

E09/S/c

**NHS STANDARD CONTRACT  
FOR PAEDIATRIC NEUROSCIENCES- NEURODISABILITY**

**SCHEDULE 2 – THE SERVICES A. SERVICE SPECIFICATIONS**

<b>Service Specification No.</b>	<b>E09/S/c</b>
<b>Service</b>	<b>Paediatric Neurosciences - Neurodisability</b>
<b>Commissioner Lead</b>	
<b>Provider Lead</b>	
<b>Period</b>	12 months
<b>Date of Review</b>	

## 1. Population Needs

### 1.1 National/local context and evidence base

Neurodisability is an umbrella term for conditions associated with impairment involving the nervous system and includes conditions such as cerebral palsy, autism and epilepsy; it is not uncommon for such conditions to co-occur. Children with a neurodisability have a range of impairments but many have complex and continuing need and as a result are frequent users of the health service at all levels, community, primary care inpatient and outpatient settings.

Disability in children and young people is common. It is estimated from a Family Resource Survey 2004 / 5 that there are 952 741 disabled children in the UK. Disability in children ([ukpmc.ac.uk/ukpmc/ncbi/articles/](http://ukpmc.ac.uk/ukpmc/ncbi/articles/)) which is 7.3% of the population of children and young people aged 0 - 18 years. This means that 8.8% of boys and 5.8% of girls are disabled. Many of these children and young people have difficulties in more than one area of daily living, with around a third experiencing two to four difficulties and more than 10% experiencing five or more difficulties. A number of recent reports have highlighted the inequalities and poor standards of care afforded to individuals with learning disabilities in the UK. (Healthcare for all: report of the independent inquiry into access to healthcare for people with learning disabilities. July 2008; Valuing people now.

Department of Health 2009; Equalities scoping study. Foundation for people with learning disabilities July 2011).

## 1.2 Epidemiology:

Many of the conditions that cause neurodisability that require care and specialist advice from specialist teams individually rare for example:

- Neurometabolic disorders and neurodegenerative conditions Batten’s Disease (1 in 12,500 live births), ataxia telangiectasia (< 1 in 40,000)
- Neurocutaneous syndromes e.g. tuberous sclerosis (< 1/ 100,000 live births);
- Profound and multiple learning disability (PMLD) groups e.g. Rett syndrome affecting less than 1 in 10,000.

Other neurodisabling conditions are more common, e.g. the autism spectrum disorders affect ~1 in 100 of the population and the cerebral palsies ~1 in 400, severe intellectual disabilities ~3 in 1000. However, the range of associated conditions and nuances of individual presentation are such that specialist neurodisability expertise is required for accurate assessment and management. For example, 10-15% of all children and young people with cerebral palsies have developmental brain anomalies, some of which are genetically determined and may have implications for the wider family as well as implications for language and learning for the individual.

## 2. Outcomes

### 2.1 NHS Outcomes Framework Domains & Indicators

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

- Through the provision of a multi-disciplinary neurodisability service children, young people and their families health outcomes are maximised as a direct outcome of

engagement and proactive management by the specialist multi-disciplinary service provided by the Neurodisability and related Clinics

- Parents/carers (and siblings) are enabled to cope effectively with the child's complex health and emotional needs
- Through early diagnosis and intervention children and young people experience a reduction in late and often more intense treatment requirements for their condition
- The emotional needs of children and young people are anticipated with appropriate support and referral to the range of Child and Adolescent Mental Health Services where appropriate with referral through CAMHS SPA (this includes targeted provision with a nurse specialist in disability and emotional wellbeing)
- With appropriate consent, co-ordination and dissemination of information relating to specific children and young people is facilitated by appropriate attendance at multidisciplinary and multi-agency team meetings
- There is a clear processes for safeguarding which is applied in line with a national and local safeguarding policy
- All training delivered is evaluated and is of high quality
- Rates of diagnoses for sentinel conditions e.g. cerebral palsies, severe learning disabilities (defined here as IQ<50), autism spectrum disorders should be available and related to population denominators.
- Rates of specific diagnoses for those with a severe learning disability should be available and related to population denominators.
- Rates and durations of hospital admissions for those with sentinel conditions should be available and related to population denominators.

### **3. Scope**

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#### **3.1 Aims and objectives of service**

The key aims of the service is to:

- To improve the health outcomes for children and young people who have a neurodisability
- Early, appropriate and cost – effective
- Increase the focus on improving children's lives by ensuring that professional work together across organisational boundaries to meet the needs of the young people.

The key objectives are to:

- To provide a high quality, timely consultant led medical service for children and young people with complex neurodisability for children and young people under the age of 19 (or during transition into adulthood).
- Through the provision of a multi-disciplinary neurodisability service, children young

people and their families health outcomes are maximised as a direct outcome of engagement with the specialist multi-disciplinary neurodisability team.

- To support the training strategy through the delivery of training to professionals in relation to neurodisability within the regional networks and other services, health, education, social etc.
- To enable research this will provide the evidence base for future care.
- To contribute to the collection of epidemiological data pertinent to disabled children and young people, including measures of outcomes.

### **3.2 Service description/care pathway**

The service (part of an integrated multi-disciplinary team) will provide appropriate paediatric assessment, including full investigative and diagnostic service. The service will provide management for a range of related medical needs. High quality specialist child and family centred care will be delivered by appropriately qualified and skilled professionals.

Some children and young people have more specialist and complex neurodisability at times during their care that is largely provide by a secondary care team require assessments or treatments or interventions from colleagues in the area network. Each area will agree their own pathways for referral to these services e.g. complex spasticity interventions.

The tertiary neurodisability service will ensure that:

- Children and young people's health outcomes are enhanced through access to a specialist paediatric multi-disciplinary neurodisability service.
- Children and young people who are living with a Long Term Conditions (LTC) and/or disability are proactively managed and as a direct result there is prevention of unnecessary exacerbation of symptoms and in turn reduction in avoidable acute hospital admissions. Hospital admission rates for disabled children and young people will be measured over time.
- Early diagnosis and interventions contribute positively to the reduction in late and potentially, more intense treatment of presenting conditions. Diagnostic rates for primary diagnoses and secondary disabilities could be measured and related to population denominators.
- The emotional health and wellbeing of children and young people who have a neurodisability is considered with appropriate support and referral.
- The service pathway is designed to enhance user experience, enabling access to a multi-disciplinary team where appropriate, thus reducing unnecessary appointments.
- The service applies proactive management approaches to improve the equity and accessibility of the service to promote engagement with the most vulnerable and hard to reach children and young people who have a Neurodisability.
- A robust framework of safeguarding standards is applied within the service provision.
- Advice and appropriate support is given to increase the knowledge and skills of staff in community health services, secondary and primary care that are responsible for

providing services to children and young people who have a Neurodisability.

- Patients are managed effectively within waiting time standards.
- Onward referral and signposting is compliant with care pathways – and the neurodisability centre has a responsibility to ensure that this occurs
- Effective transition planning is managed in a timely manner
- The principles and standards outlined in national policy (for example – Standards within Children and Young People’s National Standards Framework (DH, 2004) are met to ensure and promote participation and cross agencies integration measured by Patient Reported Outcome Measures (PROMs).
- Families experience seamless care, including provision of appropriate equipment across all settings

The service will be available to all patients who meet the referral criteria and offers:

- Medical (multidisciplinary) assessment including full investigation and diagnostic service, on-going management for associated medical needs e.g. respiratory problems, epilepsy, feeding and nutrition, constipation, challenging behaviour and medical management of spasticity.
- Development of care pathways with networks.
- Liaison with partner agencies to promote and enable a coordinated package of support agreed with families (therapy, education, Early Years education teams, social care, and voluntary sector).
- Provision of outreach support for the care package including specific therapeutic input if not locally available e.g. Botulinum toxin treatment, challenging behaviour strategies, psychopharmacology; respiratory, enteral feeding etc.
- Transition planning (from age 14 years) into suitable adult Leading and coordinating research into translational care to provide the evidence base for treatments.

A comprehensive specialist paediatric neurodisability service comprises three aspects:

- Acute treatment alongside neurological or neurosurgical treatment e.g. Botulinum toxin, dysphagia assessment
- Tertiary specialist neurodisability interventions usually carried out at a later date e.g. detailed neuropsychological and communication assessments
- Long term disability care carried out by the community disability team embedded in the child and young person’s setting in partnership when required with the specialist network.

This service specification emphasizes that the specialist services need to work closely with the community disability teams, the “Hub and Spoke” model.

Some aspects will require shared care with other specialist services e.g. ophthalmology, ear nose and throat (ENT), wheelchair services, neurosurgery,

## **Tertiary specialist neurodisability service**

Paediatric specialist neurodisability services will be delivered by paediatricians trained in neurodisability and neurology who will be the core deliverers of care.

They will work with a team comprising of :-

- Paediatric physiotherapy
- Paediatric occupational therapy
- Paediatric speech and language therapy and assessments including for communication, social communication, augmented and assisted communication, dysphagia, feeding and swallowing
- Mobility , wheelchair and specialised equipment services
- Paediatric surgery e.g. orthopaedics, gastroenterological
- Paediatric neuropsychology and neurocognitive assessments/educational psychology
- Child psychiatry and neuropsychiatry
- Neurophysiology
- Dietetics
- Sleep specialists
- Children's nursing (children's community nurses, learning disability nurse specialists, epilepsy nurse specialists etc.)
- Specialist teachers—e.g. hospital schools, specialist teachers for those with sensory impairments, specialist teachers with expertise in information and computer technologies, specialist teachers with expertise in autism-specific teaching and communication strategies.

The service will have access to the following co-dependencies:

- Paediatric neurology
- Paediatric neurosurgery
- Paediatric ophthalmology and orthoptics
- Ear, Nose and Throat and audiology
- Paediatric gastroenterology
- Paediatric surgery and urology
- Paediatric specialist orthopaedics
- Paediatric endocrinology
- Neuro-imaging
- Neurophysiology
- Clinical genetics, cytogenetic and molecular genetics
- Specialist sleep service with Sleep laboratory studies
- Specialist paediatric orthopaedics
- Specialist biochemistry, haematology, microbiology laboratory investigation.

All the above will need to be available at an inpatient and outpatient level.

**A) Services and assessments that should be available from a specialist networked centre include:**

- Diagnostic confirmation (in neurodevelopmental disorders this is often in those with complex and multiple disabilities)
- Severe dystonic postures
- Management of spasticity
- Dysphagia management and investigations including video fluoroscopy
- Assistive technology, including environmental control and powered mobility
- Spinal/postural management in children with complex motor disorder
- Complex care packages (e.g. children requiring 1 to 1 healthcare support in the home)
- Children requiring home ventilation for neurological causes including neuromuscular illness and specialist equipment
- Severe epilepsy with challenging behaviours
- Complex neurodegenerative conditions with loss of skills
- Sensory loss with vision and hearing loss.
- Severe communication needs that require alternative and augmented communication systems
- Paediatric neuro-rehabilitation following traumatic or non-traumatic acquired brain injury (ABI) and acquired spinal cord injury (ASI), inc. post-surgery.
- Behavioural/cognitive/neuropsychological rehabilitation programmes
- Assessment and multidisciplinary management of children with neuropsychiatric conditions including chronic pain and functional disorders.
- Diagnosis and management of uncommon syndromes and developmental problems requiring paediatric neurology and specialised neurodisability services.
- End of life care for the child with complex neurodisability
- Severe sleep problems in children and young people (CYP) with LTCs and disability
- Intellectual disorders with challenging behaviours
- Any neurodevelopmental disorder with complex additional medical or behavioural disorders

Increasingly specialist tertiary paediatric neurodisability is sub specialising into teams majoring in tertiary neurodisability with complex behavioural problems, autism, epilepsy diagnoses etc. and the teams who offer expert assessment and intervention for children and young people with complex motor problems related to spasticity and dystonia.

**B) The service provided by a specialist neurodisability centre will include the following interventions.**

- Intrathecal baclofen
- Spinal dysraphism disability interventions
- Vagal nerve stimulation (VNS)

- Botulinum toxin treatment
- Complex neuropsychiatric assessments e.g. autism ,attention deficit hyperactivity disorder (ADHD), with co-morbidities, marked behaviour needs
- Co-ordination of support with respiratory specialists when breathing is significantly compromised
- Sleep studies and interpretation

All above may need:-

- Dietetic, feeding assessment and gastrostomy support
- Therapy intervention and ongoing treatment
- Case management support for families with particularly complex problems

**C) Some conditions can be managed by a shared care arrangement** between the local hospital or neurodisability paediatrician and the specialist neurodisability centre. Requiring liaison through out-reach with local services (health, social and education).

### 3.3 Population covered

The Lead Paediatrician will initiate a referral to a specialist centre.

All disabled children and young people need health care as close to home as is possible. Paediatric neurodisability is a relatively new subspecialty and as such does not fit neatly into the conventional model of secondary and tertiary care.

Regional networks should clarify with their local CCG's the specialist paediatric neurodisability pathway for their populations which may vary from one geographical area to another.

### 3.4 Any acceptance and exclusion criteria

Referrals will be through a number of avenues including:-

- Neonatal services
- Paediatric and Specialist Consultants
- Paediatric Neurology and neurosurgery teams

Several of the interventions offered by the specialist neurodisability team have clear eligibility criteria as described in national guidelines of good practice e.g. ITB.

Exclusion criteria: Patients not meeting referral criteria will be excluded.

Discharge planning will be carried out through early engagement with child, young Person, parents/carers and other services. Children with a LTC, chronic illness or disability will have a written care plan and may be treated according to the individual conditions needs.

### **3.5 Interdependencies with other services**

To the needs of the client group there is a requirement to work proactively with a range of partners and key stakeholders, including primary care, general practitioners, Children's Social Care, Adult Health and Social Care and non-NHS agencies to ensure appropriate referrals, fast response times and high quality patient care. Stakeholders and interdependencies will include outreach advice and support to:

- Parents /carers in their homes and the CYP themselves at appropriate age
- Midwifery services
- Neonatal services
- Children Centre facilities staff
- GP's
- Child and Adolescent Mental Health (CAMHS)
- Social services - children and young people's teams
- Education services
- Third sector providers of children's services
- Carer support services
- Therapy services (occupational therapy (OT), Physiotherapy & speech and language therapy (SALT), nursing teams in community locally

## **4. Applicable Service Standards**

### **4.1 Applicable national standards e.g. NICE**

#### Policy Guidance

##### National

- Safe and sustainable
- Children's neurological services in England a framework for the future. 2011
- DCSF (2007) Children's Plan: Building brighter futures
- DfES (2007) Aiming High for Disabled Children: Better support for families
- DfES (2003) Every Child Matters
- DH (2009) Healthy Lives, Brighter Futures
- DH (2008) Better Care: Better Lives
- DH (2007) Mental Health Act
- DH (2007) Children's health, our future: A review of progress against the NSF for Children and Young People and Maternity Services -2004
- DH (2006) Our Health, Our Care, Our Say: a new direction for community services
- DH (2004) National Service Framework for Children, Young People and Maternity Services –Standard 8: Disabled Children and Young People and those with Complex Health Needs
- DH (2004) National Service Framework for Children, Young People and Maternity Services – Standard 10: Medicines for Children and Young People

- HM Government (2010) Working Together to Safeguard Children: A guide to interagency working to safeguard and promote the welfare of children
- HM Government (2004) The Children Act 2004
- HM Government (1989) The Children Act 1989
- NICE Guidance for (2012) Spasticity in children and young people
- Social Exclusion Task Force (2007) Reaching Out: Think Families (Cabinet Office)
- NICE diagnosis of ASD
- NICE Epilepsy in childhood
- NICE ADHD

**4.2 Applicable standards set out in Guidance and/or issued by a competent body (e.g. Royal Colleges)**

- BPNA guide for purchasing tertiary paediatric neurological services 1998
- RCPCH (2007) Modelling the Future 1 and 2.
- Early support programme

**5. Applicable quality requirements and CQUIN goals**

**5.1 Applicable quality requirements (See Schedule 4 Parts A-D)**

**5.2 Applicable CQUIN goals (See Schedule 4 Part E)**

**6. Location of Provider Premises**

**The Provider's Premises are located at:**

**7. Individual Service User Placement**

## APPENDIX 1.

Quality Requirement	Threshold	Method of Measurement	Consequence of breach
<b>Domain 1: Preventing people dying prematurely</b>			
Quality assessment and care plan for emergencies and chronic needs	100%	<p>PREM Existence of emergency care plan held by family /school etc Neurosurgical dashboards – time to imaging etc from ABI Immunisation rates Safeguarding – death in children with a disability</p> <p>Immunisation rates in children with known disability inc 'flu jab</p>	As set out in Service Condition 21 and Schedule 4 Part G
<b>Domain 2: Enhancing the quality of life of people with long-term conditions</b>			
Reduction in time off school Support for families Reduction in challenging	All children with LTIs have access to support	<p>DfE stats Offer of respite/ PREM/PROM Before and after measure eg ABC</p>	As set out in Service Condition 21 and Schedule 4 Part G

behaviour Improved educational attainments (if appropriate) Improved well being		DfE stats  Reduced in patient stays	
<b>Domain 3: Helping people to recover from episodes of ill-health or following injury</b>			
Systematic assessments of coexisting problems as part of initial assessment Reduction episodes of inpatient care Plan for integrated care following admission eg for surgery	Included in all initial assessments  All surgical patients	In report  HES data  Evidence of plan written/integrated and planned with family  Shortened admission times Return to inclusion in school / community	As set out in Service Condition 21 and Schedule 4 Part G
<b>Domain 4: Ensuring that people have a positive experience of care</b>			
Early response to concerns Quality assessment and care plan developed with family Health passport Key worker approach for LTCs and disability/palliative care	85%	Time from concern to diagnosis  Existence of assessment and care plan Evidence of availability  Named key worker	As set out in Service Condition 21 and Schedule 4 Part G
<b>Domain 5: Treating and caring for people in a safe environment and</b>			

**protecting them from avoidable harm**

Appropriate environment for hospital admissions	80%	Children and young people trained staff  Accidents Safeguarding	As set out in Service Condition 21 and Schedule 4 Part G
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## Change Notice for Published Specifications and Products

### developed by Clinical Reference Groups (CRG)

#### Amendment to the Published Products

**Product Name**

Neurosciences- Neurodisability

**Ref No**

E09/S/c

**CRG Lead**

Ian Pople

#### Description of changes required

Describe what was stated in original document	Describe new text in the document	Section/Paragraph to which changes apply	Describe why document change required	Changes made by	Date change made
	Statement inserted under 3.2 to clarify secondary care provision and networked approach to care pathway management.	Page 4		CRG	April 2014
	Describes to clarify hub and spoke approach and outline the three main aspects that specialised neurodisability comprises and the need for	Page 5		CRG	April 2014

	shared care arrangements.				
	Outlines the anticipated service and assessments provided by a specialist centre	Pages 6- 7		CRG	April 2014
	Highlights referral to specialised services. Clarifies pathway and CCG involvement	Page 8		CRG	April 2014
	Lists quality indicators for children with long term conditions	Appendix 1		CRG	April 2014