

*Getting the right start:
National Service Framework
for Children*

Standard for Hospital Services

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Foreword

No-one wants their child to have to go into hospital – whether it's for a serious illness or a minor injury. Any child having to attend hospital as a patient, for any reason, is a cause for concern for all parents, carers and relatives. And children themselves can find a hospital visit a daunting experience.

There's nothing we can do to completely take away these concerns but there is a lot we can do to improve the way hospitals care for children so they can get on with the important business of childhood and growing up. That means designing hospital services for children from the child's point of view.

Child-friendly hospitals recognise that children are not the same as adults. And that's why we are now publishing the Children's National Service Framework standard for hospital services.

This NSF will help to ensure that the care we deliver for children is genuinely child-centred. It will assist the NHS in providing appropriate services, accessible at the right time. And it will help to extend the choices available to children and their families about the NHS care they receive. The Hospital Standard describes what a good hospital should look like. It should strike a chord with any parent who has ever had to take their child to hospital.

The standard included in this National Service Framework cover:

- The design and delivery of hospital services around the needs of children and their families.
- The safety of children while they are in hospital.
- The quality of services for children in hospital.
- The suitability of hospital settings for the care children receive.

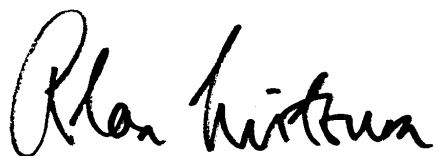
The NHS Plan we published in July 2000 set out the measures – the investment and reforms – we would take to transform the NHS, into a patient-centred service. This NSF will help to ensure that, as we reform the whole of the health service, those reforms, every bit as much as the services themselves, are sensitive to the particular needs of children.

This is just the first part of the Children's NSF, focussing on services in hospitals. In time we will publish a comprehensive, package of standards for all children's health and social care services. I am extremely grateful for the contribution of the External Working Group which has helped prepare, these standards, chaired by Professor Sir David Hall (President, Royal College of Paediatrics and Child Health) and Jo Williams (formerly Director of Social Services, Cheshire).

The standard set out here cannot be delivered overnight. It will require changes to the way hospitals operate and the way staff work. It can only be delivered in a sustained period of expansion with growing investment, more staff, new buildings and modern equipment. With the scale of the investment and reforms now going into the NHS, we can deliver the improvement in children's hospital standards we all want to see.

We all want the best for our own children. We should all want the very best for every child needing hospital care. The building blocks – investment and reform and now a set of new national standards – are in place.

Across the country, the dedicated and professional staff who work in the NHS – especially those who work with children – are giving their best to get the best care for patients. We should be grateful for their work, I hope this national standard will help them deliver even better care, for children in hospital.

A handwritten signature in black ink that reads "Alan Milburn". The signature is written in a cursive, flowing style.

Alan Milburn
Secretary of State for Health



Chapter 1: Setting the Scene

- 1.1 Nothing matters more to families than the health, welfare and success of their children. Moreover, improving the health and welfare of mothers and their children is the surest way to a healthier nation. Adults are grown up children, and carry the legacy of their childhood with them throughout their lives. The best way to achieve a healthier and fairer society for the future is to improve health and tackle health inequalities in childhood.
- 1.2 Many services need to work together to help children to reach their full potential. This National Service Framework (NSF) will set out standards for health and social care services working with children, and will look at the interface between those services and others, in particular education. It covers children from pre-birth to their nineteenth birthday. Healthy children start with healthy mothers, so this NSF also stretches back before birth to include maternity services. It also reaches across the transition into adult life and adult services.
- 1.3 This document sets a standard for the care of children and young people when they are in hospital. It is being published in advance of the rest of the NSF to meet the commitment made in the government response to *Learning from Bristol (1)*. This is not because hospital care is more important to the health of children than other services. Indeed, for most children most of the time hospitals are thankfully irrelevant. Also it does not mean that hospitals can stand apart from the rest of the health and social care system. The standard itself makes this clear.

Children and young people: their health and use of health services

- 1.4 In many ways, the picture today is an encouraging one. Children are healthier than ever before, and death in childhood is rare – although children do still die needlessly, through fatal injury, for example. However, this improving picture is marred by stark and persistent inequalities in health between children from advantaged families and those who are poor; across different ethnic groups; and across different parts of the country and different neighbourhoods. Also, whilst physical health has improved, mental health problems are on the increase. A small but increasing number of disabled children with complex health needs are now surviving into adulthood. Many are cared for at home, but rely heavily on a wide range of highly specialised services that need to mesh with each other, and to be provided as close to home as possible.
- 1.5 Children and young people are frequent users of all types of healthcare compared to adults. Healthy children are seen for routine health checks and immunisations, and need care when they are briefly unwell – although over 80 per cent of all episodes of illness in childhood are managed by parents without reference to the professional health care system. In a typical year, a pre-school child will see their general practitioner about six times, while a child of school age school will go two or three times; up to half of infants aged under 12 months and one quarter of older children will attend an Accident and Emergency (A&E) 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. Serious illness requiring intensive care will affect one in a thousand children. One in ten babies born each year will require admission to a neonatal unit, of whom about 2 per cent will need intensive care.

Guiding principles and values

- 1.6 The Children's NSF has singled out ten core principles that are fundamental to better health and social care services for children and young people (set out in *Emerging Findings (2)*). They are the roots from which the tree of standards to meet the needs of specific groups of children and young people is being grown.

The child's journey through services

- 1.7 At the heart of the modernisation agenda for the NHS (*The NHS Plan (3)*) is a fundamental change in the way that we think about health and social care services – a cultural shift to services designed and delivered around the person using those services and their needs, and not around organisations. This means building pathways of care around the child and family, seeing services through their eyes, breaking down traditional organisational boundaries, for example, between the family doctor and the hospital, and delivering more flexible and responsive care.
- 1.8 So this NSF is crafted around the 'journeys' that children take, through life as they grow up, and through services when they are ill, injured or vulnerable. Children's needs differ at different stages on their journey through an illness or injury: from prevention in the first place; through timely assessment of what the problem is and what needs to be done to address it; to treatment and care, and rehabilitation, perhaps with long term support. Thus, the care pathway may take the child through a range of health services: those accessed directly, such as the family doctor or NHS Direct (primary care); or through referral to specialist children's services (secondary care), perhaps based in the community, or at the local hospital; or to a more distant specialised ('regional specialist') centre (tertiary care). At any stage, the care pathway may need to link in social care, education, and other services. It is essential that robust relationships and arrangements are developed within and between organisations to ensure that the child's experience is as 'joined up' and seamless as possible.

A standard for hospital services

- 1.9 Hospitals must be seen in this broader context, as but one strand in a seamless mesh of services that are interlocked and interdependent from the child and their family's perspective. The need for this 'whole system' approach to service expansion and redesign is one of the core principles set out in *Keeping the NHS Local – A New Direction of Travel (4)*. It is because many patient journeys do track through hospitals at some stage, that getting this bit right must be one of the priorities for this NSF.
- 1.10 Furthermore, the Kennedy Report (*1*) into events surrounding the deaths of children undergoing heart surgery at the Bristol Royal Infirmary in the 1980s made a number of worrying observations about hospital care for children: children's rights and vulnerability overlooked; quality of care less than it should have been; fragmentation of services; absence of an open and honest relationship with children and parents as partners in care. It is clearly imperative that this NSF provides a robust framework for responding to Professor Kennedy's concerns and recommendations, and those of a number of other inquiry reports which his findings echo (*5, 6 & 7*).

- 1.11 The NSF will also need to respond to the recommendations on child protection set out in *The Victoria Climbié Inquiry* (8). A number of these relate specifically to hospitals and are reflected in the hospital standard.
- 1.12 The hospital standard, therefore, concentrates deliberately on services provided in a hospital setting. The broader task of setting standards for the care of all children in all care settings will be the business of the full NSF.

Evidence

- 1.13 Wherever possible, a base in published research has been established for proposals made. Where there is no evidence of this kind, proposals are backed in other ways, for example, expert opinion, or the views of children and parents. More detail about the range of evidence used will be given in the full NSF.

Implementing the hospital standard

- 1.14 Making the NSF standard for children in hospital a reality requires a shift in culture to gear services to the needs of the individual child and family. That shift is part of the broader programme of change across the NHS to develop care around the needs of individual service users. *Improvement, Expansion and Reform: the Next 3 Years, Priorities and Planning Framework 2003–2006* (9), which sets out targets, priorities and capacity assumptions for the NHS and social services, has signalled the importance of the Children's NSF. Success in implementing the hospital standard will depend on strong local leadership and children's champions with the ability and commitment to influence and drive change, in partnership with local people including children and families.
- 1.15 Full implementation of the standard will take time. There are examples of good practice already in services in many areas of the country, but delivering all aspects of the standard in all areas requires a long term programme of change. The pace of that change and immediate local priorities will vary, but all areas need to start work on planning now to meet the hospital standard in full within the next ten years. Although service quality levels are set firmly by the standard, and the interventions set clear objectives, detail on the 'how' is being left to a great degree to local discretion. A number of service models will be available on the NSF website that can be used as a menu of good ideas. Further material, including practical guidelines, will be developed over the next two years.
- 1.16 Following *The NHS Plan* (3) and the Kennedy Report (1), a number of changes have already been set in train to transform the quality and governance of services. This NSF signposts relevant policy and guidance, and identifies the particular response required for children and young people. Providers and commissioners need to look carefully at local implementation of other key guidance and to check first that services for children and young people are included; and second that they are not adversely affected. Implementation of this standard must sit firmly within the trust's overall clinical governance framework, for which the trust chief executive is responsible to the board.
- 1.17 Health and Social Care professionals are committed to delivering the high standards that children and their parents want and deserve. Professional bodies, such as the Royal College of Paediatrics and Child Health, the Royal College of Nursing and the Royal College of Psychiatrists, among others, are keen to improve service standards through the promotion of innovative ways of working and delivering services. The government is removing obstacles to help managers and clinicians in their work to improve service delivery and to implement this NSF. Progress against standards can be monitored in various ways:
- **Clear responsibility.** Following the Kennedy Report (1), there is an expectation that all trusts will have in place a named individual with responsibility for planning and delivering services for

children and young people. In Primary Care Trusts (PCTs), it is the role of this individual to drive change through commissioning of services, based on sound local planning that involves stakeholders and local partners, including children and young people.

- **Targets.** Strategic Health Authorities will monitor PCTs on delivery of *Improvement, Expansion and Reform (9)* targets that apply to this NSF, and will address risks identified through the performance management process.
- **Inspection.** The Commission for Health Improvement and the Social Services Inspectorate (Commission for Healthcare Audit and Inspection and Commission for Social Care Inspection when established) will take account of NSF standards in their regular inspections of health and social care organisations and can undertake themed inspections. Inspection will be a powerful lever for ensuring that the changes outlined in this NSF happen.
- **Patient involvement.** The drive to improve the patient experience includes new arrangements to enable users of services to identify where those services are not meeting standards locally: a Patient Advisory and Liaison Service and a Patients Forum in every trust; local authority Overview and Scrutiny Committees; and patient surveys developed by the Commission for Health Improvement. Each Patients Forum will be required to develop strategies to include young people.
- **Best practice.** The Modernisation Agency, the National Institute for Clinical Excellence (NICE), the Social Care Institute for Excellence and the Improvement and Development Agency will promulgate, spread and support best practice. For example, the appraisals and guidelines produced by NICE expect that clinical practice follows the best available research evidence. National audit programmes give the public powerful comparative information on performance in complex areas such as paediatric intensive care.
- **Change and leadership.** The Modernisation Agency will continue to work with health communities to stimulate and spread change and to strengthen leadership through a range of projects: Changing Workforce; bespoke improvement programmes from the Clinical Governance Support Team; clinically-based initiatives such as the cancer collaborative and Action On programmes. Future programmes will take account of the Children's NSF and will support its implementation.
- **Information.** *Delivering 21st Century IT Support for the NHS (10)* and the NSF Information Strategy (11) are delivering better information: for children, young people and their parents on health and health services, and how to access them; about children receiving care, to support an integrated care pathway; to support clinical practice; and for monitoring and continual improvement of services. The Integrated Care Record Service (10) will be central to the co-ordinated delivery of services envisaged in this NSF.
- **Performance indicators.** As part of the NHS performance rating assessment, a range of children's service indicators are being developed with the Commission for Health Improvement. Trusts that perform well against these indicators will be better placed to achieve or maintain three star status and have access to associated earned autonomy freedoms or possibly foundation trust status. PCTs will set local indicators, focused as far as possible on outcomes, and will performance manage progress.

Other National Service Frameworks

- 1.18 Other NSF's have set standards that apply to children and young people, and include interventions that are relevant to them. In particular, strong links need to be drawn with the NSF's for Mental Health (12), Coronary Heart Disease (13), and Diabetes (14). NSF's for renal disease and for long term conditions are in preparation, and they will contain standards that are relevant to children and young people (15 & 16).

A note on terminology

- 1.19 Throughout this document, the term 'child' is used to include babies and children, and 'young person' to cover older children and young adults. However, 'child'/'children' is frequently used as shorthand to cover all under 19s. We have used the term 'parents' as shorthand to include mothers, fathers, carers and other adults with responsibility for caring for a child or young person, including for example, those with responsibilities for looked after children and young offenders.

Chapter 2: Standard for Hospital Services for Children

Aim

- 2.1 To deliver hospital services that meet the needs of children, young people and their parents, and provide effective and safe care, through appropriately trained and skilled staff working in suitable, child-friendly, and safe environments.

Scope

- 2.2 This standard applies to *every department and service within a hospital that delivers care to children and young people: all* newborns, babies, children and young people being cared for in hospital; and **all parts** of the hospital that provide a service to children. It covers not only the quality of each element of hospital service, but also how well the parts fit together, from the child and family's point of view. It also begins to address how well hospital services link with services provided by other agencies, particularly social services, although integration and co-ordination of services around the child's journey through an illness, or as they grow up, will be a central theme of the full NSF, which will revisit the part that hospitals play in the whole system. Important topics to be covered more fully then include access to health services, care planning and discharge, and death in childhood.
- 2.3 This standard covers:
- Inpatients, including those in neonatal, paediatric and adult intensive care units; outpatients; and children in ambulatory settings, short stay and day wards, including those admitted for day surgery or investigation.
 - Accident and Emergency Departments.
 - Planned and unplanned attendances and admissions.
 - Children under the care of paediatric medicine and adult medical specialties.
 - The full range of surgical specialties, including general surgery, paediatric surgery, ear, nose and throat surgery, orthopaedics, dental surgery, ophthalmology, cardiac surgery, and gynaecology.
 - Support, therapy and other services, such as radiography, pathology, pharmacy, rehabilitation, dietetics, phlebotomy, physiotherapy, occupational therapy, speech and language therapy, and psychological support services.
 - Links with child and adolescent mental health services (CAMHS), drug and alcohol services.
 - Co-ordination of social care, education, and other services.

- 2.4 The standard has three parts, reflecting the three dimensions of quality that a hospital needs to get right if it is to provide the service that children deserve:

Standard

Part One: Child-centred Hospital Services

Children and young people should receive care that is integrated and co-ordinated around their particular needs, and the needs of their family. They, and their parents, should be treated with respect, and should be given support and information to enable them to understand and cope with the illness or injury, and the treatment needed. They should be encouraged to be active partners in decisions about their health and care, and, where possible, be able to exercise choice.

Children, young people and their parents will participate in designing NHS and social care services that are readily accessible, respectful, empowering, follow best practice in obtaining consent and provide effective response to their needs.

- 2.5 Child-centred hospital services are services that:
- Consider the ‘whole child’, not simply the illness being treated.
 - Treat children as *children*, and young people as *young people*.
 - Are concerned with the overall experience for the child and family.
 - Treat children, young people and parents as partners in care.
 - Integrate and co-ordinate services around the child and family’s particular needs.
 - Graduate smoothly into adult services at the right time.
 - Work in partnership with children, young people, and parents to plan and shape services and to develop the workforce.

Part Two: Quality and Safety of Care Provided

Children and young people should receive appropriate high quality, evidence-based hospital care, developed through clinical governance and delivered by staff who have the right set of skills.

- 2.6 This means:
- Clinical governance systems that give proper and explicit focus to the different needs of children and young people.
 - Staff treating and caring for children having the education, training, knowledge and skills to provide high quality care.

Part Three: Quality of Setting and Environment

Care will be provided in an appropriate location and in an environment that is safe and well-suited to the age and stage of development of the child or young person.

2.7 That is:

- ‘Child-friendly hospitals’.
- Hospitals that are safe and healthy places for children.

Rationale

2.8 Children are different from adults, so they need distinct and tailored services:

- Children’s physiology differs from that of adults and changes as they grow and develop.
- Children suffer from a different range of diseases and disorders to those commonly seen in adults. This includes a higher proportion of rare and often complex congenital and inherited disorders.
- Children’s mental capacity and level of understanding, for example about their bodies, illness and death, may differ from that of most adults, and changes as they develop.
- Children’s legal status, for example, in respect of consent to treatment, differs from that of adults, and changes, in the eyes of the courts, at certain key points in chronological age, and with developmental and emotional factors.
- Children are more vulnerable than most adults, and have a greater need for safeguarding their welfare.
- Children using health services are usually accompanied by a parent or other responsible adult. This person may have distinct legal rights in respect of the child, for instance over consent to treatment. They will also have their own needs, for example, for explanation and reassurance.
- Children are strongly affected by the context in which they live. Usually the most important element of this context is the family; followed by friends, school, neighbourhood and community.
- Children will become adults; and there is a growing understanding of the effects of childhood experiences, including illness, on their adult life.

2.9 Set against this background, much of what made Professor Kennedy so angry about what he saw of the services offered to children in hospitals falls into place. Kennedy found evidence that services treated children as if they were simply mini-adults, needing ‘smaller beds and smaller portions of food’;¹ that made little effort to tailor explanations to the understanding of children or their parents; and that failed to note significant contextual matters that might affect the progress of disease and recovery. He found staff skilled in treating adults; but with no specific additional training in treating children; and facilities designed with little acknowledgement of the differing needs of small children, older children, adolescents, and parents. He found hospitals operating in self-contained worlds, as if the prior experience of the child in front of them had no bearing; and as if what happened to them afterwards, or outside the hospital, was of no concern.

¹ *The Report of the Public Inquiry into children’s heart surgery at the Bristol Royal Infirmary 1984-1995: Learning From Bristol.* (July 2001), p.419.

Do children need to be in hospital?

- 2.10 Children's best interests are served, on the whole, by being in hospital for the briefest possible time needed to provide safe and effective treatment. Evidence also suggests that most parents would prefer to care for their sick child at home, where this is an option. Hospital is disruptive to the child and family and to the care of other children; it can be costly to the family in terms of travel, parking, meals at the hospital, time off work, and extra childcare for siblings.
- 2.11 Many conditions that commonly used to result in a child being admitted to hospital are now rare. Examples include poisonings (because of child-resistant containers); severe measles and some forms of meningitis (owing to the MMR and HiB immunisation programmes). Yet over the past 30 years the number of children admitted to hospital has gone up two to three fold – but the average length of stay has dropped from 8 days to 2 days, and the majority of children admitted spend only one night in hospital. This prompts two questions: first, should all of those children be admitted to hospital, or should other services be in place that might better meet their needs? This question will be addressed in the full NSF. Second, has hospital care modernised sufficiently to reflect this stark change in patterns of stay; and what more is there to do?

Child-centred services

- 2.12 Too often services neglect to see the child as a 'whole person' with basic developmental, physical, mental and social needs that are very different from those of an adult. Whatever the reason for being in hospital, meeting these needs is central to making the experience as 'normal' as possible for the child and family and to improving the clinical outcome. Seeing the whole child also means recognising that health protection and promotion and disease prevention are integral to their care in any setting.
- 2.13 Children and young people from ethnic minority backgrounds make up about one fifth of the total population aged under 19. This is a much higher proportion than for older age groups (around 6 per cent of the total population is from an ethnic minority), and is a crucial consideration in the design and delivery of services that need to reflect this cultural diversity.
- 2.14 The child exists in a context – family, school, friends, local community – which it is essential to understand if advice, treatment and care given are to be optimal and if important messages, for example, about convalescence, continuation of treatment, or future prevention, are to be conveyed. Education is vital, and it must be recognised that the child's time is valuable. Schooling missed through disorganised scheduling of hospital appointments or delayed treatment can severely disrupt education. Prolonged periods out of school or college can also impact on social functioning, and undermine friendships.
- 2.15 Children and young people have rights (*UN Convention for the Rights of the Child (17)* ratified by the UK government in 1991) that are not always understood and respected. They and their parents are not always treated with respect, sensitivity, and courtesy (Kennedy Report (1)). As children grow older, the fact that their needs change fundamentally, for example, an increasing concern for privacy and autonomy, is sometimes ignored. Parents and children may be pleased with the clinical outcome of the treatment, and yet, even sometimes years later, still very angry about the experience they went through. In many cases, this can be traced directly back to failures in communication.
- 2.16 A key theme of *The NHS Plan (3)* is partnership between patients and professionals. This concept can and must extend to children and young people. Children have a right to be involved in decisions about their care (*UN Convention for the Rights of the Child, Article 12 (17)*). Communication must be at a level, and by means, best suited to the child's stage of development and degree of understanding. It must

also be culturally appropriate. Their voice should also be heard in the design of services – but this is currently rare.

- 2.17 Respecting the role of the parent is a significant part of providing services to children and young people. The parent is a third party present in consultations, bringing their own rights, in terms of consent and confidentiality, and their own anxieties, expectations and ambitions for their child. As children get older, their wishes and expectations may, at times, conflict with those of their parents.
- 2.18 The central theme of *The NHS Plan (3)* is to design and deliver services around the needs of the person using them. This means seeing services through the eyes of the child and family. This is a core theme to be developed more fully in the full NSF. Highlighted here, however, is the importance of co-ordinated and collaborative multidisciplinary care planning *within* a hospital, as well as across agencies.

Quality of care

- 2.19 Children also have distinctly different needs when it comes to treatment, and there is evidence that these are being neglected in places. Extra delicacy is needed to carry out procedures on babies and small children. The use of medicines poses special problems. Services – such as pathology – need to be geared to the small samples, and interpretation of results, from children. An adequate understanding of children's physiology and development is necessary in the management of pain, or of recovery after surgery. In particular, clinicians who habitually treat both child and adult patients, for example, in A&E departments or orthopaedic surgery, need to be skilled in child-specific aspects of their work.
- 2.20 There is evidence that children with conditions that are rare, intractable, complex, unusually severe, or complicated by other disorders, do better if they are referred to tertiary services for diagnosis or treatment. However, there is considerable inequity of provision, so that some regions have a well-developed tertiary service, whereas others have rudimentary provision, or none at all. Moreover, there is much further scope to provide tertiary care closer to home for more children, through shared care and managed networks; while at the same time driving up quality and efficiency through consolidating teams for the most specialised procedures in tertiary centres.

Environment and setting

- 2.21 Care should be delivered in a safe, suitable and child-friendly environment (58 & 59). We know that children are still cared for on adult wards; conversely patients well over 18 continue to be accommodated on children's wards. Time and again when young people are asked about their hospital experience they complain that they were either cared for next to babies and toddlers in an environment suitable for young children, or in an adult ward with patients whom they regard as elderly. The first experience they dislike and the latter they may find frightening.
- 2.22 In talking to children and young people about what is important to them in hospital, food is a recurring theme and the source of considerable criticism at all ages. *The NHS Plan (3)* recognised that the quality of hospital food varied greatly across the NHS, and that food was not always served at times or in a manner that encouraged patients to eat and enjoy their meals. This can result in children and young people receiving inadequate nutrition, which may delay their recovery (60).
- 2.23 More generally, parents and children might reasonably expect that a stay in hospital should not in itself jeopardise a child's health, rather that it will be a safe and actively health promoting experience.

Chapter 3: Hospital Standard Part One

Child-Centred Services

Standard

Children and young people should receive care that is integrated and co-ordinated around their particular needs, and the needs of their family. They, and their parents, should be treated with respect, and should be given support and information to enable them to understand and cope with the illness or injury, and the treatment needed. They should be encouraged to be active partners in decisions about their health and care, and, where possible, be able to exercise choice.

Children, young people and their parents will participate in designing NHS and social care services that are readily accessible, respectful, empowering, follow best practice in obtaining consent and provide effective response to their needs.

Interventions

Meeting the needs of the ‘whole child’

Prevention and health promotion

- 3.1 Hospitals should play an active role in broader action to improve health and tackle inequalities, linking closely with community based preventative services. On the one hand, this may mean providing a properly integrated specialist and laboratory element to the various routine childhood screening programmes. On the other hand, it is a fundamental question of attitude and philosophy that looks beyond the immediate treatment of the presenting problem to ask the questions: could this illness or injury have been avoided? and how can we stop it happening again? It includes taking opportunities for prevention: for example, offering help with stopping smoking to pregnant women, parents, and young people themselves; or immunisation for children who have missed out. It also includes taking opportunities for asking about the child’s safety, if injury or illness might be a result of abuse or neglect (*Working Together to Safeguard Children, 1999 (18)* and *Safeguarding Children in whom Illness is Fabricated or Induced, 2002 (19)*.)

Assessment and support

- 3.2 At first contact, services should identify children and families requiring extra support, for example, those who need interpreters or advocates, and children in need including disabled children (*Framework for the Assessment of Children in Need and their Families (20)*). Services should be put in place before attendance or, in the case of an emergency admission, priority should be given to providing support on the spot. At no time should the child patient (or any other child) be expected to act as sole interpreter for another family member or patient, and lists of named interpreters and advocates, trained to work with children, should be available within the hospital. Where there are child protection concerns, face-to-face interpreters are preferable to remote providers of interpreting services, and such interpreters will need additional training and support.

- 3.3 The timing and type of assessment will depend on the reason for presentation and where the child's journey begins. A balance needs to be struck between establishing new facts, or those relevant to a particular profession, and avoiding multiple repetitions of the same basic questions. Every effort should be made to draw on, and add to, previous assessments, for example, through sharing records.
- 3.4 Children and their families need timely, relevant and effective personal and material support to help them cope with illness or disability. In addition to the generic support provided by all members of the multidisciplinary team, this includes:
- Specialised support, such as that provided by a mental health professional or social worker for those with emotional and psychological difficulties.
 - Spiritual support, provided by religious leaders or the chaplaincy service.
 - Support provided by peers: among children and young people and between families with similar problems.
 - Advice on available financial support, including for example, for families whose child is in hospital at a distance from home.
 - Help with child care arrangements for siblings.
 - Help with transport and travel to tertiary or other referral centres, for example, through hospital transport schemes.
 - Provision of information on support groups and voluntary organisations.
- 3.5 There is an inconsistent pattern of social work provision to hospitals that can lead to confusion for families and professionals about which local authority to contact when a social service is required, and this can make effective multidisciplinary teamwork difficult to arrange and sustain.
- 3.6 The local authority in which the hospital is located has a general duty to promote and safeguard the welfare of children in their area (Children Act 1989, section 17 (21)). They must ensure that this responsibility is properly discharged where a child is in hospital. In some cases another local authority may already be providing services for the family or the child. In such a case, the local authority in whose area the hospital is situated, must ensure that they properly discharge their responsibility to that child until alternative arrangements have been made with the other local authority. Before the local authority in whose area the hospital is situated can relinquish responsibility, both local authorities must agree how the child's care will be managed whilst the child is in hospital and on discharge. Where two or more local authorities are involved, they should, of course, co-operate under section 27. In some instances, social work teams are operating from inside the hospital; in others, local authorities have placed the hospital social workers outside the hospital in local community teams. This mixed picture has a number of consequences, including poor co-ordination when discharge is arranged and, for children in need of child protection services, the potential for return to a risky, even dangerous, environment.

Play and recreation

- 3.7 Children visiting or staying in hospital have a basic need for play and recreation that should be met routinely in all hospital departments providing a service to children. This applies equally to the siblings of patients, and so is also a consideration for neonatal units. Play may also be used for therapeutic purposes, as part of the child's care plan, and as a way of helping the child to: assimilate new information; adjust to and gain control over a potentially frightening environment; and prepare to cope with procedures and interventions. There is evidence that play hastens recovery, as well as reducing the need for interventions to be delivered under general anaesthesia.²

² *Hospital Accommodation for Children and Young People: Health Building note 23.* NHS Estates, Paragraphs 2.108 – 2.109.

- 3.8 It has been recommended that all children staying in hospital have daily access to a play specialist (22). The use of play techniques should be encouraged across the multidisciplinary team caring for children, including in A&E, with play specialists taking a lead in modelling techniques that other staff can then adopt. The team should be able to offer a variety of play interventions to support the child at each stage in his or her journey through the hospital system (guidelines are available from the National Association of Hospital Play Staff (23)).

Education

- 3.9 Staff, facilities and equipment are required to meet the ongoing educational needs of children and young people staying in hospital, with reference to the Department for Education and Skills guidelines on the education of sick children in hospital (24). This includes access to therapy input for children who need special equipment, such as seating and communication aids, in order to participate. Where a child's condition will affect schooling, hospital staff need to liaise with and involve the school from an early stage. This is particularly important if the child is likely to be away from school for some time, or the child's condition has long term implications for education. Evidence suggests that this is not always handled effectively, which can have an impact on educational attainment.³ In addition, early education for 3 and 4 year olds, though not compulsory, is an entitlement for all 4 year olds and will be for all 3 year olds by 2004. If the hospital provision is included on the local education authority's (LEA) Directory of Providers, then funding for this should be available from the LEA.

Treating children and their families with respect

Respecting children and young people

- 3.10 Every effort should be made to respect a child's need for privacy; observe courtesies; explain what is going on; and ask permission, for example, for a student to observe. All hospital departments need to understand and provide for the young person's changing needs as they grow up, for example, for increasing independence and privacy, and different styles of communication, peer support and leisure pursuits. This includes recognising that preparation for the move to adult services includes a gradual increase in the involvement of the young person in decision making, while helping the parent take a 'back seat'.⁴
- 3.11 In some circumstances, children and young people may ask to see a health care professional of the same sex, and hospitals should try to accommodate this. Moreover, in certain circumstances, such as those involving children who have been the victim of sexual abuse, the sex of the health care professional may be of considerable importance. More generally, a trusted adult or member of staff must be available when any child or young person is to be examined without their parent present.
- 3.12 Staff have a duty to understand and meet their legal responsibilities towards the children and young people they are caring for (*Children Act 1989 (21)*). This includes the legal and ethical position on real or potential conflicts between the interests of the child or young person and those of the parents. This is most often an issue in child protection, but can arise in other situations as well. It is to some extent a training issue, but may need access to expert legal advice in difficult cases. Statutory government guidance makes clear that in the context of child protection, it is the child whose interests are paramount.

³ *Hospital Accommodation for Children and Young People: Health Building note 23*. NHS Estates, Paragraphs 2.112 – 2.116.

⁴ *Hospital Accommodation for Children and Young People: Health Building note 23*. NHS Estates, Paragraphs 2.73 – 2.75.

Respecting parents and the family as a whole

3.13 A respectful partnership with a sick child's parents means recognising that:

- Parents are usually the experts on their child.
- Parents may have other children to care for, and will have to balance their needs with the needs of the child in hospital.
- Parents' time is valuable. They may need to take time off work to accompany their child to hospital appointments, and repeated visits might mean they lose pay.
- Parents may have their own health or other problems to deal with; and this may affect their understanding of explanations offered, and their readiness to participate in treatment of their child.
- Health care can impose material hardship, for instance when a child is in hospital a long way from home.

Children, young people and parents as partners in care

3.14 We have come a long way since the days when sick children were intentionally isolated from their parents, so as not to upset the child or disrupt the staff's routine. Now a parent's presence is recognised as a positive factor in aiding the child's recovery; and their practical contribution to care at the bedside is often essential. Encouraging parents and children to take responsibility for administering their own medicines in hospital, where appropriate, prepares for discharge home and allows health care professionals to assess the child's and parents' abilities to cope, for example, with inhalers or more complex therapies.

Sharing information with children and parents

3.15 Children, young people and parents can only participate fully as partners in care if they have access to accurate information that is valid, relevant, up-to-date, timely, understandable and developmentally, ethically and culturally appropriate. A range of communication methods should be developed and used, and information should be available about specific conditions, medicines, procedures, services and support groups, in a variety of formats, media and languages. Audio or video tapes of the most common procedures carried out in the paediatric unit are helpful.

3.16 Staff working with children and young people should have training in the necessary communication skills to enable them to work effectively with children, young people and parents, and to support them to be active partners in decision making. Ideally, this should include:

- How to listen to and communicate with children, young people, parents and carers, and the need to understand the extent and the limits of children's comprehension at various stages of development.
- Recognition of the role of parents in looking after their children in hospital
- Providing information that is factual, objective, and non-directive, about a child's condition, likely prognosis, treatment options, and likely outcomes.
- Giving bad news in a sensitive non-hurried fashion, with time offered for further consultation away from the ward environment.

- Enabling a child and family to exercise choice, taking account of age and competence to understand the implications.

An audit of the communication skills and competencies of staff working with children and young people may be helpful as a first step in identifying the training required.

- 3.17 Keeping families fully informed will be helped by copying clinicians' letters to patients, which is a proposal in *The NHS Plan (3)* and a recommendation in the Kennedy Report (1). There are a number of NHS organisations across the country that already do this. Following evaluation of a pilot project, the whole of the NHS will be expected to have implementation plans by April 2003, with full implementation by April 2004.
- 3.18 The audio recording of consultations has been suggested as a means of improving communication with children and their families. Patients might be given the audio recording, or a written summary. There is some evidence that adult patients and parents value this approach, and that it improves information recall and satisfaction. Clinicians might consider offering audio recording of consultations to improve communication in certain circumstances, perhaps where complex and difficult information is being shared: for example, with families of children with cancer or babies in neonatal intensive care.
- 3.19 Where admission to hospital is planned, children should be prepared through pre-admission play and information. A visit to the ward should always be offered.

Giving bad or difficult news

- 3.20 The way in which health professionals present bad or difficult news is an important factor in how it is received, understood and dealt with. Such news must be shared with children and parents in a sensitive non-hurried fashion, away from possible interruptions (see, for example, the SCOPE package of guidance and training in news breaking (25)). A consistent theme from parents is the need for more information. Time must be set aside for careful and detailed explanations, repeated as often as requested, and in different forms, including written, with ample opportunity to ask questions. The joint Department of Health/ Department for Education and Skills guidance *Together from the Start (26)* can help to improve the disclosure of disability to a family. The contact details of local and national support groups including the range of literature provided by groups such as the Stillbirth and Neonatal Death Society (SANDS) (27), the Premature Baby Charity (BLISS) (28) the Children's Heart Federation (29) and Contact a Family (30), should be offered. Identifying a named person for the child and family to contact may be one way of providing ongoing support.

Consent

- 3.21 Hospitals should follow the Department of Health guidance on consent (31) and the associated report on working with children (32). (See also the British Medical Association book on consent (33), and guidance on confidentiality (34).) Trusts' policies on consent should specifically address the needs of children and young people. All professionals should be familiar with the concept of 'competence' in giving consent. Consent policies should include what to do when there is disagreement between a competent young person and their parent. They also need to address the situation where health care professionals believe that a particular treatment is crucial, perhaps life-saving, for a child but parents refuse to give consent.
- 3.22 Children, young people and parents need valid, relevant, accurate, up-to-date, easily accessible and well-presented information, that is appropriate to their level of understanding, before they can decide whether to consent to, or refuse, treatment. Information should cover: what the treatment will involve;

benefits and risks; immediate and long term implications of not having treatment; what alternatives may be available; who will be administering the treatment. Hospital pharmacists are able to provide written information in a form that is easily understandable about the medicines being used to treat children. This should be used as an integral part of the consent process and any possible effects of the medication should be made clear. Helpful information leaflets have been produced by the Royal College of Paediatrics and Child Health and the Neonatal and Paediatric Pharmacists Group (35).

- 3.23 If a procedure is unpleasant or painful, a truthful explanation is essential. Fears should be acknowledged and coping techniques identified, so that the child is given the confidence to deal well with the procedure. Occasionally, a child will choose not to help himself or herself but will consent to being held still, or restrained. In these situations, the Royal College of Nursing guidance on restraint (36) should be followed. Trusts' policies on consent should address the issue of treating a child who is unwilling to co-operate.
- 3.24 When a coroner's post mortem is required, families need to be given a clear explanation about the procedure and their consent will be required before any organs or tissues can be retained or used for any other purpose. Hospital post mortems and any subsequent retention or use of organs or tissues should be governed by the consent of the family (for draft code of practice for the handling of communications with families about post mortem examinations, with new draft consent forms, see www.doh.gov.uk/tissue (37)).

Choice

- 3.25 Real choices over aspects of treatment or care should be offered to the child or young person wherever possible. For a younger child, this could include choice about where to sit during a procedure, or whether to take tablets or a liquid medicine, or which arm to put a thermometer under. Young people should be involved in choices between treatment options, or about who should deliver treatment where there is a choice. Choices made about treatment or aftercare should be recorded as part of the care record or plan. Play techniques can help children and young people understand the options and exercise choice.

Integration and co-ordination of services

- 3.26 For parents and children, one of the biggest areas of frustration is the seeming lack of integration between different elements of service: different organisations, even different services or departments in the same hospital, not sharing information, not coinciding timings or consultations; and not being 'in tune'. It can happen during a single day of appointments, in the course of an inpatient stay; or over a longer period. Just as important is the interface with social care and with other health services, such as mental health services (see paragraphs 4.25–4.27), and those dealing with substance misuse, teenage pregnancy and sexually transmitted infections.

Planning care, including planning for discharge

- 3.27 For children and young people requiring more than just the simplest of hospital care, there should be an agreed process to plan care, involving primary care, and all relevant hospital departments and other agencies, including education and social services, to provide a joined-up, co-ordinated care package so that children, young people and their parents can access the different services easily. Planning care will be covered in more detail in the full NSF.

- 3.28 Children with complex health needs often require input from a number of different specialties. This requires careful co-ordination, if the parent is not to be left as solitary lynchpin in a chaotic system. Parents have expressed the need for a key worker to help them negotiate their way around the system and support them in accessing the different services available. This will be considered in more detail in the full NSF, though hospitals may wish to consider how this role could best be provided.
- 3.29 When a cure is not possible, and a child is going to die, much can be done to help the child and family. Planning care for any child dying in hospital should cover: good communication with the child and family; attention to symptom control; psychological and social support; spiritual support; and support to the family after bereavement. This will be covered in more detail in the full NSF and in the forthcoming Health Building note.⁵
- 3.30 Hospital stays should be kept to a minimum through the co-ordinated delivery of care. Planning for discharge, and the prevention of unnecessary readmission, should be the norm for all children and young people. Where the hospital episode has been simple, discharge planning need not be elaborate, but should at least include a letter to the GP (copied to the patient) and a briefing for the patient and their parent about likely after effects, any follow-on treatment needed, any continuing drug therapy, and the implications for school attendance, together with a contact point in case of difficulty or confusion. Where applicable, the role of the social worker in discharge needs to be effectively linked in. Where needs are more 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.
- 3.31 Where there are concerns about a possible child protection issue, it is particularly important that there is a multi-agency action plan agreed and recorded before the child leaves hospital (see paragraphs 4.9–4.14). *The Victoria Climbié Inquiry* (8) highlights the needs for this and recommends that:
- Directors of social services ensure that no child known to social services who is an inpatient in a hospital and about whom there are child protection concerns is allowed to be taken home until it has been established by social services that the home environment is safe, the concerns of the medical staff have been fully addressed, and there is a social work plan in place for the ongoing promotion and safeguarding of that child's welfare;⁶
 - Hospital trust chief executives must introduce systems to ensure that no child about whom there are child protection concerns is discharged from hospital without a documented plan for the future care of the child. The plan must include follow-up arrangements. Hospital chief executives must introduce systems to monitor compliance with this recommendation.⁷
- The need to safeguard a child should always inform the timing of their discharge, so that the likelihood of ongoing harm can be assessed while he or she is still in hospital.
- 3.32 Particular attention is required in the discharge planning of newborns from neonatal intensive care units, since these babies are at high risk of readmission to hospital. They need a properly co-ordinated programme of follow-up, with special attention to vision, hearing and developmental progress, as well as the co-ordinated input of services such as genetics.
- 3.33 Young people with long term conditions need preparation for the move from children's to adult services. All young people with on-going health needs should have a plan developed with them for the transition of their care to adult services, which is co-ordinated by a named person. Transition to adult services is considered in further detail in paragraphs 4.58–4.62.

5 *Hospital Accommodation for Children and Young People: Health Building note 23*. NHS Estates, Paragraphs 2.124 – 2.128.

6 *The Victoria Climbié Inquiry*. (January 2003), recommendation 56, pp.204 & 378.

7 *The Victoria Climbié Inquiry*. (January 2003), recommendation 71, pp.254, 276 & 379.

Children, young people and parents as partners in planning services

- 3.34 Children, young people and families should be routinely involved in the planning and improvement of services. Methods of seeking children's and young people's views should be consistent with the government principles of participation, published by the Children's and Young People's Unit (CYPU) in 2001 (38). The needs of children and young people should be specifically addressed as part of the Patient Advisory and Liaison Service and Patients Fora, ensuring that children and young people may have access to an advocate, and make a complaint if they wish.
- 3.35 Children, young people and parents should be included in trust patient surveys; the methodology will be developed as part of work on this NSF through the new Commission for Health Audit and Inspection.

Child-centred services – key points for early consideration:

Hospitals will need to consider how the services provided for children and young people in every department where they are treated can be more child-centred. In particular, they will need to:

- with local authorities, where appropriate, review the availability of, and access to social services; to age-appropriate play equipment and staffing, and the provision of education for children in hospital;
- ensure that information provided is up-to-date and meets the needs of children, young people and their parents;
- consider how they might drive up the quality of care for children across the hospital to achieve services that are well co-ordinated, particularly for those with complex conditions who may benefit from having someone available who can act as a key worker;
- ensure that children about whom there are child protection concerns are not discharged from hospital until there is a plan in place to ensure their safety;
- ensure that children, young people and their families are involved in decisions on their care, and their needs addressed through the Patient Advisory and Liaison Service and the Patients' Forum.

Workforce development and planning:

Work is in hand throughout the NHS to support the development of a workforce with the right skills and competences to work in new ways as commitments to expand staff numbers are met. As more staff become available and work on establishing the competences is developed, hospitals will need to consider the availability and the ability of staff to respond to the needs of the child and family. This includes understanding the context of the child and family, and how this may impact upon choices to be made and support provided: for example, parental mental illness, travelling families, culture and religious beliefs. Hospital staff should also understand their legal responsibilities to children. Training programmes may be needed so as to meet any gaps in skills that are identified.

Chapter 4: Hospital Standard Part Two

Quality and Safety of Care Provided

Standard

Children and young people should receive appropriate high quality, evidence-based hospital care, developed through clinical governance and delivered by staff who have the right set of skills.

Interventions

Clinical governance systems with a focus on children

- 4.1 Clinical governance is an inherent part of the way that services are planned and delivered, and therefore spans every part of the hospital standard. However, this section draws attention to those aspects that require a particular and separate response for children, within a trust's overall clinical governance framework.
- 4.2 Clinical governance systems do not always explicitly recognise children and young people as a separate and vulnerable client group. In addition to the particular issues of child protection, hospital procedures and systems themselves can jeopardise the safety and wellbeing of children. In view of this, it is essential that the care of children is given a specific focus within the clinical governance arrangements of a trust and that this focus is reinforced by appointing a board level children's lead within the trust. The clinical governance arrangements should be approached on a multi-disciplinary and, where appropriate, multi-agency basis to include social work staff and other professionals (including those employed by a local authority or a voluntary organisation). These arrangements should be clearly identified within the Clinical Governance Development Plan, and an action plan for implementation of any additional clinical governance arrangements for children should be developed as part of this process. This would include producing an annual report to the Board on children's services in the hospital.
- 4.3 There should be a reliable system in place to ensure that prior records are available whenever, and wherever, children are seen and assessed. It may be necessary to investigate prior attendance at other hospitals, particularly where there are child protection concerns. Records should be contemporaneous, clear, accurate and comprehensive, attributable to, and signed by, a health care professional and countersigned by the responsible consultant where appropriate. *The Victoria Climbié Inquiry* (8) emphasises the importance of this requirement in safeguarding children and makes various recommendations around it, including the following:
 - When concerns about the deliberate harm of a child have been raised, doctors must ensure that comprehensive and contemporaneous notes are made of these concerns. If doctors are unable to make their own notes, they must be clear about what it is they wish to have recorded on their behalf;⁸

8 *The Victoria Climbié Inquiry*. (January 2003), recommendation 68, pp.249, 259 & 379.

- When a child is admitted to hospital and deliberate harm is suspected, the doctor or nurse admitting the child must inquire about previous admissions to hospital. In the event of a positive response, information concerning the previous admissions must be obtained from the other hospitals. The consultant in charge of the case must review this information when making decisions about the child's future care and management. Hospital chief executives must introduce systems to ensure compliance with this recommendation.⁹

The record should also specify which hospital consultant is responsible for the child's care. Staff assessing children should know who to contact in social services at any time, in the event of having concerns about whether or not a child may have suffered significant harm.

- 4.4 New or experimental treatments should only be offered by, or under the guidance of, a specialist team following a comprehensive clinical governance appraisal of the treatment.

Safety of treatment and care

- 4.5 Hospital trusts' health and safety policies should be robust and explicitly cover children and young people. They should be subject to regular audit to ensure that they are being met.
- 4.6 Serious events and near misses will need to be thoroughly investigated and reported to the National Patient Safety Agency, in line with national requirements. Reporting should include stratification by age group and highlight particular issues regarding children. Significant events in delivering services to children and young people should also be reported to the trust board, discussed regularly, and used as a learning opportunity in a non-threatening, multi-disciplinary setting (including administrative staff). The trust should be able to demonstrate how learning has occurred from the monitoring of such events and how improvements in care have resulted from this learning. A risk register of actual and potential risks in the processes of care for children and young people across the trust should be developed. Risks to children will need to be managed and addressed explicitly, as an integral part of the overall clinical governance arrangements.
- 4.7 At every location within the hospital where care is provided to children there must be staff trained in life support. Basic life support is generally sufficient in most areas of the hospital. However, in clinical areas such as A&E, on inpatient medical and surgical wards, and in surgical recovery areas and day case facilities, this should be to advanced life support levels: for example, to Advanced Paediatric Life Support (APLS) or Paediatric Advanced Life Support (PALS) standard, or equivalent; and equipment and appropriate drugs should be available to resuscitate and stabilise a collapsed child. In these settings, ideally, there should be at least one person trained in APLS or PALS, or equivalent, on a shift at any time. As a minimum, an A&E receiving children should have someone trained in paediatric airways management and venous access on duty at all times. It is vital that paediatric life support trained staff receive regular updates and regular scenario practice.
- 4.8 Requirements for the transfer and safe retrieval of a child to a specialist centre in an emergency include staff with expertise in stabilisation prior to retrieval by a paediatric intensive care team. These arrangements should include a lead clinician and multi-disciplinary group that reviews the local arrangements for procedures, equipment, training and communication. Details are given in *Paediatric Intensive Care (39)* and *High Dependency Care for Children (40)*.

⁹ *The Victoria Climbié Inquiry*. (January 2003), recommendation 73, pp.260 & 379.

Safeguarding children's welfare

- 4.9 Promoting children's wellbeing and safeguarding them from harm is the responsibility of all staff working with children, parents, significant carers, or other adults who may pose a threat to children. Guidance already exists that is not always implemented correctly (*Working Together to Safeguard Children (18)*; *Framework for the Assessment of Children in Need and their Families (20)*; *Safeguarding Children in whom Illness is Fabricated or Induced (19)*, *Safeguarding Children Involved in Prostitution (41)*). In response to *The Victoria Climbié Inquiry (8)*, the government will issue a summary of the guidance, particularly aimed at practitioners responsible for safeguarding children.
- 4.10 The draft standard on child protection set out in *Emerging Findings (2)* for consultation would apply to children and young people in all settings, including hospitals, and is annexed to this document for ease of reference.
- 4.11 Trusts will need to support and supervise staff in their safeguarding role, through:
- Ensuring that staff at all levels – including those working in adult services with parents and carers – are aware of their corporate and individual responsibility to safeguard children.
 - Safe recruitment practices for all staff, including agency staff, students and volunteers, working with children, including a criminal record review on employment (see *Clothier Report (42)*).
 - Ensuring that staff working with children are:
 - trained, updated, supported and supervised in safeguarding children and promoting their wellbeing;
 - skilled in listening to children and young people, including disabled children;
 - aware of their professional accountability to take appropriate action, and are supported in doing so;
 - clear what information can be shared in child protection cases, and when;
 - aware of national as well as local guidance and procedures on child protection.
 - A clearly identified, named doctor, nurse, and, where appropriate, midwife, with allocated time to undertake the role as set out in *Working Together to Safeguard Children (18)*, and in the guidance set out in the letter from Jacqui Smith, Minister of State for Health, of 28 January 2002 to chief executives of PCTs (*43*).
 - Appropriate advice on child protection available to staff 24 hours a day, 7 days a week.
 - Agreed procedures in place for reporting concerns, including concerns about colleagues, so that early action can be taken to remedy the situation.
- 4.12 The best practice occurs when health care professionals know social services staff at a personal level, so that professional trust builds up over time. This can be achieved in various ways. The preferred option is to have a core of social service staff permanently dedicated to working with hospital services and having a base in the hospital, to enable them to provide a rapid service to children and families whilst in hospital. Other models can work effectively as well, but all need an expectation of working relationships that involve trust and respect between professionals. The same applies to links with police.
- 4.13 The hospital trust board should be kept fully informed about the trust's performance in relation to child protection, including assurance that the named doctor and nurse are in post, and have the time, training and support they need to do their job. Clinical governance and audit arrangements should be in place to

assure the quality of systems, processes and practices to safeguard children. This should include a protocol drawn up and agreed by the trust board, with the involvement of other local agencies secured through the Area Child Protection Committee (ACPC), and covering the procedures to be followed where harm is suspected. The protocol would set out:

- Action to be taken when concerns about a child's welfare have been raised, discharge procedures for such children, and arrangements for ensuring that these are carried through and checked for completion.
- The circumstances in which physical examination of the child must take place.
- Recording of information in case notes, care plan and discharge plan including records of discussions about the care of the child.
- How to address and record any disputes between professionals about a child who may have been harmed.
- Requirements for regular audit and resulting actions.
- The threshold for critical incident reporting including referral to National Patient Safety Agency.
- Involvement in serious case reviews as set out in *Working Together to Safeguard Children (18)*.

4.14 The hospital should have links both with the ACPC and local PCTs to participate in strategic planning, and to discuss complex or difficult cases or issues arising from a case or group of cases. It should also have an action plan to improve cross-agency working, agreed with partner agencies and co-ordinated by the Strategic Health Authority. There should be effective liaison between the PCT designated professionals and the named hospital trust professionals.

Evidence-based practice

- 4.15 Evidence-based protocols and guidelines can be instrumental in achieving high standards of care for children and young people, particularly if their development involves the whole multi-disciplinary team and patient representatives. Protocols should be in place across the hospital, particularly in A&E and surgical services, as well as on children's wards, and should cover: resuscitation; pain management and sedation; fluid management; antibiotic regimes; and management of the conditions with which children most commonly present to hospital – feverish illness, breathing difficulty, diarrhoea and vomiting, seizure, abdominal pain, rash, and head injury. NICE appraisals and guidelines that apply to children should be available to all clinical staff, and translated into local protocols. Protocol and guideline development needs to be linked into a programme of staff education and training. The protocols themselves should be monitored, reviewed and subject to version control.
- 4.16 Multi-disciplinary child-specific clinical audit should be undertaken in all specialties in which children are treated. Trusts should also participate in, and respond to the findings of, the Confidential Enquiry into Maternal and Child Health (44) and the Confidential Enquiry into Perioperative Deaths (45). In addition, Improvement, Expansion and Reform sets out a requirement that all appropriate units should participate in national comparative audits for paediatric cardiac surgery which applies to surgical and transcatheter treatment of congenital heart disease.¹⁰ The UK Central Cardiac Audit Database is the appropriate register for this purpose.
- 4.17 Information and the information management and technology infrastructure needed to deliver and support clinical audit and decision-making, including electronic prescribing and decision support systems suitable for paediatrics, should be incorporated as it is developed and becomes available.

¹⁰ Improvement, Expansion and Reform, p.15.

The use of medicines in children

- 4.18 The use of medicines in children should be guided by the best available evidence of clinical effectiveness, cost effectiveness, and safety, ideally derived from clinical trials conducted with children. Good practice also includes using medicines for which there is a sound theoretical basis for believing that they are effective in children, for example, medicines that have been shown to work well for adults, but have not been formally researched for use in children. In practice, therefore, this means that many children receive medicines that are not licensed for their age group or for their particular health problem (use 'off-label'); or do not have a license at all ('unlicensed'). It is recognised that this is not ideal and a variety of steps are being taken, which over time should lead to an increased range of products and formulations that carry a license for use in children across the age ranges required.
- 4.19 In the meantime, the use of unlicensed and off-label medicines has particular implications for clinical governance. Standard information leaflets packaged with the medicine may not cover its use in children, which can be a potential source of confusion. Using a medicine designed for use in adults may mean that very small amounts must be measured, or the medicine has to be diluted, adding to the potential for error. All prescribers should pay particular attention to the licensing status of medicines. Pharmacists should, when handing out medicines for children, reassure parents and children about the contents of the accompanying Patient Information Leaflet produced by the manufacturer. It is important that clinicians and parents have appropriate information about these medicines and that hospital trusts have a policy covering their use. Substantial safeguards will be in place if prescribers routinely refer to the formulary *Medicines for Children* (35). In some circumstances, other formularies may be appropriate. More generally, hospitals should have policies and procedures relating to safe medicines practice in paediatrics and neonatology, including:
- Ideally, sufficient trained pharmacy staff should be available to cater for the special needs of children, to ensure that medicines are managed safely and effectively, and to play an active role in the multi-disciplinary team caring for children.
 - Preparation of intravenous injections and infusions for children centrally under controlled conditions in the pharmacy.
 - Reporting and monitoring of medication errors, including all errors in dosage, supported by information technology, as part of adverse incident and near miss reporting, and the use of experienced practitioners to investigate incidents.
 - Controls assurance standards relating to the specific needs of children: for example, weighing all children accurately to allow drug doses to be calculated; and standards for checking medicines before administration.
 - Ensuring that formulations of medicines are appropriate to the age and ability of the child.

The use of clinical equipment

- 4.20 As part of the overall trust clinical governance framework, arrangements should be in place to secure the safe and effective use of equipment in children throughout the hospital. Equipment used must be the correct size for the child, and its design must be tailored to different needs at different ages and stages of development. Staff using this equipment should be trained to do so. This requires a programme of training, with particular emphasis on the use of monitors and infusion pumps: in A&E, recovery suites, burns and neurosurgery units, spinal injury units, as well as children's wards, neonatal units and paediatric intensive care. Staff are encouraged to seek the assistance of the NHS Purchasing and Supply Agency (46) and/or local professional supply staff in the effective specification, sourcing and purchase of equipment and devices that are suitable for use on or by children. Standards on equipment management

for children in all hospitals, and an exemplar list of equipment, can be found in the Department of Health's report, *High Dependency Care for Children (40)*. Equipment failures should be recorded and investigated.

- 4.21 The provision of equipment that a child or family needs to take and use at home will be covered in the full NSF.

Infection control

- 4.22 Hospital trusts should make specific reference to infection control amongst children in their infection control policy, including policies to minimise antibiotic resistance. Particular emphasis is needed on cross infection control, focusing on common childhood infections, such as respiratory infection, gastroenteritis, and chicken pox. A children's infection control lead should be nominated, who will take an active role in a communicable disease control network, including the immunisation co-ordinator, microbiology, and the district consultant in communicable disease control (47).¹¹

Major incident planning

- 4.23 Trust major incident plans should cater explicitly for the needs of children.

Training and continuing professional development

- 4.24 All staff treating or caring for children and young people should have appropriate training (perhaps leading to a National Vocational Qualification or similar), and should undergo regular updating and refreshment of skills. This training should cover both the technical clinical skills and the personal and communication skills necessary to treat children and their parents properly. Training could be delivered routinely through short courses, for example, organised through a children's network. At a minimum, it should cover: child development, parents as partners in care, resuscitation, use of medicines, child protection, news breaking, pain management, and care of parents after the death of their child. It should also include basic knowledge, and recognition and care of common mental health and behavioural problems, such as deliberate self harm. Joint training of staff from different disciplines is encouraged (Core Skills and Common Training Project).

Mental health

- 4.25 Attention to the mental health of the child, young person and their family should be an integral part of any children's service, and not an afterthought. In many situations social and psychological difficulties are significant, but neglected. For example, when children are critically ill, these frequently take second place to the urgent priority to keep the child alive. Where an illness has a significant psychological component, such as an eating disorder, accessible mental health consultations can save the child wasteful and intrusive tests.
- 4.26 It is, therefore, essential for a hospital with a children's service to ensure that staff have an understanding of how to assess and address the emotional wellbeing of children, and are able to identify significant mental health problems, and that there are robust liaison arrangements in place to secure child and adolescent mental health services (CAMHS) input, including psychiatry, psychology, individual and family psychotherapy, social work and CAMHS trained nurses. Good liaison depends primarily on

¹¹ *Hospital Accommodation for Children and Young People: Health Building note 23*. NHS Estates, Paragraphs 2.78 – 2.84.

secure relationships between staff, who can rely on a quick response when required. This happens best in the context of regular meetings, where the daily work is discussed and staff themselves can be supported. Liaison arrangements should also provide for the education and training of all children's health care staff in recognising and responding appropriately to the mental health needs of children and their families.

4.27 All hospitals receiving and treating children and young people should have policies and liaison arrangements in place to deal with:

- **Management of overdoses and deliberate self-harm.** Including self-mutilation and attempted suicide. This requires child and adolescent psychiatric supervision of the entire process. Although it is not always necessary for a consultant psychiatrist to see these cases, psychiatric advice must be available at all times. Suitably trained staff can carry out risk assessments once the patient is admitted to a children's or adolescents' ward. Particular attention must be paid to ensuring proper medical and mental health care provision for these young people in A&E departments, where evidence suggests that their needs can be badly neglected.
- **Acute psychiatric crisis.** From time to time young people who are psychotic or with complex, persistent and severe behaviour disorders present in A&E and are then admitted to children's wards. A children's ward may not be the best place for such patients, who may need to be in adolescent psychiatric units or appropriate, jointly agreed, facilities as soon as possible. While this is being organised, intensive support is needed from the child and adolescent mental health team.
- **Direct clinical work.** Work with children and their families referred by the children's service. Problems covered may range from phobias, pains of uncertain origin, injuries, drug reactions, and bereavement; through parental concerns about their child's illness; to previously unrecognised, long standing psychiatric problems such as attention deficit hyperactivity disorder.
- **Complex cases.** Including eating disorders and unexplained physical symptoms, which may call for psychiatric involvement, and close collaboration between all staff.
- **Child protection cases.** Mental health consultations should be available to patients or staff or both.
- **Long term and life threatening diseases.** Specialist paediatric clinics, for example for asthma, rheumatology, dermatology, cystic fibrosis, leukaemia, sickle cell and thalassaemia, and disabled children, should have ready access to a mental health liaison service. Arrangements should also ensure appropriate mental health care when these children and young people are inpatients.
- **The death of a child.** Support for the child and family. Also, staff become closely involved in the care of these critically ill children and debriefing may need to be arranged urgently.

Pain management

4.28 Pain is unpleasant, delays recovery, and adds to the trauma of illness, injury and clinical procedures. Historically, pain has been underestimated and undertreated. There is still evidence that pain is inadequately dealt with for children in hospital, requiring better prevention, assessment, and treatment.

4.29 Where procedures are planned, and pain can be predicted, the opportunity should be taken to prepare children through play and education, and to plan pain relief for use during the procedure. The use of psychological therapies, including distraction, coping skills and cognitive-behavioural approaches, provides some benefit. Treating unexpected pain from illness or trauma should also include these techniques where possible.

4.30 In order to treat children's pain effectively, a thorough pain assessment is necessary, and a number of guides are available to do this (for example, from the Royal College of Nursing (48) and the American

Academy of Pediatrics (49)). They offer different options for communication, and can be completed in different ways by the child, family or professionals, according to the particular circumstances and needs of the child and family. 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.

- 4.31 The treatment of children's pain using medicines requires appropriate choice of drug, dose, frequency and route. There are many options, but research has found that some hospital staff may be reluctant to prescribe at all, and they tend to use a dose that is too small to address the child's pain adequately. Protocols, education and training can support staff in their management of children's pain, which should be reviewed regularly through audit. The involvement of pharmacists in the development of pain management guidelines is encouraged.
- 4.32 Children with long term pain need a similar approach, spanning prevention, assessment and treatment. Special consideration should be given to children recovering from trauma and burns, and children with cancers, joint conditions, sickle cell disease, and those needing palliative care.
- 4.33 Hospital policies for managing children's pain should apply to all children in every hospital department, including newborns in neonatal units. Special focus should be given to children in A&E departments, post-operative pain, pain related to procedures, and long term pain as in cancer. They should be founded on the following principles:
- Children have a right to appropriate prevention, assessment and control of their pain.
 - Clinical staff should receive training in the prevention, assessment and control of children's pain.
 - Children can expect the management of pain to be a routine part of any treatment or procedure, in any part of the hospital. They can also expect to be involved as active partners in pain management.
 - Pain should be assessed and reviewed in all children and monitored after all procedures.
 - Protocols and procedures should support the safe use of pain controlling medicines.
 - Children's pain management should be demonstrated by regular audit.
 - Trusts should support and co-ordinate activities and resources to ensure that children's pain is recognised and addressed.

Surgery

- 4.34 Every hospital trust that receives children must have a policy for securing both emergency and non-emergency surgical services for children. This applies to all areas of surgery – including general surgery, orthopaedics, ear, nose and throat surgery, plastics, burns, and neurosurgery – and can be delivered in several different ways. It is equally vital for every acute hospital to secure and maintain a rota that includes emergency skills for resuscitation of very sick children, covering children's services, A&E and elsewhere. Over time, all surgeons operating on children should also have basic training in resuscitation and life support, and emergency care in their designated branch of service.
- 4.35 It is desirable that all surgeons and anaesthetists expected to provide care to children should undergo child-specific training, education (including communication skills) and assessment as required by the relevant Specialist Advisory Committee. They should, in addition, undertake continuing professional development in the care of children.

- 4.36 Children who have had surgery and have to stay in hospital overnight need nursing, anaesthetic and medical aftercare provided by appropriately trained staff. These are most likely to be found on a site with in-patient general paediatrics. For single specialty hospitals, in the short term, special arrangements will be needed for the provision of paediatric cover. New split-site arrangements should be avoided. Where these already exist, and where feasible, they should be phased out in time.
- 4.37 As the *Day Surgery: Operational Guide (51)* points out, day surgery is ideal for children, since overnight admission is often the most distressing part of visiting hospital for them. Day case surgery can be carried out to a safe standard on a site where there is no paediatric service, but only if staff are able to deliver paediatric life support, and if a neighbouring children's service takes formal responsibility for the children being managed there (see *Children's Surgery – A First Class Service (50)*). Registered children's nurses should be available to care for children in day surgery. Play specialists should be available and the environment should be child-friendly. Day surgery units must develop and implement a pain control policy that includes advice about pain management at home, and the provision of 'take home' analgesia where appropriate.
- 4.38 Dedicated operating lists for children are the ideal, but in many specialties this is not practical or feasible. In these circumstances, children should be put to the start of the list with appropriately trained staff in the reception, anaesthetic room, theatre and recovery areas. Policies and protocols specific to the needs of children are required on issues such as preoperative starving.
- 4.39 Children who need surgery also need a range of supporting services outside the theatres. They need paediatric nursing, radiology, pathology, physiotherapy, occupational therapy, dieticians and pharmacists, and the necessary paediatric equipment. They also need staff to have a full understanding of what it means to be cared for in an appropriate child- and family-friendly environment. In outpatient clinics where children are seen side-by-side with adults, there needs to be some geographical separation, for example, through partitioning waiting areas.

Tertiary services

- 4.40 Children's services should have robust arrangements for timely access to tertiary care when needed, both for emergency transfers to a specialised (regional) centre, for instance, for paediatric intensive care or surgery, and for planned referrals, for example, to cardiology, neurology, or renal care, for assessment. These arrangements need to cover:
- Conditions that are so serious or rare that diagnosis and all treatment will be considered specialised. These have been listed and defined for Regional Specialised Commissioning (52).
 - Severe or intractable cases of otherwise common conditions.
 - Relatively straightforward procedures, but in children with other serious underlying problems, or those that need repeating because they were not effective when first performed.
 - Simple procedures, but in neonates and very young patients who need specialised support services, such as anaesthetics, or neonatal intensive care.
- 4.41 Many children have complex disorders that cross specialty boundaries. They need access to a whole range of services, such as genetics, audiology, ophthalmology; specialist nurses, physiotherapists, speech and language therapists, imaging, dietetics, and pharmacy services; specialist laboratory services; radiologists and pathologists familiar with paediatric disorders and procedures; mental health liaison services; and social workers. These staff need to collaborate closely to ensure that children and their families are receiving consistent and co-ordinated support, and the NHS locally will need to design services to achieve this.

- 4.42 Ideally, children should only need to visit the tertiary centre for complex assessment and investigations or specialised treatment. Otherwise tertiary care can be delivered locally through outreach services operating within a clinical network, provided that the network itself is adequately commissioned, funded and staffed, and that there are clear systems for information sharing, clinical governance, accountability and staff development. This requires tertiary centres, working with local services, and with the support of commissioners, actively to remodel the way their services are provided across the care pathway. The recommendations of the *Paediatric and Congenital Cardiac Services Review (53)* (published for consultation in November 2002); www.doh.gov.uk/childcardiac are based on the same strong principles of collaboration and outreach. They aim to achieve a clear and logical network of services, with the child and family at the centre.
- 4.43 Each tertiary service will need to work together with a lead local clinician on behalf of local children's services and primary care to set up referral protocols and arrangements for local service provision. The ideal specialised service:
- Diagnoses and manages unusual problems, delivers unusual or complex treatments, and where these are new or experimental, does so in the context of a clinical trial.
 - Has sufficient staff to provide safe, round-the-clock cover for acutely ill children, and at the same time undertake a range of outreach services, including peripheral clinics, nursing support services, telephone support lines, teaching programmes and exchanges for staff.
 - Provides supportive nursing, therapy, and help in the community to meet physical, mental health and social care needs – at home and at school. Most aspects of care for even the most complex disorders can be carried out away from hospital and only occasionally does the child need repeat visits or admission to the specialised centre.
 - Admits as inpatients only those children for whom local hospital admission is not a safe or acceptable option, for instance, because surgical intervention might be needed urgently, or complex treatments, investigations or specialised nursing care are required.
 - Keeps duration of admission to a safe minimum.
 - Involves local medical, nursing, therapy, mental health and other staff, such as social workers. Establishes clinical networks, including named network leads and lead clinicians, agrees evidence-based referral guidelines, treatment and shared care protocols, and develops records of shared care and information sharing protocols, recognising the requirements of Caldicott (54) and the Data Protection Act (55).
 - Has reliable arrangements for paediatric intensive care retrieval and other emergency transfers.
 - Provides a liaison service both for families and for local clinicians, including support to enable the child to be treated locally for minor illnesses or an injury.
 - Audits quality and outcomes of the care provided across the local and specialised service, and gives parents confidence in the whole package of care.
 - Plans transition into adult care for long term conditions.
 - Develops and maintains close links with relevant patient and parent organisations and ensures that families know how to contact them.

Care of critically ill children

- 4.44 Children may require admission to critical care facilities as a planned part of their care, for example, after surgery; as a result of trauma or an acute illness; or due to extreme prematurity or illness at birth. For the family, this is a very distressing time and one during which they require support, information and frequent updates from the clinicians involved in care.
- 4.45 Contingency arrangements for the care of critically ill children should be in place in any hospital caring for children, recognising that at times this need will arise suddenly and unpredictably. These arrangements should include 24 hour availability of clinical staff with the appropriate competency in advanced paediatric life support, who have access to the range of facilities, equipment and medications required.

Paediatric intensive care (PIC) and high dependency care

- 4.46 All hospitals that admit children as in-patients should be able to carry out emergency treatment and stabilisation for any critically ill child. They should be able to offer high dependency care for children, and be able to establish intensive care and stabilise a child prior to their transfer.
- 4.47 The majority of high dependency care is provided for children on children's wards or in high dependency units, and most do not need to be transferred to a Paediatric Intensive Care Unit (PICU). However, more complex or severe disorders will require care in a PICU. It will be necessary to ensure sufficient capacity for high dependency care. This will prevent unnecessary referrals to PICUs for children who do not require intensive care. It will also ensure that children who have recovered from the critical stage of illness do not occupy PIC beds unnecessarily and can be stepped down to a hospital nearer their home.
- 4.48 Within any defined geographical area, there needs to be a system of care for critically ill children, involving A&E departments, the ambulance service, and the paediatric intensive care service, which should be delivered in facilities best able to meet the needs of the critically ill child. *Paediatric Intensive Care: A Framework for the Future (39)* sets out how all hospitals should be part of such a unified PIC service, with a lead PICU supporting local services, and the range of tertiary specialty services. Particular attention needs to be paid to PIC support for tertiary or regional centres, including those providing burns, cardiac and neurosurgery services. Children who need tertiary care are likely to need very rapid access to the lead PICU. Co-location is the solution most likely to guarantee this.
- 4.49 The PIC service will provide a retrieval service supporting a network of hospitals, each of which will need to ensure provision of high dependency care for children and be able to initiate level 2 intensive care and stabilise whilst awaiting retrieval. PICUs are all supported by a national Department of Health audit network (PICANET) which has been in operation since November 2002. Detailed recommendations for provision of intensive and high dependency care can be found in *Paediatric Intensive Care: A Framework for the Future (39)* and *High Dependency Care for Children (40)*. The model described in these documents has recently been reviewed and found to be effective in improving care and managing peaks in demand for critical care.
- 4.50 Following the government's spending review (2002), £25m has been allocated recurrently, to help PIC services plan and invest for the longer term. It is expected that this increased funding will be used to consolidate the improvements of the last five years, including investment in high dependency care in district general hospitals, as appropriate in local networks.

Neonatal intensive care

4.51 Much neonatal care is provided in district general hospitals as well as in regional units. Advice on the ways in which this can best be arranged is given in the Department of Health Review of Neonatal Intensive Care (56), which is being published alongside this document. This review suggests standards for the different levels of care that babies might need, recommends where that care might best be delivered, how services can be developed, and the sort of support and information that parents are likely to need. It proposes:

- Establishing networks of care that would provide access for all families to appropriate and high quality care.
- Defining clearly the type of care that babies might require – special care, high dependency and intensive care.
- The designation of units to provide these levels of care e.g. some units would only provide special care, most would provide high dependency and limited intensive care and some, the full range of intensive care.
- Establishing staffing levels with new ways of working.
- Recommending increase in cot capacity in the units providing intensive care and strengthening the role of SCBU [Special Care Baby Units] to provide high quality special care for babies.¹²

To help neonatal intensive care services to implement the recommendations of the review, £20m will be made available for capital expenditure, and additional funding for running costs of £12m in 2003/04, £19.86m in 2004/05 and £20m in 2005/06.

Disabled children

4.52 Disabled children have the same right to high quality services as any other child, though evidence suggests many are excluded from mainstream services. Disabled children with complex health needs are prone to additional complications, such as chest infections, that require treatment in hospital. They may need investigations or procedures, such as orthopaedic or eye operations. As more disabled children with complex needs survive for longer, they make up an increasing part of the work of children's hospital services. Hospitals need to recognise and meet the very particular needs of this group of patients and involve them and their parents in the planning of services.¹³

4.53 Parents indicate some recurring themes: staff do not know the child, so they insist on taking the child's details again; parents get fed up with having to tell the same painful story over and over again. The solution to this is a good summary in the notes, with a copy held by the parents, so that staff can concentrate on the acute episode that has brought the child into hospital.

4.54 Disabled children, young people and their parents need to know that staff understand how to support them and have a sound knowledge of the needs of disabled children. Where necessary, this includes how to communicate, support with eating and drinking, the use of specialised aids and equipment, and the delicacy required in dealing with ethical issues, such as consent to intensive therapy. Staff need competencies in supporting children with a range of disabilities, including those with learning disabilities or autistic spectrum disorder. There should be procedures for managing challenging behaviour. Suitable equipment should be available, for example a supply of hoists, seating,

12 *Neonatal Intensive Care Review – Strategy for Improvement*, (2003), p.4.

13 *Hospital Accommodation for Children and Young People: Health Building note 23*. NHS Estates, Paragraphs 2.13 – 2.15.

communication aids and incontinence protection. Hospital therapists, liaising directly with their colleagues in the community, play a vital role in supporting parents, and explaining the child's needs and the equipment they require.

- 4.55 There should be a multi-agency plan, developed and agreed with the disabled young person and their parents, and updated as needed. Following assessment (*Framework for the Assessment of Children in Need and their Families (20)*), this could be used when a child is admitted or discharged from hospital to ensure that all those involved with the child and family are informed. It should say who does what – GP, hospital, social services, therapy services, school, and respite setting. For disabled children with complex health needs, this should be expanded into a personal held record with a clinical summary of what they require, for example, therapies and equipment, support with eating and drinking, going to the toilet or communicating.
- 4.56 There are also problems related to prescribing. Parents particularly resent the removal of the child's own regular drugs and their re-dispensing from pharmacy. The parents are usually also expert in how best to give the drugs, and this is not always respected. Finally, at the time of discharge, there is often much waiting around to get the next supply of drugs. All of these things should be streamlined, with practices that reuse patient's own medicines, and offer 'one-stop' dispensing.
- 4.57 Discharge of disabled children and those with long term problems is important. After reassessment of need, the multi-agency plan and personal held record will need to be updated and information prepared for the school in a form agreed with the parents. Lessons learnt from previous discharges should be incorporated into the plan. This will be covered in more detail in the full NSF.

Growing up and moving on to adult services

- 4.58 Services for young people should be given greater focus and priority (6 & 57). The transfer of young people from child to adult services requires special attention. Evidence shows that this is generally poorly handled. Transition to adulthood and adult services, including integration with social care, education, and employment, will be covered in the full NSF. The focus here is solely on transfer within hospital services.
- 4.59 For young people with uncommon conditions, where recent medical advances are only now resulting in significant numbers of survivors to adulthood, for example, congenital heart disease and rare metabolic diseases, the main problem tends to be a lack of adult service. This is because there is little knowledge of these conditions and their treatments in adulthood, and very few clinicians have acquired the necessary expertise. The result is that the young person stays with the children's service, continues to be treated like a child, and the service fails to adapt sufficiently to recognise that he or she is maturing into an adult.
- 4.60 Young people with long term conditions that are common in adulthood, but less so in childhood, for example, diabetes or arthritis, may have a different problem. For them, the move to adult services means a shift from being 'special', in the sheltered atmosphere of a small children's service; into an environment with many older patients, that offers less social support, and where clinicians may have less time, where clinical practice may be focussed on the older end of the age range, and where the family may be excluded. Moreover, staff in adult clinics may have little interest and few skills in dealing with 'difficult' adolescents.
- 4.61 If transfer to adult services is handled badly, there is a risk that the young person will 'drop out' from medical services altogether. There is some evidence that properly planned transition programmes result in better disease control and improved patient satisfaction.

4.62 Every paediatric general and specialty clinic should have a policy on transition to adult services which should be the responsibility of a named person, covering:

- **A policy on timing of transfer.** Although it may be useful to set a target age, there is no ‘right’ time for transition. A flexible approach is called for that takes developmental readiness into account, and links to other social transitions such as leaving school.
- **A preparation period and education programme.** During this time the young person will be helped to identify and develop the skills needed to achieve satisfactory transition to the adult clinic. A timed schedule for transition should be produced and written information provided.
- **A co-ordinated transfer process.** A named co-ordinator should be identified, who will be responsible for arranging a personal introduction and a visit to adult services. This may include co-ordination across health, social care, further education and employment.
- **An interested and capable adult clinical service,** which has close links with the children’s service, an understanding of the developmental needs of young adults, and participates actively in the transition. Individual specialist disciplines such as diabetes, epilepsy, rheumatic disease, and congenital heart disease, should provide specifically for the needs of young people, and, where numbers justify, develop a separate young people’s service. They should also ensure that social, psychological, education and employment needs are addressed.
- **Administrative support,** to ensure smooth transfer of medical, social care and other relevant records, provision of summaries, including a handheld summary for the patient’s own use, and efficiently organised appointments.
- **Primary health care and social care involvement,** for continuity and to meet broader health and social care needs.

Quality and safety of care provided – key points for early consideration:

The hospital's clinical governance arrangements will need to reflect the additional arrangements required to meet the explicit needs in all areas of the hospital where children and young people are treated. A board level children's lead should be appointed within every trust to oversee these arrangements. The trust board should consider regularly the hospital's performance in relation to child protection and ensure close liaison with the ACPC. The named doctor and nurse should have the training, time and support to carry out this role which should be reflected in their job plan.

Hospital policies in a number of areas, such as infection control, health and safety, medicines and the use of equipment, should be reviewed or put in place to ensure that they reflect the particular concerns involved in caring for children. Hospitals will wish to consider the arrangements for disabled children and young people, for those with mental health problems where improved liaison may be needed, and for those requiring in-patient elective and emergency surgery. Every trust dealing with young people should have a policy on transition to adult services.

In line with Improvement, Expansion and Reform, all appropriate units should participate in national comparative clinical audits for paediatric cardiac surgery, which applies to surgical and transcatheter treatment of congenital heart disease.¹⁴

Hospitals will need to look at the clinical network arrangements for all paediatric services, starting with neonatal intensive care as funding comes onstream, and the funded, proposed improvements to paediatric intensive care. Mechanisms will be needed to plan, support and sustain tertiary services for children with specialised conditions.

Workforce development and training

Hospitals will need to assess the needs of their staff for child-specific education and training in:

- Child development, parents as partners in care, resuscitation, use of medicines, child protection, news breaking, pain management and care of parents after the death of their child.
- The technical skills and competencies required to provide treatment and care for children.
- Assessing and meeting the needs of disabled children in hospital.
- Operating on, and anaesthetising children.
- Robust infection control for children.
- Awareness of promoting children's mental health in paediatric settings and of managing acute mental health crises.

Chapter 5: Hospital Standard Part Three

Quality of Setting and Environment

Standard

Care will be provided in an appropriate location and in an environment that is safe and well-suited to the age and stage of development of the child or young person.

Interventions

Child-friendly and safe environment

- 5.1 Hospital care of children and young people should be provided in buildings that are accessible, safe, suitable, and baby, child and family-friendly. *Improving the Patient Experience – Friendly healthcare environments for children and young people* (58), published alongside this document, should be used to guide all future new build or refurbishment of facilities for the care of children in hospital. This NHS Estates (NHSE) document identifies the core principles of providing a friendly environment for any young people who access healthcare facilities. Reference should also be made to the forthcoming NHSE Health Building Note (2003) (59) which complements the hospital standard. Outpatient, A&E and day care facilities need to be accessible for all children, with facilities for wheelchairs and buggies, accessible car parking, clear sign posting, and low reception counters.
- 5.2 Facilities should also cater for parents and siblings, with suitable provision for overnight stay. These must include access to meals and relaxation, and must respect parents' privacy.
- 5.3 The environment should be secure, and paediatric departments should regularly review the security of the wards to ensure that access is limited to those who need it. Any breach of security should be investigated, and procedures should be in place covering the involvement of the police.¹⁵
- 5.4 Children should not be cared for on adult wards, but on wards that are appropriate for their age and stage of development. Actual age is less important than the needs and preferences of the individual child or young person. In particular, the needs of adolescents require careful consideration. In general, adolescents prefer to be located alongside other people of their age who are more likely to meet their need for social interaction and this makes it easier for staff to meet their needs for different forms of entertainment, education and additional privacy. The care of young people should be reviewed in the particular circumstances of each hospital, to make sure that their separate needs, including for safeguarding, are recognised and met. Separate adolescent units may be the best solution, but this will not always be the case, and many hospitals will address their needs quite adequately by grouping them together in separate bays in the paediatric ward. Sensibly flexible approaches should be adopted in certain cases. For example, on rare occasions the care of a profoundly disabled young person or one with a terminal illness may be better provided on a children's ward even though the patient is over the usual age limit. Wherever facilities allow choice, the views of the child or young person about where they would prefer to stay in the hospital should be taken into account and respected. Hospitals should stratify

¹⁵ *Hospital Accommodation for Children and Young People: Health Building note 23*. NHS Estates, Paragraphs 2.85 – 2.88.

admissions data by age in order to monitor which wards children and young people are being admitted to, and to ensure that these are appropriate.¹⁶

- 5.5 In A&E departments, surgery recovery areas, and outpatient clinics, there should be physical separation between children and adult patients, so that children are not exposed to potentially frightening behaviour; and equally, so that adults feeling ill are not disturbed by noisy children.
- 5.6 Children and young people staying in hospital should be provided with a range of equipment appropriate to their age, including a bedside TV with headphones, telephone, and radio, provided free of charge, wherever possible (*The NHS Plan (3)*). Facilities should also be available for more active play, if the child wishes, and their condition allows.
- 5.7 All departments that provide a service to children and young people, including A&E departments, all imaging facilities, outpatient clinics, and other day care facilities, should ensure that there are appropriately equipped, baby and child-friendly treatment or imaging rooms; and that waiting areas have suitable play and recreational equipment. Mothers will need facilities to enable them to breastfeed in hospital departments, as well as access to baby-changing facilities. The environment should be suitable and spacious enough to accommodate the equipment required to meet the needs of a disabled child. Disabled children should be able to access play and recreation facilities with toys and equipment suitable to their age and individual needs.

Hospitals as healthy settings

- 5.8 Hospitals should in themselves be healthy settings that present a consistent approach to health promotion and protection through their policies and day-to-day routine. A stay in, or visit to, hospital should not in itself jeopardise the health of a child or young person further. Moreover, hospital may be a good environment in which to introduce health promotion messages. A&E departments have a particular role to play in injury prevention, which includes collecting good quality information about injury attendances to inform local prevention programmes.
- 5.9 Good eating habits can be encouraged by the hospital menu, and by the availability of healthy snacks, including good quality fresh fruit and drinks, including water which is fresh and, wherever possible, chilled. This should extend to healthy food options for visitors, and policies on vending machine provision. However, the objective must also be to ensure that children eat sufficient food to meet their nutritional requirements as soon as possible after admission, and particularly following surgery or during treatment, when they are most vulnerable. The nutritional value of food not eaten is nil. The importance of this cannot be overstated. Children need to be tempted to eat. This means they should be able to decide what they want to eat; unfamiliar or 'strange' foods should be avoided; and effort needs to be put into presentation. The menu should also offer choices that are appropriate to the different cultural needs of children and their families and respect their traditions. Standards for hospital food have been set out in *Better Hospital Food Programme: Services for Children and Young Adults (60)*.
- 5.10 Increasing breast feeding rates will be a core priority for the full NSF, and is an important target area in *Improvement, Expansion and Reform (9)*.¹⁷ Hospitals should take every opportunity to encourage and facilitate breast feeding (Baby-friendly hospitals initiative (61)).
- 5.11 Hospital departments where children and young people are treated should provide access to up-to-date health promotion material in an accessible form, covering smoking, alcohol and substance misuse, diet and nutrition, and sexual health. This should be regularly checked to ensure that it is meeting the needs

16 *Hospital Accommodation for Children and Young People: Health Building note 23*. NHS Estates, Paragraphs 2.73 – 2.75.

17 *Improvement, Expansion and Reform*, p.20

of the children, young people and families using the hospital. It should be clear who to contact to answer any questions that may arise.

- 5.12 Protecting children from other people's tobacco smoke, preventing them from taking up smoking themselves, and helping young people who are smokers to give up will also be NSF priorities. Hospital smoking policies need to reflect these concerns, and effective links should exist with smoking cessation services that specifically cover the needs of young people and pregnant women.

Quality of setting and environment – key points for early consideration:

Hospitals should consider the guidance, *Improving the patient experience – Friendly healthcare environments for children and young people* (NHS Estates 2003 (58)) when planning and designing new facilities or refurbishments where children are to be treated, and the forthcoming Health Building note. Hospitals should work towards meeting the standards set out in the *Better Hospital Food Programme: Services for Children and Young Adults Report (60)*, using patient surveys and the Best Practice Audit Tool to monitor progress.

Draft Standard on Child Protection

Aim/area to be covered by Standard

Children have a right to be protected, and adults a responsibility to protect them from harm. Children who have been neglected or abused, other children in the household and their carers should be assessed and services and support provided to meet identified needs.

In every area there will be systems and services in place which will aim to promote children's wellbeing and prevent them from suffering harm, safeguard children who are being harmed, and facilitate their full recovery.

Action

- Over half of the recommendations in Lord Laming's report relate to improving basic good professional practice in police, health and local government services. A checklist of these recommendations has been issued and chief executives asked to ensure that this basic good practice is in place.

Other suggested actions

- In every area there is a preventative strategy with the aim of raising awareness of how to safeguard children among agencies, staff and the wider community and ensure they know what to do if they have concerns about a child's welfare.
- In each area, agencies work collaboratively to develop and implement relevant child protection policies, procedures and protocols.
- Staff having contact or working with children are recruited and managed in a manner that safeguards children (police checks and whistle blowing).
- All staff (including managers and support staff) working with children, or their parents and carers, receive adequate training on child protection issues in order to safeguard children.
- Children who may be or are suffering significant harm are assessed in terms of their developmental needs, their parents' capacity to respond to those needs appropriately and wider family and environmental factors. Such assessments incorporate the wishes and feelings of the children.
- Based on this assessment, relevant services are provided to address the child's identified needs, including ensuring that they are safeguarded from further harm, and provided with services that promote their development and enable them to recover from abuse or neglect and promote their developmental progress.

- Based on the above assessment, services are provided to other children of the household, parents, carers and wider family members, including those with responsibility for the abuse or neglect, in order to help them ensure that the vulnerable children are safe and their developmental progress is being maximised.
- All agencies contribute to Serious Case Reviews and ensure that action plans are drawn up and implemented.

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Glossary

Action On

The *Action On* programmes are part of the government's modernisation agenda. They consist of a number of projects originally set up under the auspices of the National Patients' Access Team (NPAT) which aim to generate real improvements in access to services.

The *Action On* programmes are all about finding better ways of working to improve frontline services for patients, making the service more convenient and faster.

Advanced Paediatric Life Support (APLS)

See Paediatric Advanced Life Support.

Analgesia

The relief of pain, without loss of consciousness, through the use of an analgesic agent into the spinal canal.

Area Child Protection Committees (ACPC)

Multi-agency committees responsible for developing, monitoring and reviewing child protection policies, procedures and practice throughout England and Wales.

Attention deficit hyperactivity disorder

A condition where there is increased motor activity in association with poor attention span.

Audiology

The study of hearing.

Autistic Spectrum Disorder

Autistic Spectrum Disorder is a lifelong developmental disability that affects the way a person communicates and relates to other people. Those affected have a triad of impairments:

- In social interaction (e.g. appearing aloof and indifferent to others);
- In social communication (e.g. difficulty understanding the meaning of gestures, facial expressions or tone of voice); and
- In imagination (e.g. impaired ability in the development of play).

BLISS

The Premature Baby Charity.

Care Pathway

An agreed and explicit route an individual takes through health and/or social care services. Agreements between the various professionals involved will typically cover the type of care and treatment, in which professionals will be involved and their level of skills, and where treatment or care will take place.

Clinical audit

Clinical audit is the regular systematic review of healthcare procedures against defined standards. These audits are overseen by CHI (definition above).

Clinical Governance/Framework/Support Team/Plan

A framework through which NHS organisations are accountable for continuously improving the quality of their services and safeguarding high standards of care by creating an environment in which excellence in clinical care will improve.

Commission for Health Audit and Inspection (CHAI)

See CHI below.

Commission for Health Improvement (CHI)

The Commission for Health Improvement is an independent body covering England and Wales established to provide independent scrutiny of local efforts to assure and improve quality in the NHS, help tackle local service problems and help to monitor the NHS's efforts to address inappropriate variations in service standards.

A Health and Social Care Bill, currently being discussed in Parliament will make provisions for establishing CHAI, which will incorporate the health value for money work of the Audit Commission, the work of the Commission for Health Improvement and the private healthcare role of the National Care Standards Commission.

Commission for Social Care Inspection (CSCI)

Legislation is being put in place for the creation of a new Department of Health body, the Commission for Social Care Inspection. This body incorporates the roles of the Social Services Inspectorate, the social care functions of the National Care Standards Commission, and the functions of the Audit Commission Joint Review team. It will be fully operational from April 2004.

Contact a Family

A national charity for families who care for children with any disability or special need.

Cystic fibrosis

A genetic disease that affects almost all the mucus-producing glands of the body. The effect is that the lungs, pancreas (an internal organ which controls blood sugar and produces enzymes to break down food), intestines and other organs tend to get clogged up with thick, sticky mucus.

Dermatology

The study and treatment of skin disorders.

Dietetics

The study and regulation of diet.

ENT

Ear, nose and throat.

Genetics

The study, investigation and treatment of patterns of inherited traits.

HiB

A vaccination given to infants to protect against haemophilus influenza b, which causes meningitis.

Imaging

To look at parts of the body using, for example, X-rays (radiography), magnetic resonance (MRI scans) or ultrasound (US Scans).

IM&T

Information, management and technology.

Intensive care

Critically ill children need different levels of care, depending on the nature and severity of their illness. Three levels of care, in ascending order of intensity, have been defined:

Level 1 high dependency care – for children needing close monitoring and observation, but not requiring the assistance of a life-support machine. This is usually undertaken by paediatric services operating from the local district general hospital. It may also be provided as a ‘step down’ facility for a child in a PIC unit who is recovering.

Level 2 intensive care – for children requiring continuous nursing supervision while incubated (usually to assist breathing/ventilation). Two or more organ systems may also need support.

Level 3 intensive care – for children needing intensive supervision at all times, and requiring complex nursing and therapeutic procedures. This category would include ventilated patients who are undergoing kidney dialysis, and patients with multiple organ failure.

MMR

A combined vaccine for measles, mumps and rubella.

Modernisation Agency

The NHS Modernisation Agency is a Department of Health body, which develops policy on health care improvement and leadership development within the NHS. It supports NHS clinicians and managers to deliver improvements to their services.

National Institute for Clinical Excellence (NICE)

The National Institute for Clinical Excellence is a Special Health Authority, which promotes clinical excellence and the effective use of available resources in the health service.

National Patient Safety Agency (NPSA)

The National Patient Safety Agency is a special health authority, which improves the safety and quality of care through reporting, analysing and learning from adverse incidents and ‘near misses’ involving NHS patients.

NHS Estates

NHS Estates is an executive agency of the Department of Health. The Agency issues information and guidance on estates and facilities management to Ministers, the Department of Health and the NHS.

Occupational therapy

A form of therapy that instructs on activities for therapeutic or remedial purposes in mental and physical disorders.

Ophthalmology

An area of medicine dealing with the eye.

Orthopaedics

An area of medicine concerned with the preservation, restoration, and development of form and function of the muscles and skeleton.

Overview and Scrutiny Committee

As part of the new governance arrangements put in place by the Local Government Act 2000, local councils are required to establish Overview and Scrutiny Committees (OSCs) of elected members to scrutinise services intended to promote the wellbeing of local people.

Paediatric Advanced Life Support (PALS)

PALS and APLS are structured courses in paediatric resuscitation designed to teach and rehearse skills in a practical way, so that in an emergency everyone works to an agreed protocol, as a team, and with the practical skills to do what is needed.

Pathology

The study of the disease process.

Patient Advisory and Liaison Service

The Patient Advisory and Liaison Service is available in every NHS Trust in England. The service provides help, advice and information on a treatment or service a person is receiving and can assist with any complaint.

Pharmacy

A place where medicines are stored, prepared and dispensed.

Phlebotomy

Puncturing a vein to withdraw blood.

Physiotherapy

A use of exercise and physical activities to condition muscles and improve level of activity.

Planning and Priorities Framework (full title *Improvement, Expansion and Reform: the Next 3 Years, Priorities and Planning Framework 2003 – 2006*).

The document, produced by the Department of Health, sets out what health and social services will need to achieve in key delivery areas, and introduces a new system of three year planning and allocations. The change, from an annual planning round will provide a more stable basis for the NHS and social services to deliver locally on nine key national priorities: waiting, booking and choice; emergency care; cancer; coronary heart disease; mental health; older people; life chances for vulnerable children; patient experience and public accountability; and tackling health inequalities.

The framework also identifies three underpinning strategies for the NHS: increasing physical capacity; expanding the workforce; and improving information management and technology.

Primary Care Trust (PCT)

There are 303 PCTs in England, which are given funding from the Department of Health to plan and commission health services for their local communities – a role previously carried out by health authorities.

Procurement and Supplies Agency (PASA)

PASA is a Department of Health agency, which acts as a strategic advisor to the NHS on supply issues.

Radiography

The making of film records of internal structures of the body by passage of X-rays or gamma rays through the body to act on specially sensitised film.

Rehabilitation

A programme of therapy designed to restore independence and reduce disability.

Rheumatology

An area of medicine concerned with the diagnosis and treatment of arthritis.

SANDS

Stillbirth and Neonatal Death Society. A national charity.

Sickle cell

An abnormality in the blood haemoglobin. If the oxygen content in the haemoglobin is low, it causes a change in the shape of the red blood cells. Haemoglobin is a special protein in red blood cells that carries oxygen around the bloodstream.

Significant Event Auditing

Significant Event Auditing is a structured assessment of clinical or organisational events in a primary care setting.

Social Care Institute for Excellence (SCIE)

SCIE is an independent organisation created to drive improvement of quality in social care services across England and Wales.

Social Services Inspectorate (SSI)

The SSI Inspection Division undertakes a programme of national (England) inspections in order to: evaluate the quality of social services provision; improve the efficiency and effectiveness of social services delivery; and provide information to influence social care and health policy development.

Specialist Advisory Committee

A Specialist Advisory Committee is a committee set up by a Royal College to oversee training standards in a particular subject or speciality. It defines areas such as, length of training, assessment methods and acceptable training posts.

Strategic Health Authorities

Strategic Health Authorities are responsible for developing strategies for the local health services and ensuring high-quality performance. They manage the NHS locally and are a key link between the Department of Health and the NHS.

Tertiary (care)

Specialised health services. For example, using the family doctor or NHS Direct is sometimes called primary care, because these services can be accessed directly and are usually the first point of contact with health services. Local children's specialist services are sometimes called secondary care, because usually they cannot be accessed without a referral, for example from the GP. Tertiary, specialised services, often at a more distant hospital or major regional centre, require a referral from primary or secondary care.

Thalassaemia

A genetic form of anaemia in which there is an abnormality of the globin portion of haemoglobin (an oxygen carrying protein in the blood).

Trust

Hospital trusts are found in most large towns and cities, and usually offer a general range of services to meet most people's needs. Some trusts also act as regional or national centres of expertise for more specialised care, such as acute illness, while some are attached to universities and help to train health professionals.

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