

#### E09/S/a

# 2013/14 NHS STANDARD CONTRACT FOR PAEDIATRIC NEUROSURGERY SERVICES

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

Service Specification No.	E09/S/a
Service	Paediatric Neurosurgery Services
Commissioner Lead	
Provider Lead	
Period	12 months
Date of Review	

## 1. Population Needs

#### 1.1 National/local context and evidence base

It has been estimated that 2-3% of the child population will have some level of special needs and/ or neurological disability. 0.3-0.5% will have severe learning disabilities. Paediatric epilepsy is the commonest neurological disorder, affecting about 0.7% of all children as shown in the table below:

Condition	Prevalence
Epilepsy	7 per 1000 children
Severe learning difficulties	3 per 1000 children
Cerebral palsy	3 per 1000 live births
Acquired brain injury	18 per 100,000 children
Muscular dystrophy	3 per 100,000 male births

Around 4200 paediatric neurosurgery operations are performed on children in England each year, of which 70% are emergency and 30% elective, Hydrocephalus accounts for 1700 procedures each year and central nervous system tumours, craniofacial disorders and epilepsy each account for about 400 cases each year. The remaining caseload comprises children with spinal dysraphism (forms of spina bifida), head injury and other disorders. The National Specialised Services Safe and Sustainable Team have carried out a national review of paediatric neurosurgical services in England on behalf of the NHS Medical Director. A range of standards that support an agreed model of care for these services has been developed and

distributed widely for comment and the comments have been incorporated into the document "Children's Neuroscience Networks (For The Neurosurgical Child). A Framework for Services in England. December 2012.. The document describes exemplar pathways for brain tumour, brain trauma, epilepsy, hydrocephalus and spinal neural tube defects. The model of care will be to establish regional children's neuroscience networks (for the neurosurgical child).

#### **Evidence Base:**

- Department of Health (2005) 'Long-term (neurological) conditions national service framework'
- Available from the National Institute of Health and Clinical Excellence www.nice.org.uk
- 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'
- NHS Specialised Services (2012). Safe & Sustainable Children's Neurosurgical Services Review (<a href="http://www.specialisedservices.nhs.uk/safe\_sustainable/childrens-neurosurgical-services">http://www.specialisedservices.nhs.uk/safe\_sustainable/childrens-neurosurgical-services</a>)

#### 2. Scope

#### 2.1 Aims and objectives of service

The aim of the service is to provide neurosurgical care by a team of people with skills and expertise to support the individual child and their family in a caring atmosphere that creates confidence and safety for that child and their parents. The objectives of the service are:

- To provide a sustained and integrated network of care involving a variety of organisations and professionals
- To provide a comprehensive service focussed on outcomes and the quality standards outlined in The Safe and Sustainable Paediatric Neurosurgery report (2012
- Through the managed clinical network, to provide 24 hours a day, seven days a week care that revolves around the individual child's needs
- To ensure that children should receive a package of care that covers if necessary the entire pathway of care up to the end of their 18 year and leads to a smooth transition into adult neuroscience services.

# 2.2 Service description/care pathway

Centres providing specialised paediatric neurosciences services (paediatric neurosurgery, neurology and neurodisability teams) adopt an integrated (multidisciplinary team - MDT) approach to the diagnosis and management of a large variety of neurological disorders, many of which are relatively rare. The services are both centrally-based (in-patient and outpatient) and outreach to local hospitals where the centre staff work in partnership with local paediatricians and therapy teams to facilitate care as close to a child's home as possible.

Pathways of Care for the five main areas of paediatric neurosurgery activity (hydrocephalus, brain / spinal tumours, epilepsy surgery, brain trauma and spinal dysraphism) are described in detail in the NHS Specialised Services standards document entitled "Children's Neuroscience Network (for the Neurosurgical Child) Specification Standards" 2012

http://www.specialisedservices.nhs.uk/document/steering-group-reports

All children must have access to consultant paediatric neurosurgical advice and care within a network on a 24 hour, 7 days per week basis, with a formal designated rota which is widely shared and understood within the network of referring hospitals and any other regional networks and services (such as trauma). Middle grade neurosurgical cover must be available within 30 minutes.

All centres will have access to a full range of diagnostic procedures and anaesthesia sessions to support this if required. There must be access to the full range of diagnostic equipment including computerised topography (CT) scanner, CT angiography magnetic resonance imaging (MRI) and Functional MRI.

The following intraoperative techniques will be available:

- Spinal cord monitoring 5 day access
- Electroencephalography (EEG) / cortical monitoring 5 day access
- Evoked potentials 5 day access
- Intraoperative image guidance system 24/7
- Neuro-endoscopy 24/7 access
- Imaging ultrasound 24/7 access
- Ultrasonic aspirator 24/7 access.son

All paediatric neurosurgery (for a planned operation or for an emergency procedure) must be carried out in a dedicated theatre specifically equipped and staffed for paediatric neurological surgery. Theatres will be equipped with the specialist equipment required for paediatric neurosurgery.

In addition to medical and nursing staff the MDT will include:

- Neuropsychology
- Neuroradiology
- Dietician
- Play Specialists
- Physiotherapists

- Occupational therapist
- Speech and language therapist
- Paediatric pharmacist access to advice at all times
- Hospital school teacher access to service
- The attendance of a neuropathologist at multi-disciplinary team meetings.

The MDT must also have access to an othortist, neurophysiologist, Child and Adolescent Mental Health Services, Childrens orthopaedics and endocrinology services at the relevant stages in the child's care.

There will be access to dedicated neuro-rehabilitation facilities either on site or as part of the care pathway, the centre will be responsible for managing the early rehabilitation plan. (Services for neuro-rehabilitation are outlined in another service specification).

Transition arrangements will be in place for age appropriate continued follow-up.

#### **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 service will be available for all children with a neurosurgical condition up their birthday. Neurosurgical Networks will evolve in 2012 covering the whole population of children in England.

#### 2.4 Any acceptance and exclusion criteria

Specifications for complex syndromic craniofacial disorders are covered under highly specialised services.

# 2.5 Interdependencies with other services

The service will comply with the requirements of the DH Commissioning Safe and Sustainable Specialised Paediatric Services: A framework of Critical Interdependencies.

### 3. Applicable Service Standards

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

NHS Specialised Services standards document entitled, Children's Neuroscience Network (for the Neurosurgical Child) Specification Standards 2012 http://www.specialisedservices.nhs.uk/document/steering-group-reports

Key elements of the standards that have been identified for paediatric neurosurgery within this document include:

- Leadership
- Lead Clinician Paediatric Neurosurgeon Lead Nurse
- Anaesthetics
- 24/7 paediatric anaesthesia rota / cover
- Intensive Care (On-site Paediatric Intensive Care Unit (PICU) /Neonatal Intensive Care Unit (NICU) and High Dependency Unit (HDU)
- Diagnostic / Radiology
- 24/7 MRI and CR service availability onsite
- 24/7 paediatric (neuro)-radiology rota for opinion across the network Time specified job plan
- Paediatric Neurosurgery 24/7 rota across network
- Allied Health Professions (AHP) Standard D24 and need to make sure time specified in hob plans
- Children's Neuro Nurse Specialist Standard D22
- Audit of emergency transfer times
- Theatre access for dedicated and unplanned cases (no delays) –Standard D13
- Ward nursing and resources (bed capacity) Standards D10 & 11

# 4. Key Service Outcomes

Key Paediatric Neurosurgical Measures are shown in the table below:

Domain	Measure	Measurement definition	Numerator	Denominator	Data Thresholds
Domain 1: Preventing people from dying prematurely	30-day mortality childhood tumour	Proportion of parents aged 0 - 16 years who die within 30 days of first tumour operation	Number of patients aged 1 - 16 years who die within 30 days of operation	Number of patients aged 1 - 16 years who have a first tumour operation	Outside 95% confidence interval (target less than 1%)
Domain 1: Preventing people from dying prematurely	5-year survival childhood tumour	Proportion of patients aged 0 – 16 years who are alive 5 years after first tumour operation (tumour specific)	Number of patients aged 0 – 16 years who are alive 5 years after a tumour operation	Number of patients aged 1 – 16 years who have had a tumour operation	Outside 95% confidence interval
Domain 1: Preventing people from dying prematurely	Emergency CT response time (D7)	Time from request for a CT scan from PICU for an urgent indication to completion time of scan	Time in minutes	Sequential episodes	60 minutes
Domain 1: Preventing people from dying prematurely	Elective (planned) Intervention -related mortality	Number of deaths within 30 days of any elective paediatric neurosurgical procedure or neuroradiological interventional procedure	Number of deaths within 30 days of any elective paediatric neurosurgical procedure or neurorariolog ical interventional procedure	Total number of elective / planned interventions	Less than 1%
Domain 1: Preventing people from dying prematurely	Early head injury mortality	Proportion of children dying within 30 days of a severe head injury	Number of children dying within 30 days of a severe head injury	Total number of admission s with severe head injury	Less than 10%
Domain 4: Ensuring that people have a positive experience of care	Complaints (C13)	Categorisation of complaints into 4 categories: communication; clinical services; non-clinical services; other	Number of complaints in 4 defined categories	Total number of paediatric inpatient episodes	Less than 1%
Domain 4: Ensuring that people have a	Open access to ward for	The number of parents who were able to access the ward	Number of parents who felt they had	Total parent contacts	At least 95%

positive experience of care	parents of children with hydrocephal us.	directly with their shunt concerns	good access to the ward		
Domain 5: Treating and caring for people in a safe environment and protecting them from avoidable harm	Shunt reoperation	Proportion of paediatric patients who require a second shunt operation within 30 days of the first	Number of paediatric patients who require a second shunt operation within 30 days of the first	Number of paediatric patients receiving a first shunt operation	Outside 95% confidence interval (target less than 25%)
Domain 5: Treating and caring for people in a safe environment and protecting them from avoidable harm	Staff training (D10)	Proportion of staff with paediatric training and neuroscience s training	Ward staff with paediatric training and staff with neuroscience training	Total number of ward staff	TBA by RCN
Domain 5: Treating and caring for people in a safe environmen t and protecting them from avoidable harm	Emergency care refusal s (D18)	Number of patients refused admission due to lack of beds either delaying admission or requiring admission to another centre	Number of refused admissions categorised into: lack of PICU; lack of ward bed	Number of unplanned inpatient episodes	Less than 0.5%
Domain 5: Treating and caring for people in a safe environment and protecting them from avoidable harm	PICU transfer delays (D28)	All transfer delays reported for individual cases	Delays defined as É	Total number of PICU transfers for paediatric neurosurg ery	None
Domain 5: Treating and caring for people in a safe environment and protecting them from avoidable harm	Shunt infection	The number of operations for shunt infection as a proportion of total number of shunts inserted	Operations for shunt infection confirmed by microbiolog y	Total number of new shunt insertions or revisions	Less than 10%

Domain 5: Treating and caring for people in a safe environment and protecting them from avoidable harm	Early shunt failure	The number of shunt revisions within 30 days of insertion	Shunt revisions within 30 days of shunt insertion	Total number of new shunt insertions	Outside 95% confidence interval (target less than 15%)
Domain 5: Treating and caring for people in a safe environment and protecting them from avoidable harm	Brain injury transfer time to specialist care	TBI: Time from first hospital to tertiary centre	For all patients admitted with moderate and severe head injury time first hospital to tertiary centre	Sequential episodes	None

#### **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 minimize 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 (DH)

# **Imaging**

All services will be supported by a 3 tier imaging network ("*Delivering quality imaging services for children*" DH 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 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. 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 comorbidity. 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 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

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

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 2RCNs 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 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.
- 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 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 III 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:

- Ensures the medicines given are appropriate and person-centred by taking account of their age, weight and any learning disability
- ensuring 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.

<ul> <li>Providers should ensure that:</li> <li>They are supported to have a health action plan</li> <li>Facilities meet the appropriate requirements of the Disability Discrimination Act 1995</li> <li>They meet the standards set out in <i>Transition: getting it right for young people. Improving the transition of young people with long-term conditions from children's to adult health services.</i> Department of Health, 2006, London</li> </ul>