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**education and skills**



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*National Service Framework for Children,  
Young People and Maternity Services*

## **Children and Young People who are Ill**

*Change for Children - Every Child Matters*

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# Standard 6: Children and Young People who are Ill

## 1 Introduction

1.1 The National Service Framework for Children, Young People and Maternity Services establishes clear standards for promoting the health and well-being of children and young people and for providing high quality services which meet their needs.

1.2 There are eleven standards of which this is the sixth. They cover the following areas:

**Standard 1** Promoting Health and Well-being, Identifying Needs and Intervening Early

**Standard 2** Supporting Parenting

**Standard 3** Child, Young Person and Family-centred Services

**Standard 4** Growing Up into Adulthood

**Standard 5** Safeguarding and Promoting the Welfare and Children and Young People

**Standard 6** **Children and Young People who are Ill**

**Standard 7** Children and Young People in Hospital

**Standard 8** Disabled Children and Young People and those with Complex Health Needs

**Standard 9** The Mental Health and Psychological Well-being of Children and Young People

**Standard 10** Medicines for Children and Young People

**Standard 11** Maternity Services

1.3 This standard addresses the requirements of children, young people and their families when they have an acute illness or injury and also children and young people who have (or are at risk of a long-term condition which is not disabling; it should be read in conjunction with Standards 1-5 and Standard 8 which addresses children and young people with complex health needs. The care of children in hospital is covered in Standard 7. All professionals caring for children and young people who require medicines should also take account of the issues covered in Standard 10.

### **Vision**

#### **We want to see:**

- > Children and young people who are ill receiving timely, high quality and effective care as close to home as possible.
- > Children and young people who are ill and their families being cared for within a local system which co-ordinates health, social care and education in a way that meets their individual needs.

### **Standard:**

**All children and young people who are ill, or thought to be ill, or injured will have timely access to appropriate advice and to effective services which address their health, social, educational and emotional needs throughout the period of their illness.**

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### Markers of Good Practice

1. Services are designed so that local children's clinical networks are in place which ensure that parents, children and young people are able to receive optimum care and support as close to home as possible.
2. Parents, children and young people receive information, advice and support to enable them to manage minor illnesses themselves, and access appropriate services when necessary.
3. Children, young people and parents are provided with information about their illness, diagnosis and treatment options, and relevant support networks and are able to participate in care planning and delivery.
4. Ill children and young people have access to high quality, evidence-based care developed through clinical governance and delivered by staff who have the right skills for assessment, diagnosis, treatment and ongoing care.
5. There is continuity between care delivered in different settings; this is supported by systems for sharing relevant information about children and young people in a timely way.
6. Health care is delivered in a way which promotes participation in education, thereby maximising the child or young person's potential.
7. Community Children's Nursing Teams are available (as part of Children's Community Teams) in each locality.

## **2 Rationale**

- 2.1** Children and young people are frequent users of all types of healthcare compared to adults. Over 80% of all episodes of illness in childhood are managed by parents without reference to the professional health care system. However, in a typical year; a pre-school child will see a general practitioner about six times, while a child of school age will go two or three times; up to half of infants aged under twelve months and one quarter of older children will attend an accident and emergency department. In any year, one in eleven children will be referred to a hospital outpatients clinic, and one in ten to fifteen will be admitted to hospital. The majority of children's admissions to hospital are unexpected, as is much surgery on children. Most of these children will have one short admission, but a few will spend long periods in hospital or be admitted often.
- 2.2** The change in public expectations, patterns of disease, technological developments, the shift from hospital in-patient care to community care and the impact of the European Working Time Directive and other workforce pressures require services to modernise, focusing on both process and role redesign. Local Children's Clinical Networks need to be developed and managed to ensure there is a comprehensive, integrated, safe local service for children and young people when they are ill. The focus of a Local Children's Clinical Network is on the relationships between the different parts of the local service. This differs from Specialist Clinical Networks for illnesses such as heart disease or cancer, which focus on the relationships and arrangements between local and tertiary services, and are described in Standard 7.
- 2.3** Children may become sick very quickly. At the onset of an illness it can be very difficult to distinguish between a trivial problem such as a viral infection and a much more serious condition such as meningitis. Key to the effective care of children and young people who present with an acute illness is the provision of services which ensure timely high quality assessment, diagnosis and treatment.
- 2.4** This standard describes Local Children's Clinical Networks and then takes a 'journey' approach starting with providing care for minor illness, it addresses the access points in the local network, assessment, diagnosis and treatment and the specific needs of children with long term illness.



## Interventions

### 3 Providing Comprehensive and Integrated Local Services

#### 3.1 Services are needed in each locality which:

- > Provide evidence-based quality-assured care;
- > Give information and choice to children, young people and their families as to where they access the service and how they are cared for;
- > Meet the needs of different communities;
- > Recognise that as a general principle, children are best cared for at home whenever possible;
- > Have the flexibility and capacity to care for children and young people with complex health needs at home (See Standard 8);
- > Utilise the best of innovative service models already developed;
- > Recognise the role of rapidly developing technology to support these new models; and are
- > Delivered through integrated and co-ordinated working.

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## Managed Local Children's Clinical Networks

**3.2** All children and young people must have access to primary, secondary and tertiary medical services if and when they need them, whether they live close to, or remote from a centre of care. Managed clinical networks, both Local Children's Networks and Specialist Clinical Networks, are a means of ensuring this; they bring together the range of services outlined in Box 1.

### Box 1: Components of A Local Children's Clinical Network

- > NHS Direct;
- > The Ambulance Service;
- > Primary Care provision  
(including general practice and out-of-hours services and walk-in centres);
- > Community Pharmacy;
- > Accident and Emergency/Minor Injuries Units;
- > A Base Unit, providing children and young people's in-patient services and training and support to the other components, and can support one or more local units;
- > Local units – in some areas these local units may not provide a full in-patient paediatric service, but may provide a range of assessment and short interventions/treatments as determined by local need;
- > Community children's nurses able to provide home-based assessment and care for acutely ill children, where appropriate;
- > Children's community teams providing health and social care and family support;
- > Specialist clinical networks that ensure the best expert advice is available 24 hours a day at local level;
- > Other local health services which see children and young people;
- > Managerial/administrative support; and
- > Formal links with education and social services.

**3.3** The Local Children's Clinical Network needs to take account of:

- > The characteristics of the child population, measures of health need and the needs of vulnerable groups. This includes likely changes in numbers of children in the area, socio-economic factors, transient and hard-to-reach populations, and the need for interpreting services;
- > Geography, transport links and patient flows;
- > Staffing pressures and workforce issues, in the current service and proposed models;
- > The need to increase the capacity of primary care and skills to deliver a range of services to children, including chronic disease management, e.g. asthma, in line with the national target on chronic disease management;
- > Maternity, neonatal and accident and emergency services – changes in acute service provision for children have immediate impact on these services. Accident and emergency services are a vital component of ambulatory services.

**3.4** Essential features of a managed clinical network are:

- > Clinical and managerial leadership and accountability;
- > Trust between participants;
- > Common protocols for care;
- > Management of resources; and
- > Audit and governance.

Each health economy develops a managed Local Children's Clinical Network to meet the needs of the local population.

Any such network has explicit links to wider services for children which are provided by other agencies. Plans to develop or change services for acutely ill children are made with reference to inter-agency planning processes for disabled children and children at risk.

#### **4 Information for Children, Young People and their Parents**

- 4.1** Parents and their children should be central to the process of decision-making about their care, and receive appropriate information to exercise choice. They need to be fully informed and provided with information about the nature of the illness, different interventions and treatment options available to them and relevant support groups and voluntary organisations that might help them. Information needs vary at different stages of the patient journey so the provision of information should continue throughout the child or young person's journey. It is government policy from 1st April 2004 that children and their parents should receive copies of relevant communications, including letters and reports. Best practice guidelines are available to support implementation at [www.dh.gov.uk/policyandguidance/organisationpolicy/publicandpatientinvolvement/copyingletterstopatients/fs/en](http://www.dh.gov.uk/policyandguidance/organisationpolicy/publicandpatientinvolvement/copyingletterstopatients/fs/en) *See Standards 2 to 4 and 10*

In line with the PSA target on improving the patient/user experience, services ensure that children and young people receive information to enable them to make decisions and choices which take into account their age and development, increasing autonomy with age and the need for confidentiality balanced with the need for parents to have information.

NHS Trusts develop methods of communication to ensure that children and young people and their parents receive timely copies of relevant communications (including letters and reports). Consideration is given to providing the facilities to tape record important consultations to enable patients to listen to the consultation again. Other methods of communication such as e-mail and texting are explored.

Children and their families are provided with information regarding the use of medicines. *See Standard 10*

## 5 Supporting Self-Care

- 5.1 The service requirements for promoting effective self-care vary, to some extent, with the age of the child or young person, partly because the range of common health concerns varies with age, but also because of the differing routes to professional help that different age groups and families may take. Rather than consulting a health visitor, general practitioner or practice nurse with their parents, an older child may obtain information from their peers, school, magazines, television or the internet. A young person may additionally be able to access adolescent clinics and family planning services, and be more confident in approaching primary care services directly, if these are seen to meet the needs of young people. Some disabled children and young people may need targeted support to give them the skills and confidence to manage their conditions themselves.
- 5.2 Even when consultations seem to professionals to be unnecessary, they are important to the parent or young person and can provide a valuable opportunity to explore parents' and young people's underlying concerns, to explain carefully the nature and the likely cause of symptoms and signs, the reasons for recommending (or not) a medicine or the type of preparation, how it will work and what the medicine is expected to do. Parents may be disempowered if they are left confused, and will be unlikely to manage future episodes appropriately.
- 5.3 Many parents, children and young people will need support to deal with the anxiety caused by illness, to manage the illness effectively and with confidence, and to understand when it is appropriate to seek further professional help. The parents of very young children are particularly likely to need advice about whether symptoms are a cause for serious concern and how they should be treated. *Birth to Five*<sup>1</sup> can provide useful information and advice. The NHS Direct Self-Help Guide is also a useful reference which and is being delivered to all homes (in *Thomsons Local*).
- 5.4 A significant number of ill children and young people visit a community pharmacy for advice and treatment on self-care including the management of minor ailments. *See Standard 2*

Primary Care Trusts, Local Authorities and services ensure that parents, children and young people are provided with consistent information which addresses:

- > The prevention and self-management of health problems (*see Standards 1 and 2*);
- > Details of local NHS services, and how to access them;
- > How to recognise significant changes in a child's condition and what to do if symptoms worsen;
- > Commonly used treatments and medicines;
- > Other relevant local services, and
- > Appropriateness of school attendance.

Primary Care Trusts consider implementing carefully targeted, pharmacist-led minor ailment schemes to meet the needs of patients who would otherwise go to their doctor for a prescription.

Formal partnerships are developed with all local providers and commissioners of services to children and young people, to determine local service provision and develop consistent protocols for care and advice.

## 6 Access

- 6.1 Children and young people with minor medical problems or minor injuries need ready access to local services. A sick child may access care via community pharmacists, NHS Direct, general practitioners, primary care (including its out-of-hours service), through allied health professionals, the ambulance service, an accident and emergency department, a walk-in centre or minor injury unit. The Royal College of Paediatrics and Child Health has suggested guidelines for children's minor injury units<sup>2</sup>.
- 6.2 Children and young people with long-term health conditions may become acutely ill as part of their condition, or because they develop an unrelated illness or an injury which may have consequences for the management of their long-term condition. Professionals who are dealing with the acute illness need to understand how these may inter-relate.
- 6.3 Children and young people being referred from primary to secondary care need timely access to an out-patient appointment to ensure they receive a specialist opinion and any required treatment as soon as possible. *National Standards Local Action*<sup>3</sup> sets out a new maximum waiting time target of 18 weeks from general practitioner referral to hospital treatment by 2008. Waits from general practitioner to initial outpatient consultation will not normally exceed six weeks. *See Standard 3*

Local arrangements for emergency care of ill or injured children and young people, both in working hours and out-of-hours, are clear and well-publicised.

For children and young people with a long term or complex disorder, this system is supported by access to appropriately trained staff (e.g. clinical nurse specialists).

Children and young people can access services in line with the access to service targets set out in the *National Standards, Local Action*<sup>3</sup>, and Primary Care Trusts and NHS Trusts agree more challenging access targets where possible.

## NHS Direct

**6.4** A high proportion of calls to NHS Direct, particularly those made out-of-hours, are made by parents concerned about their children. Many out-of-hours services now use NHS Direct as their first point of contact. Parents may be seeking advice about a child with a fever or other symptoms of acute illness or need support or reassurance in caring for a child with a minor illness. Handling such calls sensitively and providing clear and high quality medical advice is crucial and may determine where, when and by whom a child is seen. For a small number of children who are critically ill, this may determine whether or not the child survives.

Users of the service are directed to the most appropriate service for their age, needs, condition and location.

Each NHS Direct Management Unit has a nurse with the knowledge, understanding, and accredited competencies in paediatrics to support and advise colleagues about children and young people and to act as a resource to ensure training needs are met.

Each NHS Direct Management Unit has a named and specifically trained professional for safeguarding children and young people, to ensure that the service is delivered within agreed policies and procedures and has strong links with relevant local agencies and the local Area Child Protection Committee/Local Safeguarding Children Board.

*See Standard 5*

All NHS Direct staff receive high quality child protection training such as that developed through partnership between NHS Direct and the NSPCC<sup>4</sup>. *See Standard 5*

The content of the NHS Direct Clinical Assessment System is evidence-based and systematically reviewed to ensure it incorporates new evidence and NICE guidelines.

The NHS Direct Clinical Assessment System and operational procedures enable an appropriate response for those children with special or complex health needs, e.g. those with chronic conditions or those with pre-determined health/social care plans.



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NHS Direct performance in the delivery of care for children and young people is monitored and subject to audit in line with its clinical governance responsibilities. Processes for the reporting, management and review of patient safety incidents are in line with guidance issued by the National Patient Safety Agency and the Healthcare Commission.

NHS Direct induction programmes include specific sessions on the care of children and young people to ensure that all staff have the necessary underpinning knowledge to complement the Clinical Assessment System algorithms.

NHS Direct has plans in place to ensure that:

- > Prioritisation, training and operational systems recognise the increased level of urgency when a worried parent contacts the service more than once for further advice.
- > Multi-agency systems are in place to follow up all cases where vulnerable children fail to attend accident and emergency departments or other urgent appointments after a contact with NHS Direct.
- > NHS Direct On-line consider opportunities to target access to information/linked websites designed to meet the needs of children and young people.

## Primary Health Care

- 6.5** Young people, children and their parents should have guaranteed access to a primary health care professional within 24 hours and to a primary care doctor within 48 hours. Primary care services should be provided to take account of the special needs of children and their families, with appropriate cover for urgent cases at all times.

To minimise waiting times, primary health care services ensure that their staff resources include the necessary skill mix to provide access to the full range of services they are contracted to provide for children and young people.

Primary Care Trusts ensure that appointment booking systems minimise the amount of time children and young people will be away from school awaiting appointments; and take into account the particular needs of disabled children and young people who find it hard to wait before being seen (e.g. by offering double appointment times, or first or last appointment times).

Protocols are agreed between agencies/professionals (e.g. speech and language therapists, occupational therapists and dieticians) which specify maximum waiting times and demonstrate efforts to co-ordinate appointments, to reduce repeated visits to services and improve access for children.

Primary Care Trusts and NHS Trusts ensure that treatment adheres to NICE guidelines and appraisals where available, and compliance with these is monitored.

All patients records held by primary health care services include a clear summary of their main conditions, and medicines prescribed in date order; including notifications of attendances received from accident and emergency departments, minor injuries units or paediatric assessment unit visits, and hospital admissions. These records are readily retrievable and preferably electronically stored.

## Out-of-hours Care

6.6 Access to out-of-hours care may be provided through GP co-operatives, NHS Direct, NHS walk-in centres, community pharmacists, minor injuries units, commercial providers and accident and emergency departments.

- > Primary Care Trusts ensure that arrangements are in place for safe out-of-hours assessment and management of ill children and young people.
- > All services providing out-of-hours care delivers clear and consistent advice derived, where possible, from high quality evidence and meet the *Quality Standards for the Delivery of GP Out-of-Hours Services*<sup>5</sup>.

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## Ambulance Services

**6.7** Ambulance services are often called upon to respond to emergency and non-emergency calls involving children. Ambulance staff play an important part in the initial assessment and clinical care of babies and children and may influence their subsequent treatment. They also have an important role in providing initial reassurance and support to them and their families at times when levels of stress and concern are naturally very high.

This will require Ambulance Trusts to:

- > Review and revise their treatment protocols to ensure they reflect this National Service Framework.
- > Ensure that their operational staff, including those dealing with emergency calls in ambulance controls, are fully aware of the special needs of children and young people; how to reduce anxiety for children and the needs of parents or carers. In particular, they ensure that clinical staff are aware of the need for and means of pain control, including non-pharmacological methods (*see section 12*).
- > Ensure all paramedics and emergency medical technicians are competent in neonatal and paediatric life support and that joint training courses between ambulance and hospital professionals are encouraged.
- > Ensure that staff have access to appropriate and timely advice regarding the care of sick children and young people.
- > Work with hospitals to ensure that all inter-hospital transfer procedures and arrangements for neonates and children are jointly agreed, that key items of equipment are compatible and familiar to ambulance and hospital staff undertaking such transfer and ensure child friendly features in the interior design of vehicles.
- > Appoint a named professional for safeguarding children and young people.  
*See Standard 5*

## Accident and Emergency Departments

**6.8** Four out of five accident and emergency contacts with children and young people are for injuries. However, about one in five attendances result from parental concern about illness, usually in younger children. Some children attending accident and emergency departments do so with a major life-threatening or serious illness such as collapse from meningococcal disease or seizures, but the majority attend for a wide range of 'medical' disorders or injuries.

**6.9** Emergency Care Networks are being developed with the aim of optimising emergency care to all patients in each locality, ensuring ease of access to appropriate services, at the appropriate time, and co-ordinating emergency healthcare across organisations in the community. These will need to take account of the children's clinical networks described below and vice versa. An children's urgent care checklist is available at [www.dh.gov.uk/PolicyAndGuidance/OrganisationPolicy/EmergencyCare/EmergencyCareChecklists/fs/en](http://www.dh.gov.uk/PolicyAndGuidance/OrganisationPolicy/EmergencyCare/EmergencyCareChecklists/fs/en) and provides a useful resource for meeting the needs of children in a range of urgent care settings.

*See Standard 7*

Children and young people who attend accident and emergency departments receive care which is based on agreed protocols which incorporate the best available evidence.

When children and young people are discharged from care, they receive information which informs them and their parents about their condition, the treatment they have received and what to do if their condition deteriorates or if they have concerns.

Named individuals are identified in both emergency care networks and children's clinical networks to ensure that each locality makes appropriate and co-ordinated emergency provision for children.

## 7 Assessment of the Ill Child

- 7.1 Clinical assessment of the ill fractious child requires skill and experience. Re-assessment after a period of observation or after initial treatment is often essential. In any single illness episode, where possible, the referral should result in an assessment by staff who are more senior/experienced in clinical care of children than the person making the referral.
- 7.2 Children and young people are likely to be assessed in many different locations in the local children's clinical network; in particular, where local services are redesigned and modernised, this is likely to be in paediatric assessment units, co-located or separate, but supported by the base unit.
- 7.3 Children and young people may require a health assessment as a result of concerns raised through the use of the Common Assessment Framework currently being developed. Findings from health assessments may also trigger the use of the Common Assessment Framework. *See Standard 3*

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Primary Care Trusts and NHS Trusts ensure that all children and young people presenting with undifferentiated illness in any location (e.g. primary care, walk-in centres, minor injuries units and accident and emergency departments) are assessed by staff who are competent and trained in assessment of children.

Services ensure that staff of sufficient seniority and relevant experience are available to take rapid and effective decisions.

There is the facility for timely re-assessment of a sick or injured child after a period of observation, either in hospital, or by more than one primary care contact.

Primary Care Trusts and NHS Trusts ensure that protocols are in place for the management of the common acute illnesses and injuries of childhood and for the assessment of children who re-attend. For example, see Advice on the Management of Common Medical Emergencies in Primary Care (due to be published by the Kingston PCT and the Modernisation Agency, Autumn 2004). Adherence to such protocols is audited.

For children with known medical disorders, there is a plan describing action to be taken in the event of deterioration. Copies of this are held by parents, by NHS Direct, and filed in the medical notes with timely access to these in the relevant clinical areas.

Local audit ensures that at each level of assessment, children and young people with potentially serious illness who need to progress to the next level of care are accurately identified whenever possible and referred appropriately.

Every assessment results in a clear management plan in the patient record, based on evidence-informed protocols, guidelines and pathways.

Services ensure that when a child or young person does not require admission to hospital, the parents are fully involved in the development of the care plan which includes the criteria for when to contact somebody again, who to contact, where and how.

At the end of an assessment, there is a written communication to relevant professionals involved with the child's or young person's day-to-day care and to the parents when appropriate.

## 8 Diagnosis

- 8.1 Accurate diagnosis is essential to facilitate treatment, specialist care, access to information, support and access to services, especially for rare conditions. Children and young people and their parents require an explanation of all diagnostic procedures. A DVD is being launched to update training of healthcare professionals in the diagnosis and management of acute illness in children<sup>6</sup>.

*See Standard 8 section 4.*

Primary Care Trusts and NHS Trusts work with Strategic Health Authorities to ensure that diagnostic facilities are:

- > Promptly accessed by children and young people (e.g. efforts are made to avoid inappropriate waits for ultrasound examinations);
- > Appropriate for children and young people (e.g. X-rays are performed in a child-friendly environment by appropriately trained staff);
- > Use child-friendly methodology (e.g. capillary blood samples for blood tests where possible);
- > Are as comfortable as possible (e.g. analgesic cream for blood tests), and
- > Are delivered by staff with the appropriate skills and knowledge; results of investigations are interpreted with an understanding of paediatric normal ranges.

Informed consent is obtained for invasive procedures from the parent or from a competent child or young person. *See Standard 3*

Services ensure that waits for investigation results are kept to a minimum and the family are informed of the results of all diagnostic tests; where this is done verbally, it is supplemented with written information.



## 9 Quality of Treatment

- 9.1 Evidence-based protocols and guidelines can be instrumental in achieving high standards of health care for children and young people, particularly if their development has involved the whole multi-disciplinary team and patient or parent representatives. *See Standards 3 and 7*

NICE appraisals and guidelines, and guidelines produced by other appropriate bodies that apply to children and young people are available to all clinical staff and are translated into local protocols.

Protocol development is linked into a programme of staff education and training. The protocols themselves are implemented, monitored and reviewed in line with changes in the evidence-base or source guidelines and subject to version control.

Multi-disciplinary, child-specific clinical audit is undertaken in all specialties in which children are treated.

## 10 Children with Long Term Health Conditions

- 10.1 For many children with long term health conditions, the aim of treatment and care is to manage their illness in such a way that they are able to enjoy and achieve fully in their lives and make a positive contribution.
- 10.2 Children young people and their families should have the opportunity to become 'expert patients'. To achieve this, they should have access to services that help them to develop the self-confidence and self management skills needed to deal with the impact of the condition on the child and their family or carers; these services may be similar to those run under the 'expert patients programme' (EPP) which will be rolled out to parents and young people.
- 10.3 There is much happening nationally and locally in chronic disease management. *The NHS Improvement Plan* <sup>7</sup> and *National Standards, Local Action* <sup>3</sup> highlight the need to do better in supporting people with long-term conditions. Improving care in primary and community settings for children and young people with chronic long-term conditions will be part of achieving the national Department of Health target for reducing emergency bed days and offering a personalised care plan for the most at risk vulnerable people. Primary Care Trusts, working with Local Authorities and other partners, will need to agree plans that will support delivery of the national target on supporting people with long term conditions (including children and young people).  
*See Standards 3 and 8*

Primary Care Trusts ensure that children and young people have the opportunity to become expert patients and to participate in an expert patient programme, when developed.

Training is provided to parents possibly through an expert patient programme, to become experts in managing the common issues related to a child with long term illness and condition-specific issues.

Primary Care Trusts ensure that chronic disease management programmes are developed for children and young people as well as other client groups.

## Supporting Children and Young People's Emotional, Developmental and Educational Needs

- 10.4** Much can be done to help children and young people with long-term conditions experience an ordinary life. A key element of this support should be good mental health input to maximise emotional well-being and prevent or minimise problems.
- 10.5** Children and young people who have either an acute or a prolonged illness are at risk of missing out on educational opportunities due to prolonged absences from school, either as a result of ill health or because of frequent attendance at clinics and hospitals. A range of issues need to be addressed at local level to ensure health and education services work together in a supportive, co-ordinated way to support the child or young person to develop and achieve their full educational potential. This includes developing processes for effective communication about short and long-term needs of an individual child and supporting the re-integration of a child back into school after treatment for acute illness or injury.
- 10.6** Social services may be able to provide support to the child or young person and their family to ensure that parents or carers receive the support they need to enable them to continue providing the level of care their ill child requires. Social services can also be able to help children and young people both to understand their illness and to make critical decisions, and to ensure that their wishes and feelings are taken into account in decision-making processes.
- 10.7** Systems need to be developed to ensure that health and social services provide information, training and support to schools and early years settings, in caring for children and young people with medical needs. The needs of young people attending college and university also need to be considered at the local level. *See Standard 4*
- 10.8** There is evidence to demonstrate that children living in disadvantaged areas or communities are more likely to have increased absences from school due to poor health. This is a particular concern as it will contribute to a cycle of poor education, low-paid employment and ill-health. *See Standards 1 and 9*

Ensuring that the emotional well-being of the child, young person and their family is regarded as an integral part of service provision.

All staff working with children and young people with a physical illness have an understanding of how to assess and address the emotional well-being of children and are able to identify significant mental health problems and make appropriate referrals for specialist help. *See Standard 9*

Hospital departments and clinics synchronise their appointment systems so that families make a minimum number of visits to hospitals/clinics. Where multiple appointments are required, these happen on the same day.

Health services maximise offers of appointments in school settings or outside school hours to ensure minimum absence from school.

Health and education services develop joint local protocols for managing the needs of children and young people with a long-term condition, including the management of transition between schools, which are in line with legislation and *Supporting Pupils with Medical Needs*<sup>8</sup>.

Primary Care Trusts and NHS Trusts work in collaboration with LEAs to contribute to the DfES national PSA target on maximising school attendance.

Local protocols include the identification of a Named Health Contact and a Named Teacher, who are jointly responsible for the reviews of health care plans for each child, which details the child's health care needs and the support to be provided in schools; these plans are reviewed by the multi-disciplinary, multi-agency team and the family on an annual basis. The Named Health Contact ensures that information is promptly passed on to schools when changes occur in the child or young person's condition, medication or treatment.

For children who are unable to attend school, procedures are in place which follow the guidance in *Access to education for children and young people with medical needs*<sup>9</sup>.

The forthcoming Common Assessment Framework is used where there are concerns that children and young people may require support being provided by more than one agency. It is important that the various professionals who are involved in assessing the child's and the family's needs work in partnership and share relevant information as required. *See Standard 3*

Where a child or young person is considered to be a child in need under the Children Act 1989, including where there are concerns about a child or young person's safety, referral is made to social services for a more specialist assessment using the Framework for the Assessment of Children in Need and their Families <sup>10</sup>.  
*See Standard 5*

## **Ensuring continuity of care**

**10.9** Children and young people may come into contact with the NHS via a number of different channels at different times. The current system of paper or disparate local electronic records mean that each of these contacts may result in a separate record being kept for the child. This makes it impossible for anyone involved in the child's care to have a clear overview. Patient-held or parent-held records, with care plans being used across settings, are an effective way of ensuring information is available wherever the child or young person is (this may not be effective in some vulnerable groups of children and their families, particularly those with problems such as drugs misuse who may have chaotic lifestyles).

Local arrangements are in place to ensure relevant information on a child's plan of care is available wherever he/she may require care within the local health system.  
*See Standard 3*

- 10.10** Transitions occur when a child's life, school or family context changes, e.g. if parents separate and the child lives between two parental homes. If a child with a long-term condition moves area, there is a need for that transition where possible to be planned and managed. It is important that the education service is aware of any child or young person moving into its area who is unable to attend school because of a medical condition and who therefore requires support from the hospital and home teaching service.
- 10.11** When a child or young person is looked after by the local authority, the local authority should follow the department of health guidance *Promoting the Health of Looked After Children*<sup>11</sup> to ensure their health needs can be met before arranging a new placement.

Services ensure that where possible transitions are planned ahead of time. Information is passed from one healthcare provider to another prior to the move, to enable services to be in place when the child or young person arrives.

There is timely communication between health, education and social services, where appropriate, to meet the needs of children and young people, especially if the child's name is on the child protection register and/or is looked after by the local authority.

## Equipment

**10.12** Accessing appropriate equipment may be a vital component of caring for a child or young person at home. Poor local arrangements can result in delayed discharge from hospital, introduce unnecessary risks to the child at home and cause frustration for parents.

Local providers and commissioners jointly agree plans for the timely assessment, provision and maintenance of both short and ongoing equipment and supplies.

Staff are competent in assessing the need for equipment and understanding the function and risks of equipment supplied in the home and in schools.

Parents are trained and given written information in the use, supply and maintenance of home equipment, including who to contact in an emergency and out-of-hours.

*See Standard 8*

## Genetic Diseases

**10.13** Genetic diseases constitute a high proportion of childhood disease and disability. Access to genetic services can ensure they receive a timely diagnosis and subsequent referral to expert help and support.

**10.14** Tests for genetic diseases which may affect health in late adult life but which do not affect the health of the child, and for which there is no established prevention, are not recommended for children until they are able to understand the full implications of the tests and their results. This also applies to tests for carrier status of diseases which will never affect that individual, but may be passed on to their children.

**10.15** The White Paper on genetics <sup>12</sup> sets out plans to increase the capability of staff in non-specialist settings such as primary care to be further involved in the provision of care and advice to children and their families with genetic disorders.

**10.16** There are likely to be particular effects on the siblings of children with genetically-determined disorders, whether or not they are known to be carriers of the relevant mutated gene.

Primary Care Trusts and NHS Trusts ensure that families with a child or young person with, or at risk of, a genetic disorder have access to staff who can give information about the condition, the test and the implications of the results.

Local service provision ensures that patients can get timely advice on genetic matters. This is achieved through strengthening access to existing clinical genetic services and other specialist services e.g. haematology and pre-conception services, and by developing appropriate services in primary care.

Services ensure that support and information is available to siblings of children with genetically determined disorders at times and stages appropriate to their individual needs.

Health and social care staff who deal with children and families who have concerns about familial conditions are trained to recognise those families who might benefit from genetic services and information. This is achieved through an understanding of family history, in assessing the risk of disease or disability and having knowledge and understanding of the utility and limitations of genetic testing and information. They know when and how to refer to specialist genetic services.

## Children with Incontinence

**10.17** There are at least 500,000 children who suffer from nocturnal enuresis and a significant number with daytime wetting and faecal incontinence, yet services are currently fragmented and often made up of a collection of professionals providing different levels of intervention in both the community and hospital. This currently results in big gaps in service provision, inappropriate hospital/specialist referrals and a waste of money in providing products instead of expertise.

**10.18** Incontinence is distressing for children and young people and can be indicative of both physical and emotional problems; it can lead to bullying at school and cause emotional and behavioural problems.

**10.19** *Good Practice in Paediatric Continence Services – Benchmarking in Action*<sup>13</sup> sets out an “Essence of Care” benchmarking best practice tool. This may be used to develop appropriate services.



An integrated community-based paediatric continence service, informed by *Good Practice in Paediatric Continence Service*, ensures that accessible, high quality assessment and treatment is provided to children and their parents/carers in any setting, including, for example, children looked after and children at boarding schools.

Children and young people with special needs and/or disabilities have equal access to investigation and treatment programmes.

## **11 Admission to Hospital**

**11.1** Admission to hospital is a key transition point when information about a child and family held by those caring for a child at home is often not known by the team caring for the child and young person in hospital. *See Standard 7*

Primary Care Trusts ensure that there are local systems to trigger staff working in primary care to communicate with the hospital team to ensure staff caring for children and young people are fully informed about their needs and family circumstances.

Hospital staff actively seek information already held in primary care or with other professionals.

## 12 Pain Management

- 12.1** Children and young people have a right to appropriate prevention, assessment and control of their pain. Pain is unpleasant, delays recovery, and adds to the trauma of illness, injury and clinical procedures. Historically, pain has been underestimated and under treated in children and particularly babies. There is still evidence that pain is inadequately dealt with for children, requiring better prevention, assessment and treatment.
- 12.2** In order to treat children's pain effectively, a thorough pain assessment is necessary; a number of guides are available to do this <sup>14, 15</sup>. Particular attention should be given to children who cannot express their pain because of their level of speech or understanding, communication difficulties, or their illness or disability. This includes babies, children with communication or learning difficulties, and those with altered consciousness or serious illness.
- 12.3** The treatment of pain using medicines requires appropriate choice of drug, dose, frequency, route and formulation. *See Standards 7 and 10*
- 12.4** Care for children and young people with long-term pain needs to span prevention, assessment and treatment. Special consideration needs to be given to those recovering from trauma and burns, and children with cancers, joint conditions, sickle cell disease and those needing palliative care.

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The management of pain is a routine part of any treatment or procedure in all settings. Children and young people are involved as active partners in pain management.

Protocols are in place for the assessment, prevention and management of pain for children and young people in every relevant clinical area (including ambulance services).

Where procedures are planned and pain can be predicted, children are prepared through play and education, and plans are made for pain relief for use during the procedure.

Children are helped to manage pain through the use of psychological therapies, including play, distraction, coping skills and cognitive-behavioural approaches.

Children are offered adequate analgesia for more minor procedures such as blood sampling.

The effectiveness of children's pain management should be demonstrated by regular audit.

### **13 Children's Community Teams**

**13.1** Children's Community Teams are essential to support the care of children and young people who require healthcare outside a hospital setting. These teams need to be multi-agency and include many different professionals (including allied health professionals); all these professionals must have the skills to work with sick children and young people. The service should be an integral part of other primary health care and community provision. It should be easily accessible with open referral pathways and should be capable of a timely response.

**13.2** Children's Community Teams including Community Children's Nursing Services need to provide appropriate support to children, young people and their families which responds to local needs and takes account of the need to prevent hospital admission, facilitate early discharge, and care for children with complex needs. Ideally, these should work across a number of settings, for example, hospital, home and school, improving continuity and maximising the available skills.

Local Children's Community Teams are developed in an integrated way across each locality.

## Community Children's Nursing

**13.3** There is great scope to develop children's community nursing along a number of different lines to meet local needs; these are outlined in Box 2. An integrated programme of nursing care is central to the development of ambulatory models of care.

### Box 2: Opportunities for Developing Children's Community Nursing Roles

- > A team of nurses may provide both emergency care and triage alongside other emergency care staff, together with support for acute illness in the ward, paediatric assessment unit or at home. The team can reduce first admissions, the duration of admissions, second admissions for the same problem, and second attendances at outpatient follow-up. In some areas, this is described as a "hospital at home" service.
- > Community children's nurses may provide care and support for children and young people in the community with long-term disorders as well as for those with palliative care needs. *See Standard 8*
- > Community children's nurses may adopt "consultant" roles for caring for children and young people with particular conditions. Emphasis needs to be placed on supporting their development and ensuring that they receive sufficient on-going training and updating in their field of expertise.

**13.4** There is a need for developments in community children's nursing to ensure there is a sufficient pool of nurses able to undertake these roles, and local organisation is needed to allow efficient use of scarce staff, for example, by considering cross cover between hospital and community or between adjacent communities.

**13.5** Additional funding has been made available to increase capacity. Where these services are not in place locally, this funding can be used to develop them.

Primary Care Trusts ensure that Community Children's Nursing Teams are available in each locality (as part of the Children's Community Teams) and are based on local need. Services are developed in an integrated way across the local health economy.

Clear lines of responsibility are identified at all times as patients pass through the various agencies.

Primary Care Trusts and Children's Community Nursing Teams ensure that care is based on protocols and integrated care pathways which are informed by the best available evidence.

## 14 Discharge from Services

- 14.1 Discharge from a range of settings (from accident and emergency services to out-patients clinics) can cause anxiety for parents and children. Parents and children need sufficient information to manage the transition successfully. Transfer of information between relevant agencies can be crucial. Where needs are complex, detailed planning may be required, for example, for equipment or to ensure that rehabilitation programmes can be continued at home, or that social care needs are addressed. The Laming report <sup>16</sup> identified two particular areas of concern: children being discharged without being registered with a general practice, and a child about whom there are child protection concerns being discharged by a consultant who was not familiar with their care plan. *See Standard 5*
- 14.2 The *Achieving timely 'simple' discharge from hospital toolkit* focussing on adult services will nevertheless be useful for staff wanting to improve their discharge practice for children.<sup>17</sup> *See Standards 7 and 10*

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Services ensure that when children or young people are discharged from secondary or tertiary services, as part of routine practice, a letter is sent to the general practitioner and all professionals involved with the child's care (copied to the patient or parent), and a briefing is given to the patient and their parent about likely after-effects, any follow-on treatment needed, any continuing drug therapy, and the implication for school attendance, together with a contact point in case of difficulty or confusion. Where appropriate, the social worker needs to be effectively involved in planning the child's discharge from hospital.

Primary Care Trusts ensure that children or young people who require ongoing care have access to a children's community team regardless of condition or geographical location. This is taken into consideration when writing care plans and planning discharge from hospital. Where appropriate, there may need to be 24 hour access.

Hospital and community services discuss recommendations for care at home before the child or young person is discharged from hospital services.

Children or young people who are identified as not being registered with a general practice are notified to the appropriate contact in the Primary Care Trust for arranging registration.

Services ensure that children or young people for whom there have been concerns about their safety or welfare are not discharged until the consultant paediatrician under whose care they are, is assured there is an agreed plan in place which will safeguard the child's welfare. *See Standard 7*

For children or young people who are being discharged from hospital into foster care, arrangements are made for the foster carer to be given all the information, training and support normally given to parents.

## 15 Training & Development

- 15.1 Delivering this standard requires a broad skill mix of appropriately trained staff providing high quality care to ill children in a range of settings. The competencies of the staff are more important than their professional background and a range of new or extended roles may be appropriate within the skill mix, for example:
- > Paediatric nurse practitioners - the Royal College of Nursing see an expanding role for these practitioners (i.e. registered children's nurses with additional education and training to enable them to assess, diagnose, treat, discharge children without reference to a medical practitioner) within primary care settings, such as in general practice, minor injury units, walk-in centres and ambulatory care units;
  - > Health care assistants and support workers – new support roles have proved invaluable in addressing skill shortages in other areas and could add value here;
  - > Practitioners with a special interest – clinicians, including general practitioners, with a special interest in paediatrics;
  - > Extended nursing roles in paediatric pain management;
  - > New clinical nurse specialist roles to support children with long-term or complex disorders;
  - > New roles within primary health care teams to ensure that teams can provide a full range of services to children, and
  - > New roles within children's community teams.
- 15.2 Staff need to be equipped to be “fit for purpose”. Health professionals with no paediatric training are currently providing care, advice and treatment to children and young people in many settings, without the necessary knowledge base, skills or competencies. In the short-term, these health professionals will need to continue to provide care, but in the medium-term there is a need to develop externally validated, competency-based, accredited training for these staff. In the long-term, there is a need to ensure accurate workforce planning and education commissioning to meet the need for children trained staff across all areas of primary and acute health services where children and young people receive care and treatment.
- See Standard 8*



All staff working with ill children have the common core of skills, knowledge and competencies set out in Standard 3. In addition, local training strategies are produced, with the involvement of service users, to include appropriate multi-disciplinary training and education on the management of minor illness and to ensure that consistent advice is given to parents and young people across primary and secondary health care, education and social care. This training covers:

- > The prevention of minor illnesses (for example, stopping smoking, improving nutrition, weight management, and practical steps to reduce exposure to allergens);
- > How parents and young people can manage common minor health concerns themselves, and
- > How to engage in “self-care aware” consultations with parents, children and young people to educate and empower them to manage future episodes.

In addition, the following specific training is needed:

- > The prevention, assessment and control of children's pain;
- > Skills in physical examination (such as otoscopy) to minimise distress to the child;
- > The ability to recognise families who may benefit from genetic services;
- > Assessment of children for staff working in locations where children present with undifferentiated illness (e.g. primary care, walk-in centres, accident and emergency departments);
- > Staff working in minor injury units need to be trained in recognition of a sick child, communication with children and their families, drug choice and administration, assessment, the alleviation of pain, paediatric basic life support skills, and suspected non-accidental injury or welfare concerns and child protection;
- > Ambulance paramedics need opportunities to access appropriate neonatal and paediatric life support training courses and participation in joint training with hospital professionals should be encouraged, and
- > Health Care Assistants and support workers require competency-based training, focused on outcomes and standards.

Particular attention is given to the continuing professional development requirements of staff such as clinical nurse specialists working with community nursing teams, or those with new or extended roles, to enable them to stay updated in their field.

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