of functional status post discharge.

The paediatric team also provides in-reach and paediatric services to the POLAR team in respect of children with limb absence.

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.

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 child/young person cannot or are anticipated not to be 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 therapeutic services at regular intervals throughout their childhood to benefit from the identified pathways/treatment guidelines for brain injury, spinal injury, and limb absence.

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

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

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

- Child's needs cannot be met in the community.
- Significant rehabilitative potential is seen by Clinician with clear/specific achievable goals identified for the proposed intervention. Goals should be achievable within a maximum timeframe of 3 treatment sessions.
- The treating clinician can respond to this child's outreach needs within proposed weekly schedule without any impact on either a) inpatient (both

direct & indirect), b) preadmission assessments or c) administration responsibilities.

The child will then be placed back on a waiting list and managed through the waiting list process.

When any issues of concern are raised in the OPD Review, Consultant will make referrals for an appropriate intervention, be they 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.

Outreach

A critical component of service delivery is the outreach aspect which is provided for children at any stage of the rehabilitation journey.

At Pre-admission: by the Consultant and/or the Paediatric Liaison Nurse or the full team in very complex cases. It can be telephone contact/advice or visits and pre-admission assessment. Parents/families can attend the NRH in advance of an admission to meet with nursing and social work staff and have a tour of the facilities.

Outreach activity also occurs during the child's rehabilitation programme in that the team may seek re-injury/admission reports from medical services and schools as well as liaison in relation to transition back to home and community. Community and school staff often attend the NRH for case conferences and training and some school age patients attend local schools for part of the week if this is beneficial.

Post Discharge, outreach activity via the phone or in person with families, schools, and community staff to see how the child/young person is coping and/or to plan for reviews.

There will also be follow up outreach work after OPD clinics. 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.

Transition to Adult service

The over-arching aim of transitional care is to help young people achieve the best possible health, social and vocational outcomes as they enter adulthood, and this is of particular importance in the setting of an acquired brain injury.

Preparation for transition should be planned and phased, given that paediatric care is family-centred and developmentally focused and in this respect differs from adult medical services which support patient autonomy in healthcare planning and decision making. Whilst there is not universal agreement about the age threshold or number of steps necessary, all would agree that the concept of transition should be introduced in early adolescence.

Candidates for the Transition Clinic will have been identified at an earlier stage in their rehabilitation (e.g. from age 14 – 17 years) under the care of the NRH Paeds team who will have provided some education and support on the process of transition. Formal written referrals for the Transition Clinic is generated by the Consultant Paediatrician or her deputy and these are screened by the lead physician for the clinic who, in consultation with interdisciplinary colleagues, may decide to accept or recommend an alternative care pathway for the individual. An appointment will be offered based on the urgency of clinical need and availability of clinic slots.

For transition to be successful, the following are important considerations:

- Effective **communication** and exchange of clinical records between paediatric and adult services.
- Flexibility with respect to the **timing of transition**, as not all young people will be ready to make the transfer to adult services at the same age. Issues such as cognitive and physical development, emotional maturity and general health status should be taken into account when planning transition. This is particularly relevant for young people with co-existing medical and/or mental health conditions.
- Appropriate **educational interventions** should be available to help the young person understand the nature of their brain injury, residual impairments, activity limitations and participation restrictions, including how to navigate the healthcare system and seek help from appropriate health professionals.

Criteria for referral/transition to NRH Adult Services

- Be current or previous patients of the NRH Paediatric Programme
- Be 18 or approaching 18 years of age.

- Need 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 conflict with the needs of other patients of the Paeds programme

Discharge Criteria

Persons attending the Transition Clinic will be considered for discharge if they fulfil any of the following criteria:

- Attainment of age 25 years
- Deemed by the clinic personnel to have fulfilled all goals identified in the initial consultation
- Require other medical, surgical, or psychiatric treatment which would preclude continuing attendance at the Transition Clinic
- Needs can be met appropriately in another health care environment
- No longer willing to attend or participate in the clinic

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.