1. Population Needs

1.1 National/local context and evidence base

Alternative and Augmentative Communication (AAC) devices (also known as communication aids) are used to restore communication for people who cannot communicate using speech. They address severe impacts on independence, quality of life and an ability to maintain employment.

The communication impairment may be due to physical speech difficulties or cognitive and language difficulties and are found in a very wide array of different diagnosed conditions and across all age groups. It has been estimated that every disabled young person whose employment status changes from permanent unemployment to permanent employment as an adult as a result of use of communication aid will realise benefits in the order of £500,000 over a working lifetime (report of the Office of the Communication Champion (OCC), 2011).

The OCC Report provides an estimate of prevalence of 0.05% of children and young people needing high technology AAC and specialist services. http://www.fastuk.org/pagedocuments/file/AAC%20Report%20Final.pdf.

Communication aids use language and communication software designed to produce spoken output. The spoken utterances can be accessed using symbols and/or text. Programming of relevant vocabulary needs to reflect the user's needs and developing language skills.
AAC systems may additionally include any of the following elements:

- Access and control by switches and control devices operated by hand, foot, body, head, breath and eye.
- Mounting systems for switches and control devices.
- Positioning and support systems provided to the individual (often using a wheelchair) in order to access the AAC system.
- Supportive software.

The systems prescribed may be commercially obtained or at specialist level be assembled to meet individual need and may include a custom manufactured or bespoke element.

For many years AAC users, professional bodies, service providers and charities such as Scope and Communication Matters, have raised concerns about inequality of access to local AAC services, inequality of access to the more specialised regional AAC services and to AAC provision in general.


John Bercow Member of Parliament (MP) carried out a review which reported in 2008, and led to the appointment of the Communication Champion for children and young people aged 0-19 in England who reported on practice in AAC provision:

- Some primary care trusts and local authorities were providing local multi-agency specialist teams with specific budgets
- Some local services were supported by regional centres of excellence.
- Available data indicated that the estimated level of need was not being met and, while NHS guidance indicated that specialised equipment services should be commissioned regionally, only one of ten NHS regional commissioning teams was fulfilling this function for AAC services.

Like other specialist equipment services, AAC services are characterised by the complexity of service user needs (complex physical/cognitive/language/sensory disability often in combination), need for expert and independent assessment, user and carer training to maximize effectiveness and independence, timely review and re-assessment for changing needs and finally on-going, life-long maintenance/replacement and user support.

The NICE has not issued specific guidance on EAT. The National Service Framework (NSF) for long term conditions has clearly identified the need to provide Equipment in Quality requirement 7. QR 7 has recognised the role of EAT in improving quality of life, enhancing independence, and in selected cases improve the opportunities for employment.
2. Scope

2.1 Aims and objectives of service

Aims

- To provide equitable national specialist AAC assessment services across the country for children and adults with complex communication needs
- To maintain specialist loan equipment bank for assessment, trial and long term loan of specialised communication equipment
- To provide specialist AAC advice and information and training to individuals, families and professionals involved in the delivery of local AAC services
- To support the establishment, training and development of local AAC services

Objectives of the delivery of specialised AAC services are:

- To support clients to attain their personal communication goals;
- To provide timely access across England for the population that require specialised AAC services;
- To promote better use of appropriate high tech AAC interventions and minimise abandonment of these AAC systems;
- To support the development of effective local AAC teams and care pathway procedures by which to manage referrals to specialised AAC services.

2.2 Service description/care pathway

The proposed service model is a hub and spoke model.

The recommendation for a hub and spoke model is based on existing good practice which has in turn been recommended by many high level reports such as the reports from the Communication Champion (http://www.fastuk.org/pagedocuments/file/AAC%20Report%20Final.pdf) and AAC Synthesis for Commissioners from the RCSLT (http://www.rcslt.org/speech_and_language_therapy/commissioning/aac_plus_intro), and in the previous SSNDS.

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)
The term ‘specialised AAC hub’ indicates a range of activities to be undertaken (see service model section) rather than a presumption that there must be a centralised hub location or provision of hub services by a single organisation.

The service has to be sustainable based on the size of its geographical catchment area and population which makes cost-effective a level of specialism (where specialism indicates both the focus on AAC (high tech AAC particularly) and a more expert level of competence).

In line with government policy the services may be provided by statutory, voluntary or private sector organisations, or by a consortium of organisations, dependent on compliance with the required standards and capacity to meet commissioners' expectations of service delivery.

Taking into account the SSNDS document and the OCC report recommendations on the activities to be undertaken by specialised AAC hub services, the following areas of service will be undertaken:

- Specialised assessment of AAC needs
- Regional management, including procurement, of high tech AAC systems
- Training and service development of local spoke AAC teams
- Regional co-ordination of care planning, service standard development, quality assurance and improvement of local AAC teams.

In order for a specialised AAC hub service to deliver the required range of activities, in addition to those administrative and management staff required by any organisation, the hub team should include staff with the following competences:

- Electronic assistive technology (clinical scientists, clinical technologists, specialist occupational therapists, specialist speech and language therapists or equivalent):
  - Speech and language therapy with AAC specialism;
  - Learning and educational development competence to support the AAC assessment and intervention service to younger clients (often a teacher);
  - Seating and positioning (often a physio or occupational therapist);
  - Access and control methods and mounting of equipment (often a physio or occupational therapist);
  - Equipment procurement and stock management;

The hub team should also be able to evidence that it has processes and contracts in place to access, in a timely way, staff with the following competences:

- Competence in personalisation and customisation of equipment (software, electronic and mechanical);
- Cognitive assessment competence to support AAC assessment and intervention service to older clients;
- Health informatics, quality improvement and research methodology competence;
- Training and workforce development competence to support the development and competence of local AAC spoke services.

The specialised AAC hub services will work with the developing local AAC spoke...
teams to provide training and to establish a collaborative approach to outcomes measurement and data gathering on which to base quality assurance, service development and to inform future commissioning practice.

Specialised AAC services will work with their local AAC spoke teams to build their capacity to manage directly the needs of 90% of the region’s AAC population and to jointly manage the needs of the 10% of the region’s population that require specialised AAC services.

An individual for whom a specialist AAC service is needed would have/be
- In need of a complex assessment (but not necessarily complex equipment)
- Able to understand the purpose of a communication aid.
- Developed beyond cause and effect understanding.
- Communication technology needs beyond the competence of the local AAC service.

In addition they may have / be some or all of the following:
- Severe physical disability especially of the upper limbs.
- Additional sensory impairment to the communication impairment.
- In need of specialist switch access, which may need to be bespoke.
- In need of a device that integrates spoken and written communication, as well as environment control.
- Multiple disabilities which in combination impact on the individual’s ability to communicate.
- Experience of using low tech AAC which is insufficient to enable them to realise their communicative potential.

A ‘specialised service’ would provide:
- A multi-disciplinary team (MDT) assessment including Speech and Language Therapists (SLT), Clinical Scientists and Technologists, Occupational Therapists (OT), Specialist Teachers and access to Physiotherapists, Psychologists and other relevant professionals.
- Technological and engineering facilities for customisation and modification to the individual.
- An assessment and loan bank of possible technologies offering a diverse range of solutions.
- An extremely wide range of software, vocabulary packages and resources.
- Expertise in procurement and equipment management.
- An ability to issue, monitor, maintain, recall and refurbish equipment.
- An ability to manage, aggregate and analyse user information to enhance the service and streamline day to day operations.
- An ability to integrate services and equipment with other assistive technologies such as Environmental Control.
- An ability to educate and train a wide range of stakeholders from the user, families, spoke service members and local team members.
- An ability to take account of Co-morbidity issues such as Postural support needs.
- Work with local health and social care professionals in areas where service uptake is low to facilitate referral of those who could benefit from specialist.
assessment and equipment provision.

- Experience, capacity and remit to deliver services across a wide geographical region
- An expertise in complex low tech AAC strategies and techniques

The breadth of issues to be considered when assessing the individual for AAC are shaped by the World Health Organisation (WHO) International Classification of Functioning, Disability and Health (ICF) and include:

- the individual, their impairment(s), predicted progression, abilities, learning and communication requirements, preferences, life experiences and attitudes
- the tasks that the individual wishes and needs to undertake
- the individual’s care networks and the social, cultural and physical environments in which the individual and their system will have to operate.

The issues that are likely to require referral to a specialised AAC service in relation to the possible technology solutions also include:

- the features of available and emerging technologies, an assessment of immediate and lifetime costs and interoperability issues
- software requirements, interoperability with related electronic assistive technologies and mainstream technologies;
- access and control methods
- the need for custom made devices and equipment
- mounting of equipment or switches and positioning of the individual.

By way of contrast and to clearly articulate the difference between a hub and spoke (local) service an individual for whom a local AAC services is needed would have (a combination of):

- No/mild physical disability
- Communication technology needs within the competence of the local AAC Workforce
- Co-morbid conditions that do not impact on the individual’s communication disability
- Minimal upper limb impairment
- Preverbal communication skills
- Not achieved cause and effect understanding

Consequently, a local spoke service would provide:

- An expertise in non-complex low-tech AAC strategies and techniques
- A more limited multi-disciplinary team including at least SLT, OT and teachers where appropriate
- Ability to modify equipment and software using only facilities within the equipment itself, not requiring workshops and engineering skills
- A loan bank of the more common and less expensive AAC devices
- An ability to contribute to data collection using data systems managed by the Hub
- Training of the team around an individual
- Ongoing support for individuals referred to the hub, with responsibility for re-referral if and when appropriate
- An ability to pass on training materials
- An ability to identify where co-morbidity issues influence AAC and pass on this information to the hub
- Simpler and cheaper non customised solutions

The care pathway will be as follows:

- Referrals will be accepted from health, education and social care professionals working in local teams
- Additional information to the referral may be required from other health, education or social care agencies or the individual’s General Practitioner (GP), especially for self-referrals or those from non-health professions
- All referrals will be acknowledged within 10 days of receipt by the service and it be stated if there is reason to delay the assessment or referral acceptance, such as insufficient referral information
- Otherwise, the service will assess all patients fulfilling the acceptance criteria, typically within 6 weeks from the date of acceptance of the referral
- Patients will be assessed in the most effective location e.g. their home, place of residence, hospital, school, or workplace by competent, experienced personnel and in collaboration with other services where necessary or by remote access if appropriate.
- Equipment shall only be provided after the assessment. The assessment recommendations shall be confirmed in writing to the patient, referrer, GP and other stakeholders as appropriate
- Opportunity for a temporary trial of suitable sample equipment shall be recommended and made available when indicated, such as when there is doubt over the patient’s motivation or ability to use the equipment. The outcome of the trial, either to continue with or to cease provision shall be based on suitable outcome measurement
- When equipment provision is recommended at the assessment, this shall normally be available for use by the patient within 12 week of the assessment. Exceptions to this target may occur due to dependencies on other agencies or when the recommended solution involves custom or bespoke or integrated equipment
- All patients provided with equipment shall receive adequate training in its use with necessary information in an appropriate format to them. Additional tuition shall be available as required, in consideration of the possible cognitive impairment of some users
- Each user of equipment shall receive ongoing support in case of its malfunction, an annual service maintenance visit including statutory testing of equipment and timely review of equipment appropriateness for them
- In response to reported malfunctions of the equipment, the service shall ensure that the user is contacted as soon as possible and remedial action for critical functions taken within a clinically appropriate time
- The frequency of user and equipment review shall be determined on a case by case basis
case basis by service personnel with the ability to respond appropriately to changes in clinical conditions (e.g. people with rapidly progressing neurological conditions)
- Adjustments, modifications or change of the equipment provision shall be provided when indicated following review due to change in patient clinical condition, functional impairment or circumstances. A full re-assessment of their needs shall also be available when appropriate
- Equipment no longer required by users due to change in their circumstances, shall be reclaimed, decontaminated and refurbished to standards agreed with manufacturers prior to becoming available for re-issue.

In addition the service will undertake (or arrange through subcontractors);
- Re-conditioning of equipment ready for re-use
- Technical evaluation and management of equipment to ensure it is fit for purpose
- Development of custom or bespoke or integrated equipment solutions for individual patient’s EAT needs when these are identified.

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.

Specialised AAC services deliver high-cost, low-volume interventions that aim to restore a degree of communication for severely or profoundly communication impaired people. Communication impaired people in this context means those adults and children who have an impairment that impacts on their ability to communicate using speech and/or language or written communication. This does not cover those people with communication problems arising primarily from hearing or vision impairments.

Communication impairment may result from physical, sensory, intellectual, learning or cognitive disabilities. This would include children born with a communication impairment (for example and in no order of precedence, those resulting from cerebral palsy, developmental disorders and learning disabilities such as autism) and
children and adults who become communication impaired (for example through stroke, cancer, brain and spinal injury and neurological diseases such as Parkinson’s, Alzheimer’s, Multiple Sclerosis or Motor Neurone Disease).

A particular service will normally serve the population within a determined geographical area with a population size sufficient to generate the critical mass of referrals to support the service.

2.4 Any acceptance and exclusion criteria

In line with the SSNDS definition of specialised services, “it is the complexity and severity of the person’s condition, and the expertise required to assess/ support and provide/ maintain equipment for each individual that defines a requirement for a specialised AAC service as opposed to the nature of the equipment itself.”

The requirement for a specialised AAC service must arise when the task of matching the individual to the most effective solution is judged, by the local team themselves, as beyond their capability. Self-reflection and judgement of capability by local teams will be supported by training and professional development support from the specialised hub teams in relation to the Quality Standard for AAC services.

Exclusion criteria for provision of equipment by the service would be:
- No/mild physical disability although people with a complex combination of sensory impairment but with good physical function may be appropriate for specialist service referral
- Preverbal communication skills
- Not achieved cause and effect understanding.
- Impaired cognitive abilities that would prevent the user from retaining information on how to use equipment.

2.5 Interdependencies with other services

AAC Services should have a relationship with the following:

The sector's Quality Standard for AAC services notes a requirement for continuity of AAC services between children and adult services and between AAC services, other relevant local and specialised electronic AT services, including wheelchair and environmental control services and allied services such as for posture and seating. The SSNDS Definition 5 also highlights the importance of these linkages. With some functions common between environmental control systems and high tech AAC systems, it would be expected that specialised services demonstrate how they intend to work collaboratively with NHS EAT services and to provide electronic assistive technology services in an integrated way.

Between local and specialised services: The care pathway outlined in this specification indicates the close interdependence required between local spoke AAC teams and specialised hub teams. Specialised AAC hub services are not viable without local spoke AAC services that will be the source of all referrals in to the
specialised AAC hub services.

The specification for specialised AAC hub services is based on the assumption that the following activity is undertaken by local spoke AAC teams:

- Local awareness raising of the need and benefits of AAC interventions with primary and community care teams, schools and colleges, NHS consultants and hospital based teams, social service teams, residential and care homes, etc.;
- Establishing local funding arrangements between health, social care, education and other relevant commissioners including the negotiation of an appropriate version of the care pathway process with their specialised AAC hub teams;
- Managing the receipt of referrals and making appropriate onward referrals to specialised AAC hub teams and other services;
- Undertaking assessment for low tech AAC and for those clients with non-complex needs, including establishing the goals and outcome measures by which to assess the impact of the intervention;
- Trial and long term provision of low tech AAC equipment;
- Implementation and support for trial and long term provision of low and high tech AAC systems, including technical training for individual AAC users, their families and communication and support networks;
- Monitoring and recording outcome measures using the regional database and, using information extracted from the database, reviewing the impact of individual care plans and analysing and reporting data in relation to the local AAC population to commissioners at local and regional levels;
- Collaboratively co-ordinating the care of their AAC population with their regional specialised AAC hub services.

3. Applicable Service Standards

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

There are a number of quality standards that have been developed for the AAC sector specifically and some which relate to the wider scope of SLT services which may provide contextual guidance.

Standards that are AAC specific:

- The most directly relevant quality standard is the Quality Standard for AAC Services was developed by ‘Communication Matters’, as a result of a 2 year project working closely with the AAC and SLT sectors. [http://www.communicationmatters.org.uk/nationalaacstandards](http://www.communicationmatters.org.uk/nationalaacstandards).

Standards relating to assistive technology provision more generally:

- Care Quality Commission: All providers of health and social care in England have by law to be registered with the Care Quality Commission, initially by meeting its ‘Essential Standards of Quality and Safety’, and then by continuing to meet these as evidenced by inspections and assessment. All NHS hospitals
and community services, adult social care and independent healthcare providers in England, including EAT and AAC services, must be registered. The Standards are based on statutory regulations. Standard 3 covers safety, including infection control and use of equipment, in all settings including the home.

- BSRM (2000) ‘Electronic assistive technology’

Standards relating to speech and language therapy (SLT) services:

- Department for Education and Science (2000) ‘Report of the working group on the provision of speech and language therapy services to children with special educational needs (England)’
- Department for Children, Schools and Families (2008) ‘Better communication: An action plan to improve services for children and young people with speech, language and communication needs’

4. Key Service Outcomes

Outcomes will relate to the objectives noted above. Outcome measures such as Psychosocial Impact of Assistive Devices (PIADS), TOMS or Goal Attainment Scaling are currently in use in some specialised AAC services.

Further guidance on appropriate outcome measures will be available in September 2012 from a ‘Communication Matters’ AAC Outcome Measures working group publication. These guidelines detail a range of suitable outcome measures from different stakeholder viewpoints, for example for Providers and Commissioners.

Specialised AAC services will put in place mechanisms to measure relevant activity such as access to services, high tech AAC system adoption and abandonment rates across the region, as well as activity undertaken to implement local care pathway processes. Specialised AAC hub services will measure indicators of activity to meet the quality standards noted in the sector’s Quality Standard for AAC services.
ANNEX 1 TO SERVICE SPECIFICATION:
PROVISION OF SERVICES TO CHILDREN

Scope

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 (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
Imaging

All services will be supported by a 3 tier imaging network (‘Delivering quality imaging services for children’ Department of Health, 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 (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. 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 and should maintain the competencies so acquired*. 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.
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 Service Standards

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
• 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)
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 Sexually Transmitted Infections (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
- ensures that staff handling medicines have the competency and skills needed for children and young people’s medicines management
- ensure 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, 2006, London.