

E03/S/f

**2013/14 NHS STANDARD CONTRACT
PAEDIATRIC MEDICINE: HAEMATOLOGY**

PARTICULARS, SCHEDULE 2 – THE SERVICES, A – SERVICE SPECIFICATION

Service Specification No.	E03/S/f
Service	Paediatric Medicine: Haematology.
Commissioner Lead	
Provider Lead	
Period	12 months
Date of Review	

1. Population Needs

1.1 National/local context and evidence base

Prevalence

There is a wide variation in the prevalence/incidence of haematological conditions. There is a spectrum, ranging from conditions such as nutritional iron deficiency anaemia, which is one of the most common problems in childhood. This condition can have a significant impact to the patient if left untreated, but can be delivered by non-specialist teams; to other conditions which are rare and often require specialist diagnosis and management. The more rare, specialised conditions are likely to be underestimated as molecular techniques for their diagnosis are only now being developed and many still lack a genetic marker. Examples representing the whole range of diverse conditions covered in this service specification:

- Iron deficiency anaemia: peak prevalence 4-8% in children aged 1-3 years of age
- Hereditary spherocytosis: 1 in 2,000 of Northern European ancestry.
- Glucose-6-phosphate dehydrogenase (G6PD) deficiency - up to 26% in particular ethnic groups and 10% in certain districts of England
- Pyruvate kinase deficiency: 51 cases per 106 in the Caucasian population
- Aplastic anaemia: 2-5 persons per 106 per year
- Fanconi anaemia: 1 in 350,000 births
- Diamond Blackfan anaemia: 7.3 per 106 live births

- Autoimmune neutropenia childhood: incidence 1 per 100,000 children per year
Haemophagocytic lymphohistiocytosis: 1.2 cases per 106 children
- Immune thrombocytopenia: 2.2-5.3 per 100,000 children per year
- Thrombosis: incidence 0.7 – 1.0 per 100,000 population, prevalence 5.3% per 10,000 hospital admissions

This service offers frequent consultations for the management of haematological manifestations of other service specifications.

2. Scope

The service outlined in this specification is for patients ordinarily resident in England*; or otherwise the commissioning responsibility of the NHS in England (as defined in „Who Pays?: Establishing the responsible commissioner’ and other Department of Health guidance relating to patients entitled to NHS care or exempt from charges).

* Note: for the purposes of commissioning health services, this EXCLUDES patients who, whilst resident in England, are registered with a GP practice in Wales, but INCLUDES patients resident in Wales who are registered with a GP practice in England.

2.1 Aims and objectives of service

The aim of this service is to provide family centred specialist care for adolescent and adults (and families) with haematological disorders and promote their optimal future and quality of life.

Key Objectives:

- To provide optimal care for children with haematological conditions and support other specialities whose patients have haematological manifestations
- To identify children with haematological conditions or manifestations
- To provide appropriate care for haematological conditions
- To prevent complications of haematological conditions

2.2 Service description/care pathway

Children with haematological disorders should be cared for as close to home as possible with the local hospital providing as much of the care as possible. Some of the most common acute complications involve treatment of infections and many

conditions require the regular transfusion of blood products, both better provided locally. This aim has to be viewed in the context that, other than for self-limited conditions or those with low risk of complications, the diagnosis should be confirmed and a management plan formulated and regularly reviewed by one of the Paediatric Haematology Specialist Centres in England. Where appropriate, outreach clinics will be provided which have an important role in the diagnosis of conditions with limited complexity and follow-up of patients. A key aspect of the specialist centres is access to the multi-disciplinary (MDT) team, including psychosocial expertise and integrated laboratory medicine, which cannot be offered by outreach clinics. Hence, the care of primary haematological conditions should be located in such centres and resources provided so that they can offer a 24/7 specialised service. Local services, often involving the team working between a paediatrician and a haematologist offering transfusion and laboratory support, should be integrated in a network along with the centre.

Conditions

A diagnosis and management plan, unless otherwise indicated, is to be made by the Paediatric Haematology Specialist Centre. Pathways should be developed to identify conditions suitable for outreach clinics and to deliver care at secondary level.

Paediatric Haematology Specialist Centre	Local Centre
Vitamin B12, iron and folate deficiency anaemia <ul style="list-style-type: none"> • Intrinsic factor deficiency • Selective B12 malabsorption with proteinuria • TCII deficiency • Congenital folate malabsorption • IRIDA 	Hereditary haemolytic anaemia <ul style="list-style-type: none"> • Hereditary spherocytosis
Anaemia due to enzyme disorders <ul style="list-style-type: none"> • G6PD: chronic non spherocytic anaemia • Disorders of glutathione metabolism • Disorders of glycolytic enzymes • Disorders of nucleotide metabolism 	
Hereditary haemolytic anaemia <ul style="list-style-type: none"> • Nutritional anaemia not presenting with pancytopenia • Monitoring of stable disease • Uncomplicated G6PD • Mild hereditary spherocytosis Monitoring of anaemia • Hereditary elliptocytosis • Other membrane disorders • Alternative and unstable haemoglobins 	

Acquired haemolytic anaemia	
<ul style="list-style-type: none"> • Drug induced • Autoimmune haemolytic anaemia • Other non-immune haemolytic anaemia • Paroxysmal nocturnal haemoglobinuria 	
Acquired pure red cell aplasia	
<ul style="list-style-type: none"> • Transient • Chronic 	
Aplastic anaemia	
<ul style="list-style-type: none"> • Inherited bone marrow failure syndromes • Drug induced • Idiopathic aplastic anaemia 	
Sideroblastic anaemia	
Congenital dyserythropoietic anaemia	
Methaemoglobinemia	
Neutropenia	
<ul style="list-style-type: none"> • Acquired • Congenital 	Acquired uncomplicated secondary neutropenia
Functional disorders of neutrophils	
Other disorders of white cells	Secondary eosinophilia
Myeloproliferative disorders	
Myelodysplasia	
Haemophagocytic lymphohistiocytosis	
<ul style="list-style-type: none"> • Primary • Secondary 	
Asplenia	Post-surgical
Hereditary or acquired coagulation deficiencies	
<ul style="list-style-type: none"> • Diagnosis before referral to haemophilia centre 	Disseminated intravascular coagulation
Purpura and other haemorrhagic conditions	
<ul style="list-style-type: none"> • Qualitative platelet defects • Acute ITP – complicated • Chronic ITP • Complicated secondary thrombocytopenia 	Uncomplicated newly presented ITP Uncomplicated secondary thrombocytopenia
Thrombosis	

Expert opinion, both clinical and laboratory, is given to other specialities and secondary care. Specialist centres have a significant amount of activity in

transfusion medicine, paediatric intensive care, cardiothoracic surgery, liver transplantation and particularly neonatal/fetal medicine. Paediatric haematology is delivered as part of a clinical network in order to provide the best patient care, facilitate optimal use of resources and maximise local access to patients. The clinical network is led by the specialist centre which must include outreach work as part of its specialist care.

The specialist centres are defined by:

- 24/7 access to care by consultant paediatric haematologist (2 years training in paediatric haematology as part of 5 years training in haematology, Member Royal College of Pathology(MRCPPath) plus Membership Royal College Paediatrics and Child Health(MRCPCH)/Member Royal College Physicians (MRCP)
- Paediatric haematology clinical nurse specialist and pharmacist, Monday to Friday 09.00-17.00
- Paediatric haematology clinical psychology and play specialists
- Haematology laboratory scientists with expertise in paediatric haematology conditions and Clinical Pathology Accreditation(CPA).

Specialised care includes outreach by the specialist centre defined as specific clinics which include:

- Paediatric haematologist from the specialist centre
- Paediatric haematology clinical nurse specialist
- Local general paediatrician
- ± local clinical nurse specialist
- ± local haematologist

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

This service will be provided to all children up to their 19th birthday.

2.4 Any acceptance and exclusion criteria

The referral criteria depend on the complexity of the condition, interventions required for diagnosis and management and the natural history of the disease as indicated in

section 2.1. Self-limited conditions, and those with low risk of complications, can be managed entirely by the local team, but the diagnosis should be confirmed and a management plan formulated and regularly reviewed by one of 17 Paediatric Haematology Specialist Centres in England. For some conditions, as stipulated in the network arrangements, the outreach clinic setting will be suitable. Haemoglobinopathies, haemato-oncology, haemophilia and blood and marrow transplantation are covered by separate service specifications.

2.5 Interdependencies with other services

Specialist services should be co-located with the following for diagnostic and management purposes:

- Paediatric surgery
- Paediatric radiology
- Critical care and anaesthesia

Many of the haematological conditions have multi-system manifestations requiring access to the following paediatric specialities and, in addition, there is a need to ensure adequate growth and development:

- Cardiology: associated congenital abnormalities and complications arising from the haematological disorder.
- Respiratory medicine: associated congenital abnormalities, manifestation of the condition and complications arising from the haematological disorder.
- Gastroenterology: associated congenital abnormalities, manifestation of the condition and complications arising from the haematological disorder, exclusion of alternative possibilities as part of differential diagnosis.
- Clinical immunology
- Histopathology: diagnosis at presentation and of complications
- Endocrinology: monitoring of growth and development, surveillance of complications of treatment.
- Dentistry: consequences of extramedullary haemopoiesis, infection in neutropenia and neutrophil disorders, bleeding in bleeding disorders
- Microbiology and virology
- Neurology: associated congenital abnormalities and manifestations of haematological disorder.
- Gynaecology: associated congenital abnormalities, surveillance of increased risk of cancer
- Ear nose and throat (ENT): associated congenital abnormalities, manifestations of the condition, surveillance of complications of treatment, surveillance of increased risk of cancer
- Ophthalmology: associated congenital abnormalities, manifestations of the condition, surveillance of complications of treatment

In addition, most are chronic conditions and often require a significant number of

interventions, hence play specialists and psychology will be part of the service provision, which will be integrated with the paediatric haematology service. There will also be access to social work.

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3. Applicable Service Standards

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

Standards of Care

Available from the British Committee for Standards in Haematology - www.bcsguidelines.com

- Addendum on use of rabbit Anti-thymocyte globulin(ATG) for immunosuppressive therapy (addendum to 2009 guidelines on the management of aplastic anaemia): 2011
- The diagnosis and management of hereditary spherocytosis: 2011
- Review of guidelines for the prevention and treatment of infection in patients with an absent or dysfunctional spleen: 2011
- Guideline on the investigation and management of adults and children presenting with thrombocytosis: 2011
- The investigation, management and prevention of venous thrombosis in children: 2011
- Guidelines on the use of irradiated blood components: 2010
- International consensus report on the investigation and management of primary immune thrombocytopenia: 2010
- Testing for Heritable Thrombophilia: 2010
- Guidelines for the diagnosis and management of aplastic anaemia: 2009
- The administration of blood components: 2009

Available from Fanconi Hope <http://www.fanconi.org.uk/clinical-network/standards-of-care/>

- UK Standards of Care Fanconi anaemia: 2009

Available from British Journal of Haematology

<http://onlinelibrary.wiley.com/doi/10.1111/j.1365-2141.2008.07269.x/pdf>

- Diagnosing and treating Diamond Blackfan anaemia: results of an international clinical consensus conference: 2008

4. Key Service Outcomes

General outcomes

- To minimise mortality and morbidity by providing early diagnosis and the most appropriate care for children with haematological disorders.

- To ensure that there is a sufficient, skilled and competent multi-disciplinary workforce to manage children with haematological disorders.
- To ensure that children have their healthcare and any social care plans coordinated.
- To ensure that children are treated in line with national guidelines and agreed local pathways.
- To ensure paediatric haematology and transfusion laboratory equitable plus comprehensive provision

Specific outcomes

Specific outcomes will vary according to the condition.

ANNEX 1 TO SERVICE SPECIFICATION:

PROVISION OF SERVICES TO CHILDREN

Aims and objectives of service

This specification annex applies to all children's services and outlines generic standards and outcomes that would be fundamental to all services.

The generic aspects of care:

The Care of Children in Hospital (Health Service Circular (HSC) 1998/238) requires that:

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

Service description/care pathway

- All paediatric specialised services have a component of primary, secondary, tertiary and even quaternary elements.
- The efficient and effective delivery of services requires children to receive their care as close to home as possible dependent on the phase of their disease.

- Services should therefore be organised and delivered through “integrated pathways of care” (National Service Framework for children, young people and maternity services (Department of Health & Department for Education and Skills, London 2004)

Interdependencies with other services

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

Imaging

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

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

Specialist Paediatric Anaesthesia

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

As well as providing an essential co-dependent service for surgery, specialist anaesthesia and sedation services may be required to facilitate radiological procedures and interventions (for example magnetic resonance imaging (MRI) scans and percutaneous nephrostomy) and medical interventions (for example joint

injection and intrathecal chemotherapy), and for assistance with vascular access in babies and children with complex needs such as intravenous feeding.

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

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

References

1. Guidelines for Providing Anaesthetic Services (GPAS) Paediatric anaesthetic services. Royal College of Anaesthetists (RCoA) 2010 www.rcoa.ac.uk
2. Certificate for completion in training (CCT) in Anaesthesia 2010
3. Continuous performance 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 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 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 two RCNs in total)

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

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

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

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

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

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

- ensuring that staff and people who use services understand the aspects of the safeguarding processes that are relevant to them.
- ensuring that staff understand the signs of abuse and raise this with the right person when those signs are noticed.
- ensuring that people who use services are aware of how to raise concerns of abuse.
- having effective means to monitor and review incidents, concerns and complaints that have the potential to become an abuse or safeguarding concern.
- having effective means of receiving and acting upon feedback from people who use services and any other person.
- taking action immediately to ensure that any abuse identified is stopped and suspected abuse is addressed by:
 - having clear procedures followed in practice, monitored and reviewed that take account of relevant legislation and guidance for the management of alleged abuse
 - separating the alleged abuser from the person who uses services and others who may be at risk or managing the risk by
 - removing the opportunity for abuse to occur, where this is within the control of the provider
 - reporting the alleged abuse to the appropriate authority
 - reviewing the person's plan of care to ensure that they are properly supported following the alleged abuse incident.
- using information from safeguarding concerns to identify non-compliance, or any risk of non-compliance, with the regulations and to decide what will be done to return to compliance.
- working collaboratively with other services, teams, individuals and agencies in relation to all safeguarding matters and has safeguarding policies that link with local authority policies.
- participating in local safeguarding children boards where required and understand their responsibilities and the responsibilities of others in line with the Children Act 2004.
- having clear procedures followed in practice, monitored and reviewed in place about the use of restraint and safeguarding.
- taking into account relevant guidance set out in the Care Quality Commission's Schedule of Applicable Publications
- ensuring that those working with children must wait for a full CRB disclosure before starting work.
- training and supervising staff in safeguarding to ensure they can demonstrate

the competences listed in Outcome 7E of the Essential Standards of Quality and Safety, Care Quality Commission, London 2010

All children and young people who use services must be:

- fully informed of their care, treatment and support.
- able to take part in decision making to the fullest extent that is possible.
- asked if they agree that their parents or guardians are 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 peoples to adult-oriented health services can be associated with increased risk of non-adherence to treatment and loss to follow-up, which can have serious consequences. There are measurable adverse consequences in terms of morbidity and mortality as well as in social and educational outcomes. When children and young people who use paediatric services are moving to access adult services (for example, during transition for those with long term conditions), these should be organised so that:

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

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

- **A16.1** Children are seen in a separate out-patient area, or where the hospital does not have a separate outpatient area for children, they are seen promptly.
- **A16.3** Toys and/or books suitable to the child's age are provided.
- **A16.8** There are segregated areas for the reception of children and adolescents into theatre and for recovery, to screen the children and adolescents from adult patients; the segregated areas contain all necessary

equipment for the care of children.

- **A16.9** A parent is to be actively encouraged to stay at all times, with accommodation made available for the adult in the child's room or close by.
- **A16.10** The child's family is allowed to visit him/her at any time of the day, except where safeguarding procedures do not allow this
- **A16.13** When a child is in hospital for more than five days, play is managed and supervised by a qualified hospital play specialist.
- **A16.14** Children are required to receive education when in hospital for more than five days; the Local Education Authority has an obligation to meet this need and are contacted if necessary.
- **A18.10** There are written procedures for the assessment of pain in children and the provision of appropriate control.

All hospital settings should meet the „Standards for the Care of Critically Ill Children' (Paediatric Intensive Care Society, London 2010). There should be age specific arrangements for meeting Regulation 14 of the Health and Social Care Act 2008 (Regulated Activities) Regulations 2010. These require:

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

All paediatric patients should have access to appropriately trained paediatric trained dieticians, physiotherapists, occupational therapists, speech and language therapy, psychology, social work and CAMHS services within nationally defined access standards. All children and young people should have access to a professional who can undertake an assessment using the Common Assessment Framework and access support from social care, housing, education and other agencies as appropriate.

All registered providers must ensure safe use and management of medicines, by means of the making of appropriate arrangements for the obtaining, recording, handling, using, safe keeping, dispensing, safe administration and disposal of medicines (Outcome 9 „Essential Standards of Quality and Safety', Care Quality Commission, London 2010). For children, these should include specific

arrangements that:

- ensure the medicines given are appropriate and person-centred by taking account of their age, weight and any learning disability
- ensure that staff handling medicines have the competency and skills needed for children and young people's medicines management
- 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.

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