

C07/S/c

**NHS STANDARD CONTRACT
TIER 4 CHILD AND ADOLESCENT MENTAL HEALTH SERVICES
(CAMHS): SPECIALIST AUTISM SPECTRUM DISORDER SERVICES**

SCHEDULE 2 – THE SERVICES – A. SERVICE SPECIFICATION

Service Specification No.	C07/S/c
Service	Tier 4 Child and Adolescent Mental Health Services (CAMHS): Specialist Autism Spectrum Disorder Service
Commissioner Lead	
Provider Lead	
Period	2013/14
Date of Review	

This specification should be read as alongside the Tier 4 CAMHS Children’s Units, Tier 4 CAMHS General Adolescent Services, Tier 4 CAMHS Low Secure Service and Tier 4 CAMHS Learning Disability Services and Specialist Paediatric neuro-disability service specifications

1. Population Needs

1.1 National/local context and evidence base

National Context

The Tier 4 CAMHS Specialist Autism Spectrum Disorders (ASD) Services work as integrated multidisciplinary CAMHS teams providing outpatient assessment including second opinions and consultation to Tier 3 CAMHS and child health teams (including full investigation, diagnostic advice and advice on management), outreach and brief intensive specialist treatment which may include Intensive Outreach and day-Patient care for children and young people who are suffering from ASD and severe and/or complex neurodevelopmental and mental health conditions that cannot be adequately treated by general Tier 3 CAMHS and child health units/services.

The Tier 4 Specialist ASD Services work in close collaboration with specialised paediatric neurodisability services to ensure that the appropriately qualified, highly skilled professionals work together across organisational boundaries to meet the needs of the young person referred for specialist services. The Tier 4 Specialist ASD Services also work with and provide expert advice to other Tier 4 CAMHS services such as Tier 4 CAMHS Learning Disability Service, Medium Secure Adolescent

Units, Tier 4 CAMHS Low Secure provision.

Autism Spectrum Disorders (includes autism, Asperger's syndrome and all sub groupings within the Pervasive Developmental Disorders grouping) are common, lifelong neurodevelopmental disorders affecting at least 1% of the population with considerable financial and psychosocial burden on the affected individuals, their families and society. Children and young people with ASD are characterised by a broad range of impairments across three main areas of functioning: social communication, social interaction and rigid stereotyped repetitive behaviours and interests that have a pervasive impact on all aspects of functioning. Other related characteristics include communication and language impairments, additional learning and intellectual impairments, sensory sensitivities and difficulties, rigid and inflexible thinking and limited creative and imaginative play skills.

These disorders are increasingly being recognised and diagnosed in childhood thus increasing demand for local diagnostic and treatment services. Levels of understanding of ASD among healthcare and mental healthcare services and availability of services vary greatly from one area to another leading to inequalities in healthcare and service provision.

It is increasingly recognised that children and young people with ASD often have additional co-occurring mental health, developmental and other disorders: approximately 10-15% will have an identified medical disorder, 70% have at least one mental health disorder and 40% two or more mental health disorders. One in ten children currently attending general Tier 3 CAMHS will have a recognised diagnosis of ASD and a higher proportion in Tier 3 CAMHS Learning Disability services.

The management of these children with ASD and co-occurring complex mental health problems can pose specific challenges and the affected child or young person's responses to a need based intervention plan may be unexpected and cause concerns for the professionals and family leading in some cases for the need for more specialist assessment and advice. The National Autistic Society Report 'You need to know' 2010 found that Tier 3 CAMHS often struggled to provide the adaptations to treatments required for this group. Tier 3 CAMHS Learning Disability services provide care for children/young people with learning disability and ASD but development of such services is patchy. Furthermore, for some children and young people with particular co-existing conditions (such as intellectual disability and/ or other mental health disorders) and those in special circumstances (such as those in care or looked-after services) the assessment and understanding about their complex pattern of problems may be unclear. For such cases the differential diagnosis, the understanding of the developmental and emotional needs of the child or young person and whether or not a diagnosis of ASD is appropriate may require a second opinion or advice regarding management from a highly specialised group of professionals within a Tier 4 specialist ASD service. These are the types of referrals that recently published National Institute for Health and Care Clinical Excellence (NICE) ASD Clinical Guideline 128 specification recommended for referral to a dedicated tertiary/ Tier 4.

Specialist ASD Service. Access to specialist Tier 4 advice and expertise that then improves the health outcomes of children and young people with complex disorders and enables them to manage with appropriate local support from generic services close to home is also in keeping with the national recommendations in Children and Young People Health Outcomes Strategy (2012).

Approximately 3% of new referrals to local community child health and Tier 3 CAMHS are requests for a diagnostic assessment of ASD (not all these referrals will go on to receive a diagnosis). Approximately 1-2 % of these cases may require a further specialist Tier 4 ASD opinion (based on data from a multi-ethnic inner city local area team undertaking ASD diagnostic assessments for a 0-19 year population of 65,200). Therefore based on the 0-19 year population statistic for an urban-rural region of 705,700, approximately 3% (21,171 children) will be referred to local services for assessment and 1-2% (211 per year) will require a regional specialist Tier 4 service (including assessment, treatment and/or management advice).

Currently there are some Specialist Tier 4 ASD CAMHS working in collaboration with specialist Paediatric neurodisability colleagues and providing outreach services from Regional centres such as in North East England; Greater Manchester and 3 centres in London. All these exemplar services work closely supporting network of general Tier 3 CAMHS and other Tier 4 CAMHS and child health services. There is a scarcity of professionals with the necessary levels of expertise to provide this highly specialist support across the country. There is, therefore, a need for NHS national commissioning to provide a national network of specialist providers to take responsibility for the training of professionals with these specialist skills and ensure an equitable access and appropriate distribution of this level of ASD expertise specialist support for generic community services.

Evidence Base

This specification draws its evidence and rationale from a range of standards, guidance and frameworks listed in the CAMHS Tier 4 specification and in addition the list below:

- The delivery of the Autism Act places ownership for local NHS and Local Authority (LA) organisations to develop access to autism assessment and diagnostic teams.
- NICE guidance: <http://www.nice.org.uk/CG128>
- Fulfilling and rewarding lives:
<https://www.gov.uk/government/publications/implementing-fulfilling-and-rewarding-lives>
- Autism Act:
http://www.legislation.gov.uk/ukpga/2009/15/pdfs/ukpga_20090015_en.pdf
- Every disabled child matters

2. Scope

2.1 Aims and objectives of service

The key aim of the service is to improve the health outcomes of children and young people with complex neurodevelopmental disorders including ASD and co-occurring mental health conditions who are referred to specialist Tier 4 ASD CAMHS.

The key objectives of the service are:

- To provide a high quality, timely Tier 4 specialist CAMHS for children and young people (up to 19 years or during transition to adult mental health services) with complex ASD and co-occurring conditions who require more specialist services than are available in generic Tier 3 CAMHS and child health services.
- To maximise the health outcomes of children, young people and their families with these complex needs through the direct engagement with the specialist multidisciplinary professionals working within the Tier4 ASD CAMHS team in collaboration with other disciplines within specialist paediatric neurodisability services if appropriate.
- To support a national training strategy to increase expertise in the assessment and management of complex cases with ASD and co-occurring neurodevelopmental and mental health disorders.
- To facilitate research that will increase the evidence base for the understanding, assessment and treatment of children and young people with complex neurodevelopmental and co-occurring disorders including the identification of appropriate outcome measures for these complex children, young people and their families.
- To act as a focus for the investigation and evaluation of NHS Innovative practice.

2.2 Service description/care pathway

The service will be provided by a specialist tertiary consultant-led multidisciplinary team, working in collaboration with colleagues in other specialist tertiary services. This will ensure that the full range of specialist professionals are available to provide appropriate assessment and diagnostic second opinions (including a full range of specific assessments and investigations if appropriate) for children and young people who have a possible ASD and other complex mental health and/or neurodevelopmental problems.

The service will provide management advice for the treatment of complex ASD and the co-occurring conditions, brief intensive specialist treatments and consultation services to referring professionals from generic CAMHS and child health services. The work can be undertaken in a variety of settings as appropriate for the individual

needs of the patient and family such as outpatient, and some Intensive Outreach/day patient settings. For the most complex cases, the specialist Tier 4 ASD Team will work in collaboration with Tier 4 CAMHS (and Learning Disabilities CAMHS) in-patient services.

Services to be provided by the team are:

- Advice to professionals about referral for formal diagnostic assessment in cases of uncertainty as a consequence of complexity or failure of local intervention plan
- Regional second opinion (coverage more than just NHS trust) for local generic CAMHS or child health colleagues or when parents and families demand choice and/or a second opinion
- Specialist time-limited intensive outreach, outreach and day patient assessment and intervention services
- A consultation service to support local teams - assist local and gateway services in development of a care plan and or recommendations for on-going care/interventions as appropriate to the child and family
- Additional specialist assessment from a professional discipline or sufficiently specialist professional that is not available to local generic services for the investigation and treatment of more complex cases
- Teaching and training for professionals/other agencies/specialist parenting advise not available in generic services
- Advise on and/or delivery of specialist pharmaceutical interventions
- Advise on and/or use of specialist psychological interventions
- Assessments for children and young people that present with other complex conditions, co-morbid conditions in addition to autism
- To take the lead on facilitating transition arrangements between CAMHS and Adult Services ensuring that effective and suitable transition arrangements take place

Referrals

The referrals will usually come via the local area Autism Spectrum pathway team (commissioned by CCGs) with joint engagement from the local generic Tier 3 CAMHS and /or child health team who are involved with the child, the young person and their family / carers. For virtually all cases (except in very exceptional circumstances) the local clinical team will be required to continue to hold care coordination responsibilities. This ensures that throughout the referral process the family know that the overall clinical responsibility for the care and treatment of their child / young person will be in their local community as close to their home as possible.

The referral to the Tier 4 specialist ASD CAMHS will be made when there is clear uncertainty about an ASD diagnosis for whatever reason, for example because of complex presentations such as attachment disorder, looked after children, forensic history and children in special circumstances. There may also be uncertainty about additional complex neurodevelopmental and/or mental disorders. The local

team may have questions about the management of ASD and any related co-occurring problems, or concerns about lack of progress or failure to respond to specific therapeutic interventions, pharmacological and non-pharmacological. The team will also consider other complexities such as family relationship difficulties and adult psychiatric disorder in the family.

Referrals will be reviewed by a member of the specialist Tier 4 ASD clinical team and processed by the team administrator. Referrals will be considered on an individual basis and a response made to the referrer and the family within 2 weeks of receipt of the referral.

Where possible, referrals will include:

- The clinical question(s) to be addressed including Information regarding current concerns and difficulties experienced
- Summary of developmental and recent history and previous diagnostic process
- Copies of previous assessments and diagnostic reports
- Evidence that the local ASD assessment care pathway has been completed

Assessment

Once a referral has been accepted a case manager will be appointed within the Tier 4 CAMHS ASD team so that the family and the referrer have a single point of contact for any enquiries or queries throughout the period of involvement of the Tier 4 specialist ASD team. Copies of all previous reports and assessments will be obtained with the consent of the parents/ young person (where appropriate and possible). An individualised assessment and intervention plan will be designed depending on the reason for referral, this plan will be considered with the family and the most appropriate professionals within the multidisciplinary specialist team together with consideration about access to additional specialist Tier 4 CAMHS professionals to ensure a comprehensive assessment/ intervention plan can be undertaken. All patients will be managed within agreed waiting time standards. Whenever possible the assessments are undertaken as near to the patient's home as possible unless certain Tier 4 CAMHS ASD centre -based investigations are needed. Information or direct assessments are undertaken in a variety of venues. The assessment may take one or more appointments.

Once the assessment is completed the parents/carers will meet with the Tier 4 ASD team for feedback. Written reports detailing the assessment and recommendations will be sent to the family, referrers and GP and to other agencies as appropriate and subject to young person's/parent's consent. Where required a multiagency meeting involving the Tier 4 CAMHS ASD team, local providers and the family will be held to provide feedback and discuss recommendations.

Families will be provided with some information about support services for children with ASD in their own local area often in collaboration with a Parent Advisor with knowledge of ASD.

For the small number of referrals involved in brief, intense targeted interventions – such as emotional recognition work, trials of treatments for anxiety and resistant depression the primary responsibility for clinical care remains with the local generic team and formal shared-care arrangements will be agreed.

In a small number of cases where a more extensive assessment and/or brief intensive intervention is required, an outreach/day patient assessment placement will be offered. (The availability of this type of specialist Tier 4 day service provision is extremely patchy across the country- in some areas a day place in a specialist ASD service is only available at a particular time or on a time limited basis or for a limited age range of patients.) Where the Tier 4 CAMHS ASD service is co-located with Tier 4 CAMHS Children's Units and Tier 4 CAMHS Learning Disability services collaboration across the services can occur to offer consultation and expert advice for additional assessment and intervention.

Discharge

The Tier 4 CAMHS ASD services work closely with colleagues in local general Tier 3 CAMHS and child health units/services to ensure that the outcome of the specialist work enables the local health providers to support these complex young people and their families within their local community.

For all diagnostic second opinion and consultation cases, the case is closed within 2-4 weeks of the feedback appointment.

Where a time-limited intervention is offered discharge from the Tier 4 CAMHS ASD service to local Tier 3 CAMHS and / or community child health will occur once the intervention is completed. A multiagency meeting involving local providers and the Tier 4 CAMHS ASD team will be held at the point of discharge if required to ensure smooth transition back to local services.

Multidisciplinary Team

The core team will consist of practitioners with specialist expertise in ASD and related disorders. For any individual referral to the specialist Tier 4 CAMHS ASD team, arrangements will be made to ensure that the appropriate disciplines are available to conduct the assessment. This may mean involving other professionals outside of the core team. The team will also support trainees in all key disciplines to expand the number of child health professionals with ASD expertise.

The core team will consist of:

- Consultant Child and Adolescent psychiatrist with recognised expertise in ASD
- Paediatric neurologist/ paediatric neurodisability specialist
- Clinical neuropsychologist and clinical psychologist
- Occupational therapist
- Speech and language therapist
- Regional specialist ASD parent advisor

- Social Worker
- Specialist ASD Nurse
- Specialist ASD teacher
- Other specialist opinions should be available as required for individual referrals and might include.
- *Specialist transition workers
- *paediatric gastroenterologist
- *physiotherapist

* these professionals may not be part of the Tier 4 ASD specialist CAMHS team but be available through a contract with the co-terminus specialist paediatric neurodisability service.

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.

Specifically, this service is for young people up to 18 years of age where there is a concern about a possible ASD (possibly in the context of additional mental health problems) where there is a need for a more specialist ASD assessment and/or intervention to support local professionals.

2.4 Any acceptance and exclusion criteria

Acceptance criteria

These will include:

- Children and young people under 18 years of age who have been referred by local consultant child and adolescent psychiatrist or consultant paediatrician or member of the local ASD care pathway with:

- Uncertainty about diagnosis of Autism Spectrum Disorder (ASD)
- Uncertainty about additional complex neurodisability, mental health or psychiatric disorder(s)
- Uncertainty about an ASD diagnosis because of complex presentations e.g. Attachment Disorders, Complex Neuro Development disorders
- Assistant and advice for complex cases that are managed at local team level

Exclusion criteria

These will include:

- Children and young people who have not received a diagnostic assessment involving a local ASD diagnostic care pathway
- Child/young person or parent self-referral or primary care referral without the knowledge of local generic CAMHS or child health service
- Child and family not known to either local generic specialist Tier 3 CAMHS or secondary child health services
- Individuals accepted by working age adult services unless a request is made by the community adult mental health team at the time of healthcare transfer to facilitate the transition of this vulnerable young person with likely ASD and additional mental health problems.
- Over 18 years

2.5 Interdependencies with other services

Co-located services

Specialist Paediatric neuro-disability service including access to special investigations e.g. specialist Electroencephalogram (EEG), scanning Inter-dependent services

- Tier 3 CAMHS including Tier 3 CAMHS Learning Disability Services
- Community Child Health
- Other Tier 4 CAMHS
- Adult Mental Health Services for young people in transition
- Regional genetics service
- Specialist dietetics
- Sleep disorders service
- Paediatric gastro-enterology
- Specialist ASD parent advisors

Related services

- Education
- Local Authority Children's Services
- Adult social care for young people in transition

- Third sector organisations including but not limited to National Autistic Society, Contact-a-Family

Interim for adoption from 01/10/13

3. Applicable Service Standards

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

- The National Service Framework Standards for the mental health and Psychological well-being of children and Young People (Standard 9) 2004
- National CAMHS Review 2008
- Autism Act 2009 & Autism Strategy 2010
- Implementing Fulfilling and rewarding lives – statutory guidance for local authorities and NHS organisations to support implementation of the Autism strategy, Dec 2010
- NICE guidance CG 128 2011
- Adult Autism NICE guidelines published 2012
- Adult Autism NICE guidelines published 2012
- Kennedy Report 2010 & Green paper 2011
- Children and Young People Health Outcomes Strategy (2012)

4. Key Service Outcomes

The health outcomes for the children, young people and parents/carers are maximized through the timely assessments and management of interventions provided by the Tier 4 Specialist ASD CAMHS.

Children, young people and other family members are enabled to cope with their diagnoses and receive sufficient help and support to reduce the impact of their ASD and additional mental health disorders

The neurodisability and any other specialist professional needs not available within the Tier 4 ASD specialist team of the children and young people are assessed and any specific investigations and interventions organised through SPA with specialist paediatric neurodisability services and other co-terminous services

Safeguarding and all other statutory Trust and NHS procedures are complied with The work of the Tier 4 ASD CAMHS specialist services within the national network is regularly audited and similar high standards maintained across the country in all sites

ANNEX 1 TO SERVICE SPECIFICATION:

PROVISION OF SERVICES TO CHILDREN

<p>Scope</p>
<p>Aims and objectives of service</p> <p>This specification annex applies to all children's services and outlines generic standards and outcomes that would be fundamental to all services.</p> <p>The generic aspects of care: The Care of Children in Hospital (Health Service Circular (HSC) 1998/238) requires that:</p> <ul style="list-style-type: none">• 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
<p>Service description/care pathway</p> <p>All paediatric specialised services have a component of primary, secondary, tertiary and even quaternary elements.</p> <p>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.</p> <p>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 (DOH) & Department for Education and Skills, London 2004)</p>
<p>Interdependencies with other services</p>

All services will comply with Commissioning Safe and Sustainable Specialised Paediatric Services: A Framework of Critical Inter-Dependencies – DH

Imaging

All services will be supported by a 3 tier imaging network ('Delivering quality imaging services for children' DH 13732 March2010). 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 (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.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 All teaching, training and clinical supervision is regularly evaluated and the highest quality maintained during the teaching.competencies by specialist anaesthetists in both fields of practice.

References

1. Guidelines on the Provision of Anaesthetic Services (GPAS) Paediatric anaesthetic services. Royal College of Anaesthetists (RCoA) 2010
www.rcoa.ac.uk
2. Certificate of Completion of Training (CCT) in Anaesthesia 2010
3. CPD matrix

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.

3. Applicable Service Standards

Applicable national standards e.g. NICE, Royal

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:
 - 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
 - having clear procedures followed in practice, monitored and reviewed that take account of relevant legislation and guidance for the management of alleged abuse
 - 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)

4. 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 dietitians, 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.

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

Interim for adoption from 01/10/13