

E03/S/e

**2013/14 NHS STANDARD CONTRACT  
PAEDIATRIC MEDICINE: ENDOCRINOLOGY & DIABETES**

**SECTION B PART 1 - SERVICE SPECIFICATIONS**

<b>Service Specification No.</b>	E03/S/e
<b>Service</b>	Paediatric Medicine: Endocrinology & Diabetes
<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**

**National context:** Paediatric endocrinology is concerned with the diagnosis and management of children and young people with hormonal disorders (including growth and bone problems). Some of the disorders (e.g. familial short and tall stature, nutritional obesity, primary hypothyroidism, simple delayed puberty in boys) can be dealt with by general paediatricians, including those with an interest in endocrinology. However, all other endocrine conditions, which vary in incidence from 1 in 500 to <1 in 15,000, require specialist care by a paediatric endocrinologist and associated dedicated multi-professional team within a tertiary centre and/or shared care with a district hospital through an established network. The specialised paediatric endocrinology team also works in collaboration with other specialist teams to deliver specialist care to children and adolescents with complex medical problems. Services for children and adolescents with Type 1 diabetes mellitus are managed by local hospital multi-disciplinary teams which include a paediatrician with a special interest in diabetes. Specialised diabetes services are required for rarer forms of Type 1 and Type 2 Diabetes and monitoring of the complications of diabetes.

Examples of incidence rates:

Complex growth problems:

- Growth hormone deficiency ~1 in 3000-10,000

- Turner syndrome 1 in 2500 live female births (most diagnosed in childhood)
- Klinefelter syndrome 1 in 500-1000 live male births (some diagnosed in childhood)
- Precocious puberty 1 in 5000 (10 x more common in girls than boys)
- Pituitary disease:
  - Congenital hypopituitarism associated with septo-optic dysplasia 5 in 100,000
  - Craniopharyngioma 0.5-2 new cases per million with 30-50% presenting in childhood (accounting for ~10% of all childhood brain tumours)
- Thyroid disease:
  - Thyrotoxicosis 0.9 in 100,000 <15 years old
  - Thyroid cancer 0.5 per million per year (5 new cases per year)
- Adrenal Disease:
  - Congenital adrenal hyperplasia 1 in 14,000
  - Addison's disease <1 in 25,000
- Endocrine problems in cancer survivors:
  - Cancer affects 1 in 500 children <15 years old – incidence and type of endocrine effects vary by tumour type and treatment e.g. brain tumour treated with high dose cranial irradiation - ~100% have endocrine sequelae
- Severe Hypoglycaemia:
  - Congenital Hyperinsulinism 1 in 50,000
- Disorders of bone development:
  - Osteogenesis imperfecta 6-7 in 100,000
- Disorders of sex development:
  - Incidence of a baby being born with ambiguous genitalia 2 per 10,000 births
- Familial endocrine neoplasia syndromes:
  - Multiple endocrine neoplasia Type 2 1 in 50,000 Complex diabetes:
    - Non-Type 1 diabetes 1.3 in 100,000

#### **Evidence base:**

National Institute for Health and Care Excellence (NICE) ([www.nice.org.uk](http://www.nice.org.uk))

- NICE (May 2010) Human growth hormone (somatropin) for the treatment of growth failure in children. Review of NICE Technology Appraisal Guidance 42
- NICE (July 2004) Diagnosis and management of type 1 diabetes in children, young people and adults, NICE Clinical Guideline CG15
- NICE (May 2002) Human growth hormone for the treatment of growth failure in children, NICE Technology Appraisal TA42

Department of Health ([www.dh.gov.uk](http://www.dh.gov.uk))

- Department of Health (2001) 'National Service Framework for Diabetes: Standards'
- Department of Health (2003) 'National Service Framework for Diabetes: Delivery Strategy'
- Department of Health (2007) 'Making Every Young Person with Diabetes Matter'

## 2. Scope

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.

### 2.1 Aims and objectives of service

The aims of the service are: (1) to provide an expert diagnostic service for endocrine conditions, many of which are rare and may present either acutely with life-threatening problems or more subtly with potential for serious long-term morbidity and mortality; (2) to provide family-centred specialist care for children and adolescents with endocrine disease or complex diabetes (as set out in section 2.2 below) in an appropriate, safe setting by health professionals with approved training and experience in the context of a multidisciplinary team; (3) to promote the best health and quality of life possible within the context of their disorder, and (4) to seamlessly 'transition' those with an ongoing need for endocrine care to adult services with a sound knowledge of their disorder and its management. The service aims to manage these defined disorders to standards agreed by the British Society of Paediatric Endocrinology & Diabetes, including International Consensus guidelines.

The main diagnostic and monitoring methods include longitudinal assessment of growth and puberty, multiple blood sampling for hormonal levels, imaging (including plain x-rays (XRs), ultrasound scanning, computerised tomography (CT)/ magnetic resonance imaging (MRI) scan and less commonly diagnostic interventional

radiology procedures), and in collaboration with other paediatric specialist services surgical diagnostics (e.g. biopsy samples with histological investigations).

Treatments offered include medical and surgical management of endocrine disease, nutritional and psychological support for the child and their family, educational support and counselling about preparation for treatment and prognosis. Many children with endocrine disease and all with complex diabetes have a life-long chronic disease and contact with the paediatric endocrine service will be extensive

Diagnostics, monitoring and treatment are delivered predominantly in an outpatient setting and through a day-case investigation and treatment centre. However care is also delivered in in-patient settings (wards; intensive care, both neonatal and paediatric); high dependency) often with extensive shared care with other specialist services (neurosurgery, oncology).

The objectives of the service are as follows:

- To provide an accurate and timely diagnosis of the endocrine disorder, if relevant in conjunction with other specialist opinion
- To use evidence-based treatments (or internationally accepted best practice for rare disorders where the evidence base is limited) with appropriate monitoring arrangements
- To deliver the service in a safe, suitably equipped environment
- To provide timely access to the service for new referrals or acute episodes in known patients
- To provide rapid telephone advice to health professionals on paediatric endocrine conditions and complex diabetes
- To ensure that those with complex multi-system disease have appropriate input from other specialist services
- To ensure that where relevant psychological, emotional, educational and social care needs are being addressed
- To ensure that secondary and primary care services are provided with adequate diagnostic and treatment information in a timely manner, and that where relevant shared care arrangements and protocols are in place
- For conditions not constantly requiring care within a tertiary setting, to provide out-reach clinics in secondary settings so that care can be delivered closer to home, and shared care arrangements can be solidified
- To manage the transition into adult services for those with on-going needs for endocrine care, ensuring that the young person understands their condition and is developing autonomy to manage their own healthcare
- To carry out detailed audit of patient outcomes and experience, and share these data with colleagues in other centres, enabling the dissemination of best practice and appropriate benchmarking of quality

## 2.2 Service description/care pathway

This service is comprised of the following elements:

- Out-patient assessment of non-acute endocrine & complex diabetes disorders  
Diagnostic investigations and some treatments in a day-case setting  
Monitoring of the condition and treatments through out-patient assessment – this may be throughout childhood and adolescence for complex life-long conditions, or for the duration of a self-limiting condition, or for less complex conditions a return to secondary or primary care follow-up
- In-patient admission of acute, ill children with endocrine & diabetes disorders for diagnosis and treatment
- In-patient referrals from other specialist teams (e.g. neonatal and paediatric intensive care units, neurosurgery, gastroenterology) for input into the management of acutely/critically ill children with complex/multisystem disorders
- Telephone advice from the specialist consultant for new and known patients  
Telephone advice and home visit support from paediatric endocrine / diabetes nurse specialists
- Common paediatric endocrine conditions are managed in local hospitals or primary care settings, but complex and rare endocrine conditions are managed in conjunction with a specialist endocrinology centre. Specialised paediatric endocrinology services are provided from 18 centres in England, where experienced staff can maintain a safe, high quality service in conjunction with other specialised paediatric services (including neonatal/paediatric intensive and high dependency care, oncology, neurosurgery, endocrine surgery, biochemistry, genetics, imaging, histopathology, pharmacy, dietetics, physio / occupational therapy). The majority of children are assessed and treated on an out-patient or day case basis by the specialised multi-disciplinary team; these teams may focus on one set of conditions (e.g. bone disorders). Investigations are performed either on day care units or over a short in-patient stay. Treatment and follow up can be life-long and planned transition to adult services takes place via joint and/or hand-over clinics.
- The endocrine disorders outlined in Section A, Appendix 1 are either managed by the specialist paediatric endocrinology centre or, where appropriate, through outreach clinics run by the specialist team at the local centre:

The diabetes disorders that require specialised services are outlined in Section B, Appendix 1.

### **The Multi-disciplinary Team (MDT)**

The core members of the multi-disciplinary team are:

- Paediatric endocrine consultants
- Junior medical staff in training

- Paediatric endocrine /diabetes specialist nurses
- Clinical biochemistry staff with experience in endocrinology
- This team requires administrative support to maintain records and databases, and to maintain co-ordination within and between the core and extended MDTs.

The extended MDT (the composition of which will be condition/diagnosis dependent (see list above) will include:

- Psychology Dietetics Genetics
- Radiology & nuclear medicine
- Paediatric surgery/urology (and anaesthetics) Neurosurgery
- Oncology
- Histology
- Consultants in paediatric and neonatal intensive care System specific specialist consultants

The lead endocrine consultant is responsible for convening the appropriate mix of individuals to provide multidisciplinary input into a patient's management.

The care pathways for patients are as follows:

- New referral from secondary or primary care or occasionally from another tertiary centre (for a further opinion)
- Diagnosis made in out- or in-patient setting and monitoring of the condition or active treatment commenced
- Follow-up through out-patient assessments, in some with additional specialist nurse support
- There are various pathways for longer-term care: Condition resolves – discharge to primary care
- Condition stable – shared management with secondary care (including out-reach clinics)
- Condition complex and life-long – all management in specialist centre with appropriate liaison and information sharing with secondary and primary care, and in some cases shared management with secondary care (including out-reach clinics)
- For those with complex life-long conditions or those still requiring endocrine input at the completion of growth and puberty, transitional care arrangements in conjunction with the appropriate local adult specialist endocrinologist will be delivered. There are various models for the delivery of such care, but all will involve close liaison between the paediatric and adult endocrine teams. Transition involves a process of preparation of the young person for their transfer to adult services. This preparation should start from the mid-teens within the paediatric service, with a move into transitional care arrangements
- (e.g. a joint clinic between paediatric and adult teams) occurring from mid- to late teens, followed by full transfer into adult services from late teens to early

20s. The exact timing of each stage will be dependent on the condition and local resources and arrangements.

Shared care protocols are available for some conditions (e.g. growth hormone deficiency management, precocious puberty management) to provide guidance to general paediatricians and general practitioners in day-to-day care.

Some children will need to access services identified as “supra-regional”. These are highly specialised endocrine services. Access to these services will usually be through the regional lead centre.

The service will offer the following:

- Access to inpatient services (including intensive care): 24 hours/seven days a week
- On-call cover: access to tertiary advice for district general hospitals/primary care/other tertiary centre colleagues, 24 hours/seven days a week will be provided as a telephone advice on call rota. In some centres a formal on call arrangement will be provided. The latter will be undertaken when there are appropriate staffing levels (> 3 whole time equivalent (WTE) consultants).
- Day case/short stay ward: 5 days a week
- Outpatient clinics: 5 days a week, including outreach activity
- Access to tertiary advice for district general hospitals/primary care/other tertiary centre colleagues 24 hours/seven days a week
- Discharge processes must ensure timely and appropriate communications with services which are expected to provide other parts of the patient’s pathway in compliance with national guidance.

These services are currently provided in 18 centres in England (listed in Section 5).

### **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.

Each tertiary service will provide support for the surrounding childhood population in partnership with their local district general hospital services. Specifically the service is for those children and adolescents with paediatric endocrine conditions or complex diabetes as outlined within this specification. Providers require staff to attend mandatory training on equality and diversity and the facilities provided offer appropriate disabled access for patients, family and carers. When required the providers will use translators and printed information available in multiple languages.

## 2.4 Any acceptance and exclusion criteria

### Acceptance Criteria

The service will accept referrals from primary, secondary or tertiary care (the latter including both other tertiary specialised services and other tertiary endocrine services).

The service will accept referrals for those conditions listed in this specification, either suspected or with the diagnosis established. New patients presenting at any age  $\leq 16$  years will be accepted, and in general no referrals to adult services should be made for those  $\leq 16$  years of age. For those aged 16 to  $<19$  years of age, referral to paediatric or adult endocrine services may be appropriate – see below for further discussion.

Follow-up of patients already under paediatric endocrine care can occur to a later age, which will be dependent on the condition and the local transition arrangements.

The services operate with a team of consultants. Referrals will be handled in a number of ways:

- Acute  $\pm$  unwell: urgent in-patient admission under on-call consultant Non-acute:
  - Go into next available new patient appointment and remain under the care of that consultant
  - See named consultant and stay under his/her care
- After acceptance into the service, may transfer between consultants dependent on diagnosis and interests/expertise of local team
- A number of disorders are nationally commissioned through other mechanisms, including Congenital Hyperinsulinism, Bardet-Biedl and Alstrom syndromes, and complex/atypical osteogenesis imperfecta.



## Exclusion Criteria

The service will not accept new referrals  $\geq 19$  years of age. However between 16 to  $< 19$  years of age, new referrals should be made to the centre with the appropriate best expertise to deal with the presenting problem. Liaison between paediatric and adult units may be required to ensure optimal management arrangements. In this age range, discussion between the referring clinician and the specialist centre is advised.

Common conditions, such as constitutional growth and pubertal delay, acquired hypothyroidism and pubertal variants, such as adrenarche, do not usually need to be seen by the specialist service. However there may be circumstances where an opinion is requested (by phone, letter or face-to-face consultation) prior to on-going secondary or primary care.

Most services for children and adolescents with type 1 diabetes are managed by designated local hospital multi-disciplinary teams which include a paediatrician with a special interest in diabetes. These local services do not meet the remit of a specialised commissioned service.

## 2.5 Interdependencies with other services

Many children and adolescents with endocrine disorders may have involvement of more than one system. This is recognised in 'Commissioning Safe & Sustainable Specialised Paediatric Services: A Framework of Critical Interdependencies, 2008. Key interdependencies would be the availability of specialist paediatric endocrinology expertise to paediatric and neonatal intensive care and paediatric neuro-surgical and oncology patients. In addition all specialist paediatric endocrinology requires close working arrangements with paediatric radiology, chemical pathology and clinical genetics services.

It should be noted that there are a broad range of other specialised services that have important interfaces with endocrinology & diabetes.

### Co-located Services:

- Clinical biochemistry
- Radiology
- Nutrition and diatetic services
- CAMHS/psychosocial support
- Paediatric intensive and high dependency care
- Paediatric neurosurgery
- Paediatric anaesthesia & surgery

- Paediatric urology

#### **Interdependent Services:**

- Genetics
- Neonatal intensive care
- Cardiology
- Dermatology
- Gastroenterology
- Gynaecology
- Nephrology
- Paediatric orthopaedics
- Palliative care
- Respiratory
- Rheumatology

#### **Related Services**

- Social work and family support
- Patient/family support groups (local, regional, national)
- Programmes to support obesity management

Shared care arrangements and protocols are available for some endocrine treatments:

- Recombinant Human Growth Hormone is initiated in the specialised service, with prescriptions continued in primary care
- Gonadotrophin Releasing Hormone Analogue (GnRHa) treatment is initiated in the specialised service, and continued either in secondary or primary care.
- Hormone replacements (gluco- & mineralocorticosteroids, thyroxine, sex steroids, anti-diuretic hormone, insulin) are initiated in the specialised service and continued in primary care.

Other endocrine treatments will be prescribed and monitored by the specialised service e.g. bisphosphonates, Insulin-like Growth Factor-I.

### **3. Applicable Service Standards**

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

- The service will be provided from a child facility with equipment to national standards and co-location with other paediatric specialties. [DH Report 2008 "Commissioning a Safe and Sustainable Specialised Paediatric Services: A

Framework of Critical Inter-Dependencies.”]

- It is proposed that there should be one paediatric endocrinologist per 500,000 total population (British Society of Paediatric Endocrinology & Diabetes – UK Standards for Paediatric Endocrinology 2010).
- The service will be delivered in line with the ‘UK Standards for Paediatric Endocrinology & Diabetes’, 2010.

#### 4. Key Service Outcomes

##### General:

- To minimise morbidity and mortality by providing the most appropriate care for paediatric endocrine and diabetes disorders
- To ensure optimal age-appropriate care and transition into adult services. To ensure that there is a sufficient, skilled and competent multi-disciplinary workforce to manage children with paediatric endocrine and diabetes disorders
- To ensure that children with paediatric endocrine and diabetes disorders are treated in line with agreed national and international guidelines
- To ensure shared care and clinical networks deliver good specialist care closest to home

##### Specific:

- To collect data on defined conditions into secure databases for audit purposes
- To conduct regular local and national audits of service performance

#### 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 be 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

the network.

- all radiologists, and radiographers will have appropriate training, supervision and access to continuous performance development (CPD)
- 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.<sup>1</sup> 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) training<sup>2</sup> and should maintain the competencies so acquired<sup>3</sup> \*. 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 magnetic resonance imaging (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. Guidelines for Providing Anaesthetic Services (GPAS) Paediatric anaesthetic services. Royal Collage of Anaesthetists (RCoA) 2010 [www.rcoa.ac.uk](http://www.rcoa.ac.uk)
2. Certificate for completion of training (CCT) in Anaesthesia 2010
3. 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 persons 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 persons 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. National Institute for Health and Care Excellence. (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).

Accommodation, facilities and staffing must be appropriate to the needs of children

and separate from those provided for adults. All facilities for children and young people must comply with the Hospital Build Notes HBN 23 Hospital Accommodation for Children and Young People NHS Estates, The Stationary Office 2004.

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 which 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.
- Participates 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 Clinical Records Bureau 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.
- 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
- 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 – List of conditions requiring treatment at a specialised centre**

### **A – Endocrine Disorders**

- complex growth problems including Turner syndrome and growth hormone deficiency; puberty disorders including precocious, delayed or absent puberty
- pituitary disease including hypopituitarism, pituitary and peri-pituitary tumours
- complex fluid balance problems (e.g. in neurosurgery)
- thyroid and parathyroid associated disease including thyroid malignancy and thyrotoxicosis and parathyroid disease
- disorders of the adrenal glands
- endocrine disorders associated with chronic disease e.g. care of endocrine problems in cancer survivors, cystic fibrosis related diabetes, growth and pubertal problems associated with chronic renal failure and inflammatory bowel disease
- severe or repeated hypoglycaemia disorders of bone and calcium metabolism multiple endocrine neoplasia (MEN) syndromes and other familial endocrine disorders
- DSD (disorders of sex development) morbid obesity
- all rare diseases are covered by a separate service specification and will be included in the scope.

### **B – Diabetes Disorders**

- diabetes complications in childhood (e.g. nephropathy, complex compliance problems such as eating disorders)
- Type 2 or rare forms of diabetes (e.g. neonatal diabetes, maturity onset diabetes of the young (MODY))
- insulin resistance syndromes

- diabetes associated with chronic disease (e.g. cystic fibrosis or high dose steroid usage in the treatment of some cancers).
- morbid obesity associated with Type 2 diabetes.

Interim for Adoption from 01/10/13