E09/S/b

2013/14 NHS STANDARD CONTRACT FOR PAEDIATRIC NEUROSCIENCES - NEUROLOGY

PARTICULARS, SCHEDULE 2 – THE SERVICES, A - SERVICE SPECIFICATIONS

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

1. Population Needs

1.1 National/local context and evidence base

The neurological conditions covered by this specification are attached in Appendix 1. It has been estimated that 2-3% of the child population will have some level of special needs and/ or disability. 0.3-0.5% will have severe learning disabilities. The vast majority of disabilities are neurological in origin. Paediatric epilepsy is the most common neurological disorder with an overall childhood incidence of 50-70 cases per 100,000 per year and a childhood prevalence of 5-10 cases per 1,000 population. This affects about 0.7% of all children as shown in the table below.

Non-traumatic acute encephalopathy has an incidence of approximately 50 per 100,000 per year. Metabolic disorders may present either as an acute encephalopathy or as long term neurological illness. Individual conditions are rare (e.g. phenylketonuria (PKU), 8.5 per 100,000. Many of the neuromuscular conditions are rare but all lead to significant morbidity. The overall prevalence of an inherited neuromuscular disease may well exceed 33/100,000 and a large proportion of these will be in the paediatric age group.

4 per 100,000 children aged 0-16 years will be diagnosed with a tumour of the central nervous system.

Condition	Prevalence	Estimated Number in PCO
Cerebral Palsy	3/1000 live births	110
Autistic spectrum Disorder	1/100	500
Epilepsy	0.7/100	350
Severe learning difficulties	0.3/100	150
Acquired brain injury	18/100,000	9
Muscular dystrophy	0.3/1000 male births	5

Evidence Base

The evidence base for treatments for this service are contained in the following:
- Department of Health (20050 'Long-term (neurological) conditions National Service Framework'

Available from the National Institute of Health and Clinical Excellence - www.nice.org.uk.

The service should comply with the requirements of the Department of Health's 'Commissioning Safe and Sustainable Specialised Paediatric Services: A framework of Critical Inter-Dependencies'.
- NICE (2004) 'The epilepsies: the diagnosis and management of the epilepsies in adults and children in primary and secondary care, NICE Clinical Guideline, CG20
- NICE (2007) 'Chronic fatigue syndrome', NICE Clinical Guideline, CG53
- NICE (2007) 'Triage, assessment, investigation and early management of head injury in infants, children and adults', NICE Clinical Guideline CG56

NICE Clinical Guidelines in development:
- neuropathic pain in adults
- sedation in children
- autism in children and adolescents
- bacterial meningitis and meningococcal septicaemia.

2. Scope

2.1 Aims and objectives of service

The aim of the service is to ensure that children and young people with serious neurological conditions achieve the best quality of life, through the provision of excellent diagnosis, investigation, intervention, management and information. The NICE Clinical Guidelines note that optimal management improves health outcomes and can also help to minimise other, often detrimental, impacts on social, educational and employment activity. The objectives of the service are:

- To provide accurate diagnosis and cost-effective management including rehabilitation, of children with neurological disorders.
- Expert management of life-threatening and potentially treatable disorders.
- Avoidance of severe disability by preventing delay in appropriate treatment.
- Avoidance of further affected cases by the recognition of a genetic disorder and provision of appropriate counselling.
- Effective provision for educational needs by specialist evaluation (e.g. developmental language disorder)
- Avoidance of unnecessary anxiety, hospitalisation, investigation and treatment and provision of appropriate advice and reassurance.

2.2 Service description/care pathway

The service will additionally follow the standards and criteria outlined in the general specification for children’s services (attached as Annex 1to this specification). Paediatric neurology services are provided both in out- and in in-patient settings. The majority of the services are recognised as specialised (otherwise known as tertiary level) and consequently are based in Neurosciences Centres which have the necessary infrastructure in terms of diagnostic services and other specialities. However, paediatric neurology provides out-reach out-patient services based in secondary care centres around the geographical region served. This allows specialist services to be provided as near to patients as is reasonably feasible. Patients seen in out-reach clinics are usually under the joint care of a local paediatrician. Some services are run by voluntary organisations**.**

This service is commissioned to provide all treatments from the point of referral. The majority of patients cared for by paediatric neurology services are referred from secondary level paediatric services. Others are referred directly from primary care, within agreed protocols, or from other paediatric specialties, including paediatric neurosurgery. Out-patient services are provided from a range of out-patient clinics, which will include general paediatric neurology clinics and sub-specialist clinics, such as epilepsy, neuro-oncology and neuromuscular clinics. Many such clinics are multi-disciplinary, involving other medical specialists, therapists and other allied professions. Children requiring diagnostic investigations often have these undertaken as day case admissions.

Diagnostic investigations necessary for the care and management of children with neurological disorders include:

- Haematological, biochemical and microbiological investigations – paediatric
- neurological services require access to high quality haematological, biochemical and microbiological investigations, needed to detect and monitor disturbances in body systems outside the brain and to investigate infectious diseases (viral, bacterial, protozoal, fungal and prion), both of the nervous system and outside the nervous system.
- X-ray and neuroimaging – paediatric neurology services require ready access to conventional bony X-ray imaging of skulls, spines and other bones (including skeletal surveys for suspected non-accidental injury); digital subtraction angiography; computerized topography (CT) brain (including CT angiography); magnetic resonance imaging (MRI) brain (including Magnetic Resonance (MR) angiography, MR spectroscopy and functional MRI) and spine; X-ray and CT myelography; neonatal brain ultrasound examination, and doppler ultrasound vascular imaging . In addition paediatric neurology may require access to positron emission tomography (PET) and single photon emission computed tomography (SPECT). Such specialised imaging may not be available on site and may need to be accessed from a supra-regional centre.
- Neurophysiology – Electroencephalography (EEG) (including standard and sleep recordings; ambulatory EEG and EEG video telemetry; evoked potentials (visual, brain stem/auditory and somatosensory); nerve conduction studies; electromyography and electroretinography.
- Neurometabolic investigations – the ability to investigate potential neurometabolic investigations is essential to paediatric neurology. These investigations are mainly done on blood, urine and cerebrospinal fluid (CSF). Less commonly they are performed on samples derived from biopsies taken from skin, liver, bone marrow and brain. Many neurometabolic investigations will be processed on site but sent to specialist supra-regional, national or international laboratories.
- Neuroendocrine investigations – the ability to investigate potential neuroendocrionologial disorders is essential to paediatric neurology. These investigations are mainly done on blood samples and occasionally from CSF. Some neuroendocrine investigations will be processed on site but sent to specialist supra-regional or national laboratories.
- Neuroimmunological investigations – the ability to investigate potential neuroimmunological disorders is essential to paediatric neurology. These investigations are done on blood and CSF samples. Some neuroimmunological investigations will be processed on site but sent to specialist supra-regional or national laboratories.
- Neuro-opthalmalogical investigations – ready access to specialist paediatric opthalmological services able to provide direct and indirect fundoscopy, optometry and visual field testing is essential for paediatric neurology services.
- Neuropathological investigations – ready access to a neuropathology laboratory able to process and analyse CSF cystospin specimens, and biopsy material taken from brain, muscle, nerves and other body organ and tissues is

necessary for paediatric neurology. In addition access to supra-regional, national and international neuropathology laboratories is sometimes required, particularly in the investigation of children with neuro-oncological, neuromuscular and neurodegenerative disorders.

- Genetic investigations – ready access to clinical and laboratory genetic services able to provide comprehensive clinical, chromosomal and molecular DNA diagnostic genetic services is essential for paediatric neurology services.
- Psychometric testing – paediatric neurology services require access to psychologists and neuropsychologists able to undertake psychometric evaluations in children of all ages and in children with various impairments (including visual and hearing impairments).
- Cardiological investigations – ready access to 12 lead ECG is required for the investigation of many children with paroxysmal events. Access to tilt testing is required for the investigation of selected children with paroxysmal events. Cardiological assessment, including echocardiography (including trans-osophageal echocardiography) may be required in the assessment of children presenting with strokes and brain abscesses and in children with neuromuscular diseases.
- Respiratory investigations, access to lung function tests and overnight saturation monitoring is required for the investigation and management of some children with neurological conditions, especially neuromuscular diseases.
- Gastrointestinal investigations – access to speech and language feeding assessment, video-fluoroscopy and oesophageal pH monitoring is required for the management of many children with neurological disorders.
- Audio logical assessment.

Investigations

Investigations are done in a variety of settings, including out-patients, day case units and onwards. Paediatric neurology services need to be able to access many investigations out of normal working hours. This includes haematological, biochemical and microbiological services, conventional x-ray services, CT and MRI brain scans and standard EEG. Access to out-of-hours neuropathological services, including processing of samples to be analysed later, is occasionally required. Some investigations, including neuroimaging, can only be undertaken under general anaesthesia in some or all patients. 24h hour access to general anaesthetic services is necessary to provide an acute paediatric neurology service. Children with disabilities caused by neurological disorders are often under the joint care of Paediatric Neurology and Neurodisability / Community Paediatric Services. The Neurodisability / Community Paediatric service component will not be covered by this contract.

In-patient Care

In-patients are located in a variety of settings, including designated paediatric neurology beds (often in a joint neuroscience ward shared with paediatric neurosurgery), paediatric intensive care beds and on neonatal units. In-patients may be under the joint care of other consultants, especially paediatric intensivists, cardiac intensivists, neonatologists and paediatric neurosurgeons. Most in-patients will have acute neurological disorders or acute medical problems caused by an underlying neurological disorder. Hospital admission will have been necessary in order to enable diagnostic tests only reasonably available in an in-patient setting to be undertaken, or to allow in-patient based therapeutic interventions to be undertaken. Many such patients will need to be nursed in an intensive care setting or on a high dependency unit.

In-patients with disorders principally involving other body organs and systems often have associated neurological problems or complications. Paediatric neurology services provide liaison services to such children. Paediatric neurology, in collaboration, with other services, provides rehabilitation services for patients following neurological and neurosurgical problems, including traumatic brain injury. This often begins in an in-patient setting in the regional neuroscience centre, being continued in the local secondary care centre or as an out-patient.

On-going Care

Children who recover from acute or long-term neurological conditions may be discharged back to the care of their general practitioner. Children with on-going neurological problems not requiring on-going specialist neurological services may be discharged to general or community paediatric services or neurodisability services. This includes children who require or have required neuro-rehabilitation

The diversity of the disorders managed by paediatric neurology services means that the multi-disciplinary team (MDT) is large. Different members of the MDT will be more or less involved depending on the particular disorder of the individual patient. Key medical members of the MDT are:
- General and community paediatrics (especially involved in cases of non-accidental injury)
- Paediatric ophthalmology
- Neurophysiology

Key non-medical members of the MDT are:
- Neurophysiology technicians
- Physiotherapists
- Occupational therapists
- Speech and language therapists
- Neuropsychology
- Clinical psychology
- Nurse specialists (e.g. epilepsy nurse specialists)
- Neuromuscular Family Care Officers
- Hospital teacher
- 10.Play therapist

In addition, close links with health visitors, social services and education are important, depending on the needs of the individual child and/or their family

Some children with neurological disorders require long-term invasive or non-invasive ventilation. This is usually undertaken at home following initiation in hospital. An in- patient facility is needed to initiate such treatment and as dictated by the clinical condition of the patients. Paediatric neurologists are a key part of the multidisciplinary team caring for such children.

General Paediatric care

When treating children, the service will additionally follow the standards and criteria outlined in the Specification for Children's' Services (attached as Annex 1 to this specification)

2.3 Population covered

The service outlined in this specification is for patients ordinarily resident in England*; or otherwise the commissioning responsibility of the NHS in England (as defined in Who Pays?: Establishing the responsible commissioner and other Department of Health guidance relating to patients entitled to NHS care or exempt from charges). * note: For the purposes of commissioning health services, this EXCLUDES patients who, whilst resident in England, are registered with a GP practice in Wales, but INCLUDES patients resident in Wales who are registered with a GP practice in England.

The Paediatric neurology service will provide accurate diagnosis for children up the their 19th birthday presenting with symptoms or signs of dysfunction of the central and peripheral nervous system, which includes the brain, spinal cord, peripheral nerves and muscles. It is also involved in antenatal diagnosis of such disorders. Paediatric neurology will provide holistic, evidence-based management for the same group of patients. This includes provision of curative treatments, symptomatic treatments, neuro-rehabilitation, disability management, palliative care and end of life care. To do so it works closely with many other clinical and diagnostic disciplines and other agencies**.**

2.4 Any acceptance and exclusion criteria

In general children with the following conditions will be excluded from this service and will be seen/managed in secondary care or by other specialist services. Children with neurological disorders who are mainly or often managed by other disciplines are:

- 'Simple' headache (primary care and secondary paediatrics)
- Febrile seizures (secondary paediatrics)
- Some epilepsy as defined in relevant NICE guidelines(secondary paediatrics, including neurodisability)
- Learning problems (neurodisability, however, the investigation of the cause of learning problems is often under paediatric neurology services)
- Behavioural problems including autistic spectrum disorders (secondary

- paediatrics, neurodisability, Child and Adolescent Mental Health Services (CAMHS), however, the investigation of the cause of these problems is often under paediatric neurology services)
- Meningitis without significant neurological complications (general paediatrics)

2.5 Interdependencies with other services

The service should comply with the requirements of the Department of Health's Commissioning Safe and Sustainable Specialised Paediatric Services: A framework of Critical Inter-Dependencies. Co-located services:

- Paediatric Intensive Care Unit (PICU)
- Neonatal unit
- Neuroradiology (including interventional neuroradiology)
- Neurophysiology
- Therapy services (physiotherapy, occupational therapy, Speech and Language, dietetics)
- School (if rehabilitation is undertaken on site)

Interdependent services:

- Neuropsychology
- Clinical psychology
- Child and adolescent psychiatry

3. Applicable Service Standards

3.1 Applicable national standards e.g. NICE, Royal College

CORE STANDARDS

Department of Health and NICE Guidance as in Section 1

RECOMMENDED STANDARDS

The Royal College of Paediatrics and Child Health (RCPCH Spasticity in children and young people with non-progressive brain disorders. British Paediatric Neurology Association (BPNA) A Guide for Purchasers of Tertiary Services for Children with Neurological Problems (2008). Diagnosis and management of Duchenne muscular dystrophy, Part 1: diagnosis, and pharmacological and psychosocial management – Part 2: Implementation of multidisciplinary care:

- The Lancet January 2010
- Ataxia UK Guidelines (2009)

- European Consensus guidelines for management of Paediatric MS
- Muscular Dystrophy Campaign Service Guidelines.

4. Key Service Outcomes

- Reduced mortality for potentially fatal but treatable conditions (e.g. meningoencehalitis)
- Reduced morbidity for children with potentially disabling but treatable conditions (e.g. meningo-encephalitis)
- Increased remission rate for children with potentially surgically treatable epilepsy
- Reduced seizure frequency in children with non-surgically treatable epilepsy
- Improved survival in Duchenne Muscular dystrophy
- Improved quality of life in children and young people who survive brain tumours and those with epilepsy
- Improved antenatal diagnosis of severe neurological disorders leading to improved pregnancy planning
- Reduction in emergency admission

ANNEX 1 TO SERVICE SPECIFICATION:

PROVISION OF SERVICES TO CHILDREN

Aims and objectives of service

This specification annex applies to all children’s services and outlines generic standards and outcomes that would fundamental to all services. The generic aspects of care: The Care of Children in Hospital (Health Service Circular (HSC) 1998/238) requires that:

- Children are admitted to hospital only if the care they require cannot be as well provided at home, in a day clinic or on a day basis in hospital.
- Children requiring admission to hospital are provided with a high standard of medical, nursing and therapeutic care to facilitate speedy recovery and minimise complications and mortality.
- Families with children have easy access to hospital facilities for children without needing to travel significantly further than to other similar amenities.
- Children are discharged from hospital as soon as socially and clinically appropriate and full support provided for subsequent home or day care.
- Good child health care is shared with parents/carers and they are closely involved in the care of their children at all times unless, exceptionally, this is not in the best interest of the child; accommodation is provided for them to remain with their children overnight if they so wish.

Service description/care pathway

- All paediatric specialised services have a component of primary, secondary, tertiary and even quaternary elements.
- The efficient and effective delivery of services requires children to receive their care as close to home as possible dependent on the phase of their disease.
- Services should therefore be organised and delivered through “integrated pathways of care” (National Service Framework for children, young people and maternity services (Department of Health & Department for Education and Skills, London 2004).

Interdependencies with other services

All services will comply with Commissioning Safe and Sustainable Specialised paediatric Services: A Framework of Critical Inter-Dependencies – Department of Health.

Imaging

All services will be supported by a three-tier imaging network (‘Delivering quality imaging services for children’, Department of Health 13732 March, 2010). Within the network:

- it will be clearly defined which imaging test or interventional procedure can be performed and reported at each site
- robust procedures will be in place for image transfer for review by a specialist radiologist, these will be supported by appropriate contractual and information governance arrangements
- robust arrangements will be in place for patient transfer if more complex imaging or intervention is required
- common standards, protocols and governance procedures will exist throughout
- all radiologists, and radiographers will have appropriate training, supervision and access to continuing professional development
- all equipment will be optimised for paediatric use and use specific paediatric software

Specialist Paediatric Anaesthesia

Wherever and whenever children undergo anaesthesia and surgery, their particular needs must be recognised and they should be managed in separate facilities, and looked after by staff with appropriate experience and training.1 All UK anaesthetists undergo training which provides them with the competencies to care for older babies and children with relatively straightforward surgical conditions and without major co-morbidity. However those working in specialist centres must have undergone additional (specialist) training2 and should maintain the competencies so acquired3 *. These competencies include the care of very young/premature babies, the care of babies and children undergoing complex surgery and/or those with major/complex co-morbidity (including those already requiring intensive care support).

As well as providing an essential co-dependent service for surgery, specialist anaesthesia and sedation services may be required to facilitate radiological procedures and interventions (for example MRI scans and percutaneous nephrostomy) and medical interventions (for example joint injection and intrathecal chemotherapy), and for assistance with vascular access in babies and children with complex needs such as intravenous feeding.

Specialist acute pain services for babies and children are organised within existing departments of paediatric anaesthesia and include the provision of agreed (hospital wide) guidance for acute pain, the safe administration of complex analgesia regimes including epidural analgesia, and the daily input of specialist anaesthetists and acute pain nurses with expertise in paediatrics.

*The Safe and Sustainable reviews of paediatric cardiac and neuro- sciences in England have noted the need for additional training and maintenance of competencies by specialist anaesthetists in both fields of practice.

References

1. Guidance for Provision of Anaesthetic Services (GPAS) Paediatric anaesthetic services. Royal College of Anaesthetists (RCoA) 2010 www.rcoa.ac.uk

2. Certificate for Completion of Training (CCT) in Anaesthesia 2010
3. Continuous Professional Development (CPD) matrix level 3

Specialised Child and Adolescent Mental Health Services (CAMHS)

The age profile of children and young people admitted to specialised CAMHS day/in-patient settings is different to the age profile for paediatric units in that it is predominantly adolescents who are admitted to specialised CAMHS in-patient settings, including over-16s. The average length of stay is longer for admissions to mental health units. Children and young people in specialised CAMHS day/in-patient settings generally participate in a structured programme of education and therapeutic activities during their admission. Taking account of the differences in patient profiles the principles and standards set out in this specification apply with modifications to the recommendations regarding the following:

- Facilities and environment – essential Quality Network for In-patient CAMHS (QNIC) standards should apply (http://www.rcpsych.ac.uk/quality/quality,accreditationaudit/qnic1.aspx)
- Staffing profiles and training - essential QNIC standards should apply.
- The child/ young person's family are allowed to visit at any time of day taking account of the child / young person's need to participate in therapeutic activities and education as well as any safeguarding concerns.
- Children and young people are offered appropriate education from the point of admission.
- Parents/carers are involved in the child/young person's care except where this is not in the best interests of the child / young person and in the case of young people who have the capacity to make their own decisions is subject to their consent.
- Parents/carers who wish to stay overnight are provided with accessible accommodation unless there are safeguarding concerns or this is not in the best interests of the child/ young person.

Applicable national standards e.g. NICE, Royal Colleges

Children and young people must receive care, treatment and support by staff registered by the Nursing and Midwifery Council on the parts of their register that permit a nurse to work with children (Outcome 14h Essential Standards of Quality and Safety, Care Quality Commission, London 2010)

- There must be at least two Registered Children's Nurses (RCNs) on duty 24 hours a day in all hospital children's departments and wards.
- There must be an Registered Children's Nurse available 24 hours a day to advise on the nursing of children in other departments (this post is included in the staff establishment of two RCNs in total).

All staff who work with children and young people must be appropriately trained to provide care, treatment and support for children, including Children's Workforce Development Council Induction standards (Outcome 14b Essential Standards of Quality and Safety, Care Quality Commission, London 2010).

Each hospital who admits inpatients must have appropriate medical cover at all times taking account of guidance from relevant expert or professional bodies (National Minimum Standards for Providers of Independent Healthcare, Department of Health, London 2002).”Facing the Future” Standards, Royal College of Paediatrics and Child Health.

Staff must carry out sufficient levels of activity to maintain their competence in caring for children and young people, including in relation to specific anaesthetic and surgical procedures for children, taking account of guidance from relevant expert or professional bodies (Outcome 14g Essential Standards of Quality and Safety, Care Quality Commission, London 2010).

Providers must have systems in place to gain and review consent from people who use services, and act on them (Outcome 2a Essential Standards of Quality and Safety, Care Quality Commission, London 2010). These must include specific arrangements for seeking valid consent from children while respecting their human rights and confidentiality and ensure that where the person using the service lacks capacity, best interest meetings are held with people who know and understand the person using the service. Staff should be able to show that they know how to take appropriate consent from children, young people and those with learning disabilities (Outcome 2b) (Seeking Consent: working with children Department of Health, London 2001).

Children and young people must only receive a service from a provider who takes steps to prevent abuse and does not tolerate any abusive practice should it occur (Outcome 7 Essential Standards of Quality and Safety, Care Quality Commission, London 2010 defines the standards and evidence required from providers in this regard). Providers minimise the risk and likelihood of abuse occurring by:

- ensuring that staff and people who use services understand the aspects of the safeguarding processes that are relevant to them.
- ensuring that staff understand the signs of abuse and raise this with the right person when those signs are noticed.
- ensuring that people who use services are aware of how to raise
- concerns of abuse.
- having effective means to monitor and review incidents, concerns and complaints that have the potential to become an abuse or safeguarding concern.
- having effective means of receiving and acting upon feedback from people who use services and any other person.
- taking action immediately to ensure that any abuse identified is stopped and suspected abuse is addressed by:
    - having clear procedures followed in practice, monitored and reviewed that take account of relevant legislation and guidance for the management of alleged abuse
    - separating the alleged abuser from the person who uses services and others who may be at risk or managing the risk by removing the opportunity for abuse to occur, where this is within the control of the

  provider
  - reporting the alleged abuse to the appropriate authority
  - reviewing the person’s plan of care to ensure that they are properly supported following the alleged abuse incident.
- using information from safeguarding concerns to identify non-compliance, or any risk of non-compliance, with the regulations and to decide what will be done to return to compliance.
- working collaboratively with other services, teams, individuals and agencies in relation to all safeguarding matters and has safeguarding policies that link with local authority policies.
- participating in local safeguarding children boards where required and understand their responsibilities and the responsibilities of others in line with the Children Act 2004.
- having clear procedures followed in practice, monitored and reviewed in place about the use of restraint and safeguarding.
- taking into account relevant guidance set out in the Care Quality Commission’s Schedule of Applicable Publications
- ensuring that those working with children must wait for a full CRB disclosure before starting work.
- training and supervising staff in safeguarding to ensure they can demonstrate the competences listed in Outcome 7E of the Essential Standards of Quality and Safety, Care Quality Commission, London 2010

All children and young people who use services must be:
- fully informed of their care, treatment and support.
- able to take part in decision making to the fullest extent that is possible.
- asked if they agree for their parents or guardians to be involved in decisions they need to make.

(Outcome 4I Essential Standards of Quality and Safety, Care Quality Commission, London 2010)

Key Service Outcomes

Evidence is increasing that implementation of the national Quality Criteria for Young People Friendly Services (Department of Health, London 2011) have the potential to greatly improve patient experience, leading to better health outcomes for young people and increasing socially responsible life-long use of the NHS. Implementation is also expected to contribute to improvements in health inequalities and public health outcomes e.g. reduced teenage pregnancy and STIs, and increased smoking cessation. All providers delivering services to young people should be implementing the good practice guidance which delivers compliance with the quality criteria.

Poorly planned transition from young people’s to adult-oriented health services can be associated with increased risk of non-adherence to treatment and loss to follow-up, which can have serious consequences. There are measurable adverse consequences in terms of morbidity and mortality as well as in social and educational outcomes. When children and young people who use paediatric services are moving to access adult services (for example, during transition for those with long term conditions), these should be organised so that:

- All those involved in the care, treatment and support cooperate with the planning and provision to ensure that the services provided continue to be appropriate to the age and needs of the person who uses services.

The National Minimum Standards for Providers of Independent Healthcare, (Department of Health, London 2002) require the following standards:

- **A16.1** Children are seen in a separate out-patient area, or where the hospital does not have a separate outpatient area for children, they are seen promptly.
- **A16.3** Toys and/or books suitable to the child's age are provided.
- **A16.8** There are segregated areas for the reception of children and adolescents into theatre and for recovery, to screen the children and adolescents from adult patients; the segregated areas contain all necessary equipment for the care of children.
- **A16.9** A parent is to be actively encouraged to stay at all times, with accommodation made available for the adult in the child's room or close by.
- **A16.10** The child's family is allowed to visit him/her at any time of the day, except where safeguarding procedures do not allow this
- **A16.13** When a child is in hospital for more than five days, play is managed and supervised by a qualified hospital play specialist.
- **A16.14** Children are required to receive education when in hospital for more than five days; the Local Education Authority has an obligation to meet this need and are contacted if necessary.
- **A18.10** There are written procedures for the assessment of pain in children and the provision of appropriate control.

All hospital settings should meet the Standards for the Care of Critically Ill Children (Paediatric Intensive Care Society, London 2010).

There should be age specific arrangements for meeting Regulation 14 of the Health and Social Care Act 2008 (Regulated Activities) Regulations 2010. These require:

- a choice of suitable and nutritious food and hydration, in sufficient quantities to meet service users' needs;
- food and hydration that meet any reasonable requirements arising from a service user's religious or cultural background
- support, where necessary, for the purposes of enabling service users to eat and drink sufficient amounts for their needs.
- for the purposes of this regulation, "food and hydration" includes, where applicable, parenteral nutrition and the administration of dietary supplements where prescribed.
- that providers must have access to facilities for infant feeding, including facilities to support breastfeeding (Outcome 5E, of the Essential Standards of Quality and Safety, Care Quality Commission, London 2010)

All paediatric patients should have access to appropriately trained paediatric trained dieticians, physiotherapists, occupational therapists, speech and language therapy, psychology, social work and CAMHS services within nationally defined access standards. All children and young people should have access to a professional who can undertake an assessment using the Common Assessment Framework and access support from social care, housing, education and other agencies as appropriate. All registered providers must ensure safe use and management of medicines, by means of the making of appropriate arrangements for the obtaining, recording, handling, using, safe keeping, dispensing, safe administration and disposal of medicines (Outcome 9 Essential Standards of Quality and Safety, Care Quality Commission, London 2010). For children, these should include specific arrangements that:

- ensure the medicines given are appropriate and person-centred by taking account of their age, weight and any learning disability
- ensure that staff handling medicines have the competency and skills needed for children and young people's medicines management
- ensures that wherever possible, age specific information is available for people about the medicines they are taking, including the risks, including information about the use of unlicensed medicine in paediatrics.

Many children with long term illnesses have a learning or physical disability. Providers should ensure that:

- they are supported to have a health action plan
- that facilities meet the appropriate requirements of the Disability Discrimination Act 1995
- they meet the standards set out in Transition: getting it right for young people. Improving the transition of young people with long-term conditions from children's to adult health services. Department of Health Publications, 2006, London

APPENDIX 1

Neurological Conditions covered by the Specification

The largest single patient group covered by paediatric neurology services are patients with epilepsy. However, a majority of patients with epilepsy are managed wholly by secondary care providers or community based paediatricians or else by such paediatricians with advice from paediatric neurology Services. The role of paediatric neurology services in the management of children with epilepsy is defined by NICE guidelines. These indicate the need for paediatric neurology services in epilepsy beginning under the age of 2 years; epilepsy accompanied by other neuro developmental problems, such as learning difficulties; epilepsy associated with abnormal brain imaging; in cases of diagnostic doubt; and epilepsy not responding to appropriate first line anti-epileptic drugs. The guidelines also state that children and young people with recent onset suspected seizure should be seen urgently by a specialist as part of the paediatric neuroscience service. The role of paediatric neurology services includes use of newer anti-epileptic drugs, the use of non-drug treatments such as the ketogenic diet and the selection of patients for surgical treatment of epilepsy. Other patient groups include children with:

- Motor disorders (including cerebral palsy and movement disorders) – paediatric neurology services are principally involved in diagnosis and investigating underlying causes. Therapeutically many children with cerebral palsy are managed by secondary level disability services. Paediatric neurology services provide specialist spasticity management, usually working in partnership with disability orthopaedic and neurosurgery services
- Cerebrovascular disorders, including childhood stroke – paediatric neurology services, working with neuroradiology and paediatric neurosurgery, are responsible for acute management, investigation of cause and subsequent rehabilitation
- Infectious and inflammatory diseases of the nervous system, including meningitis and encephalitis and other causes of acute non-traumatic encephalopathy. Some children with these disorders are managed by secondary level paediatric services
- Traumatic brain injury, including non-accidental head injury – paediatric neurology services generally provide advice regarding specific aspects of medical management as part of a multidisciplinary team also involving various surgical disciplines and are often play a leadership and co-ordinating role in rehabilitation. Diagnosis of suspected non-accidental head injury involves a multidisciplinary and multiagency approach
- Neuromuscular disorders (including myopathies, muscular dystrophies and neuropathies) – paediatric neurology services are involved in diagnosis and in collaboration with disability services for long-term management. Management of complications requires collaboration with spinal services, respiratory services (including non-invasive ventilation) and cardiac services. End of life care is an important aspect of services for some of these disorders
- Brain and spinal cord tumours – brain tumours are the most common solid malignancies in childhood. The multidisciplinary team responsible for diagnosing and managing children includes paediatric oncology, paediatric neurology and paediatric neurosurgery
- Developmental delay, learning and behavioural difficulties, including autistic spectrum disorders – paediatric neurology services are mainly involved in investigating the underlying cause. Long-term management is usually undertaken by community services and CAMHS.
- Headache, including migraine – headache is the most common neurological disorder in childhood. It is mainly managed in primary and secondary care. However, paediatric neurology services are involved in diagnosis and managing a minority of children with complex headache syndromes, including migraine not responding to first line treatments, chronic daily (tension) headache and idiopathic intracranial hypertension
- Neurogenetic disorders and dysmorphic syndromes involving the nervous system
- Central nervous system (CNS) malformations, including spinal dysraphyism
- Functional disorders – the treatment of these children involves paediatric neurologists who will be involved in diagnosis (exclusion of physical illness) and in co-ordinating inpatient rehabilitation with a multidisciplinary team including child and adolescent psychiatrists.

- Neurometabolic disorders and neurodegenerative disorders – this is a large
- group of mostly very rare conditions. Paediatric neurology services are involved in diagnosis and long-term management. Some services are covered by the highly specialised services specification(e.g. ataxia telangiectasia). Metabolic medicine usually plays a central role in diagnosis and management of children with metabolic disorders but is only available in a few supra-regional centres.
- Neurological aspects of multisystem disease and neurological complications of disease of other systems.