

SCHEDULE 2 – THE SERVICES

A. Service Specifications

Service	Rainbows Children's Hospice
Commissioner Lead	NHS Nottingham and Nottinghamshire ICB
Provider Lead	
Period	01/10/2021 – 30/09/2024

1. Population Needs

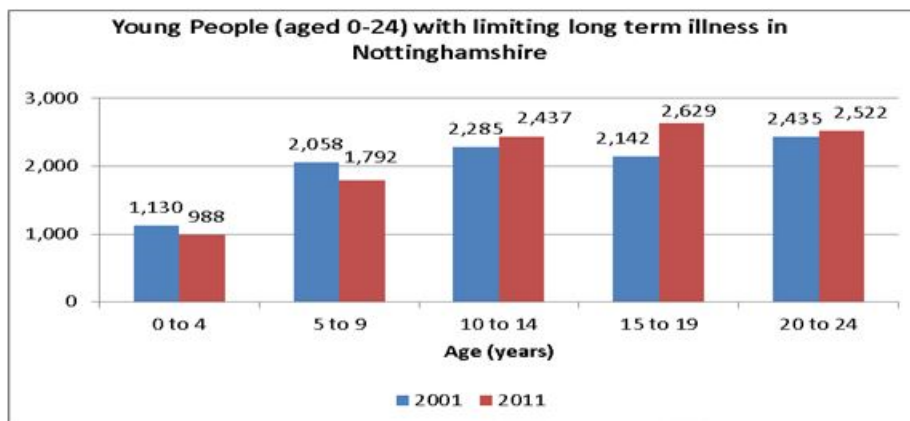
1.1 National/local context and evidence base

It is problematic to collate accurate, timely data in relation to disabled children and young people both locally and nationally, and definitions of disability vary widely. Information is collected by different agencies, is often out of date and is not shared routinely. In addition, there is no comprehensive register in the county of disabled children.

The disability needs assessment for Nottinghamshire undertaken in 2012 contains data relating to special educational needs and disability. It estimated the numbers of children and young people experiencing some form of disability as follows:

Thomas Coran Research Unit (2010): **5,300-9,000** (0-19 year olds)
 Child and Maternal Health Observatory (2000): **12,526** (0-19 year olds)
 Disability Living Allowance (2011): **7,210** (0-24 year olds)

Census 2011 data relating to children & young people's disability shows the number with limiting long term illness in Nottinghamshire, has dropped in the under 10s by about 13% and increased in the 10+ ages particularly in the 15-19 year age group by 23%.



There has been a significant increase in young claimants (0-17 years of age) of Disability Living Allowance in Nottinghamshire over the last 12 years, from 3,350 in May 2002 to 6,160 in May 2014, a rise of 70%. The steepest rise was in the 16-17 age range, which more than doubled (138% increase). This was closely followed by the 11-16 group (increase of 147%).

Key Messages

- There are estimated to be between 5,000 and 12,000 disabled young people (aged 0-19) in the county.
- There has been a 70% increase in 0-17 year old claimants of Disability Living Allowance in Nottinghamshire over the last decade.

- More than one in six Nottinghamshire pupils have some kind of special educational need (SEN) and 1.1% have a Statement of SEN. Districts with the highest percentages of children with SEN are Mansfield (20.4%), Ashfield (19.1%) and Gedling (18.0%).

2. Outcomes

2.1 NHS Outcomes Framework Domains & Indicators

Domain 1	Preventing people from dying prematurely	√
Domain 2	Enhancing quality of life for people with long-term conditions	√
Domain 3	Helping people to recover from episodes of ill-health or following injury	
Domain 4	Ensuring people have a positive experience of care	√
Domain 5	Treating and caring for people in safe environment and protecting them from avoidable harm	√

2.2 Local defined outcomes

- To offer planned specialist residential palliative respite per child/young person over a period of one year. Each respite session will include a full palliative care assessment by the relevant members of the multi-disciplinary team (medical, nursing, pharmacy and therapy) and the provision of residential facilities for the immediate family if required.
- To offer 24/7 emergency residential palliative care/symptom control and end of life support as required. This is additional to planned residential support.
- To provide family support services in the community for children/young people who meet Rainbows admission criteria and do not wish to use residential services or who require residential respite and additional services. This may include provision of nursing and medical advice or support, information and signposting.
- To offer complementary, music and play therapy at home based on assessment of needs. Age appropriate sibling support programmes and activity programmes for well and ill siblings to attend together.
- To offer medical advice to community teams and GPs from the hospice medical team.
- To provide end of life care in the hospice and support care delivered at home/in hospital working alongside providers of community or acute services to ensure excellent standards of palliative care including symptom control and practical support for terminally ill children/young people and their families (including provision of residential facilities for immediate family if required).
- To provide bereavement support for up to 2 years after the death of a child/young person for the immediate family (parents, siblings, grandparents). This support will extend into schools, community support services and the wider family unit if necessary.
- To provide symptom control, end of life care and bereavement support training courses and advisory services for community professionals working with children and young people.
- To continue to develop and work to robust organisational processes which meet legal and statutory requirements.

3. Scope

3.1 Aims and objectives of service

The service provided contributes to the core national and local objectives:-

Contribution to Local Delivery Plan Targets

Reduction in hospital admissions. Support and advice to those delivering services locally to the child/young person and their family. Integrated services for ill and well children together, support for carers (siblings and parents/family).

Contribution to National Service Frameworks

Provision of comprehensive and equitable palliative care services for all life-limited/life-threatened children and young people (0-25 years) across the East Midlands.

Contribution to other National and Local Strategies

- Work of the hospice contributes to development of regional palliative care networks.
- Supporting the development of palliative care pathways across the East Midlands (based on Association for Children with Life-Threatening or Terminal Conditions and Their Families (ACT) care pathways).
- Supports delivery of the 5 Every Child Matters targets (be healthy, stay safe, enjoy & achieve, make a positive contribution and achieve economic well-being).

3.2 Service description/care pathway

Rainbows offers short break, palliative, end of life care and symptom control for children and young people who have life-limiting, life-threatening and complex needs including technology dependency. It is available to children/young people between 0–25 years. Care is nurse to patient ratio appropriate for the care needs of the CYP during early and late shifts according to need and reviewed as required overnight.

The service includes physiotherapy, hydrotherapy, music and complementary therapy and specialist play activities. Outreach services include youth work, family, sibling, cultural, spiritual and bereavement support. Families are offered 10 nights of routine bookable short break care a year, plus unlimited emergency care. Funded packages of additional residential short break care are available on a negotiated basis.

The service also provides specialist guidance, support and knowledge to the community teams throughout the region.

3.3 Population covered

Children and young people (aged 0-25 years) registered with a General Practitioner within the NHS Nottingham and Nottinghamshire ICB footprint.

3.4 Any acceptance and exclusion criteria and thresholds

Anyone can refer a child and information is then gained to assess if a child meets the criteria. The hospice accepts families with a child who has a life-limiting condition and is not expected to live into adulthood.

The service is available 24 hours a day 365 days a year.

The timing of referral process is dependent on access of information and stage of condition of the child. If a child is being referred for end of life care, a referral can be completed within a couple of hours.

3.5 Interdependence with other services/providers

The provider will have interdependencies with:

- Integrated Children and Young People's Healthcare Programme
- Children's Centres
- Schools (including Special Schools)
- Social Work Teams
- Voluntary Agencies
- Nottingham University Hospitals Staff
- Clinical Commissioning Groups
- GPs/Practice Nurses
- School Nurses/Health Visitors
- Community Therapy Staff

4. Applicable Service Standards

4.1 Applicable national standards (eg NICE)

- HM Government (2013) Working Together to Safeguard Children: A guide to interagency working to safeguard and promote the welfare of children
<http://media.education.gov.uk/assets/files/pdf/w/working%20together.pdf>
- Legislation.gov.uk (2010) Equality Act 2010
<http://www.legislation.gov.uk/ukpga/2010/15/contents>
- 'You're Welcome': quality criteria for young people friendly health services
http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_126813
- Children and Young People's Outcomes Forum Pledge for better outcomes
https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/207391/better_health_outcomes_children_young_people_pledge.pdf
- Children and Young People's Health Outcome Forum 2014
<https://www.gov.uk/government/publications/responses-from-children-and-young-peoples-health-outcomes-forum>
- DH (2010) Achieving equity and excellence for children
http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/@ps/documents/digitalasset/dh_119490.pdf
- HM Government (2013) Working Together to Safeguard Children: A guide to interagency working to safeguard and promote the welfare of children
<http://media.education.gov.uk/assets/files/pdf/w/working%20together.pdf>
- CQC (2010) Essential standards of quality and safety
http://www.cqc.org.uk/sites/default/files/media/documents/gac_-_dec_2011_update.pdf
- HM Government (2004) The Children Act 2004
<http://www.legislation.gov.uk/ukpga/2004/31/contents>
- Children and Families Act 2014 <http://www.legislation.gov.uk/ukpga/2014/6/contents/enacted>

4.2 Applicable standards set out in Guidance and/or issued by a competent body (eg Royal Colleges)

4.3 Applicable local standards

5. Location of Provider Premises

The Provider's Premises are located at:

Lark Rise
Loughborough
Leicestershire
LE11 2HS