

BRISTOL ROYAL INFIRMARY INQUIRY

Children's Services in the NHS

Background Paper

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EXECUTIVE SUMMARY

The purpose of this paper is to use the professional, policy and research literature to provide a general overview of how children's services¹ have been conceived, planned for and provided within the NHS, with particular reference to the period from 1984-1995. The primary focus of the paper is on children's care in hospital rather than in the community or at the interface with social care. The paper does not address issues relating to the involvement of children in research.

Section 1 identifies the characteristics of children that distinguish them as a group from adults and gives an overview of how recognition of these differences has influenced the development of policy and the provision of services for children over the past 40 years in the UK.

Para 1.1 begins with some brief statistics on the number of children in the UK and the use they make of hospital services. Attention is drawn to a number of key respects in which children differ from adults and to the implications of these differences for children's health care needs. In the past ten years, the status of children as individuals with their own rights has been formally acknowledged at both national and international levels and a number of children's rights have been identified, as have some key principles for the provision of all services for children. These are outlined.

Para 1.2 outlines the key milestones in the development of government policy on children's services in the NHS up to 1995, including the recommendations of the 1959 Platt Report², the 1976 Court Report³, the 1991 Department of Health report¹ on the welfare of children and young people in hospital and the 1993 Audit Commission study on the same subject.⁴ The development of professional paediatric specialties over the same period is also briefly discussed, and attention is drawn to the important role played by voluntary organisations in promoting attention to children's health care needs.

The next three sections look in more detail at the development of policy and practice in relation to three key aspects of children's services: the principles and values underpinning the philosophy of family-centred care; the requirement for and provision of specialist paediatric staff; and the organisation and commissioning of services for this population group.

Section 2 looks at the specific philosophy of care for children's services which emphasises the need for family-centred care.

Para 2.1 looks at what is meant by family-centred care and identifies some of the uncertainties associated with its interpretation in practice. These include uncertainty

¹ Children's services traditionally care for children up to the age of 16. Adolescent services normally care for children and young people from 11 to 18 years. The Department of Health suggests that flexibility is required in defining childhood and that children have distinctive health needs until school leaving age (up to age 19).¹

about: who counts as "family"; the nature and the extent of family members' role in caring for their child in hospital; and the extent of the professional staff's responsibilities to care for family members.

Para 2.2 outlines the main government recommendations on family-centred care. These include recommendations to assist families to support and comfort their child, help with their child's care, and themselves cope with the implications of life-threatening illness. The recommendations on provision of opportunities for play and education are also outlined. Attention is drawn to the need for particular arrangements for adolescents.

Para 2.3 summarises the evidence available about the implementation of family-centred care in practice. The evidence is that this is not always successfully achieved. Problems are identified with the absence of clear operational policies for family-centred care, inadequate or ineffective communication between staff and parents, lack of recognition of the resource and other implications of such a model for ward staff, and failure to provide appropriate accommodation and facilities for families.

Section 3 outlines the main issues with regard to staffing of children's services.

Para 3.1 looks briefly at the skills required of staff who provide health care for children and outlines guidance from the government and professional organisations on the training and provision of medical and nursing staff in children's hospital services in general and in relation to specific services such as surgery, anaesthetics and intensive care. Some findings concerning the extent to which the proposed standards are being met in practice are described, but there appears to be relatively limited data available on this issue.

Section 4 looks at issues relating to the organisation, location and commissioning of children's services.

Para 4.1 highlights the basic principles for the organisation of children's hospital services i.e. that they should be grouped together in a comprehensive unit and separately provided from those for adults. Government guidance and professional recommendations in respect of specific areas of provision (A&E, outpatients, day patients, intensive care and tertiary services) are then outlined, along with a summary of evidence available about actual practice.

Para 4.2 discusses the need for a clear and comprehensive strategy for purchasing children's services and draws attention to the lack of central guidance on commissioning children's services. It summarises evidence showing that children's health services in the mid 1990s were not being given priority by commissioners. There were few examples of purchasing strategies which would allow the provision or maintenance of a child-centred service across all provider sectors.

Section 5 summarises the main reasons that have been identified for the continuing problems in providing children's services which reflect the generally

agreed standards and principles.

1. CHILDREN AND THEIR SERVICE NEEDS

This section:

- * explores the distinctiveness of childhood as a life phase and children as a population group with needs and characteristics that differentiate them from adults
- * summarises briefly how developing recognition of children's particular needs has influenced health service policy over the past four decades

1.1 Defining childhood

- i. In 1994 there were 10 million children aged under 16 in England, accounting for 21.5% of the total population.⁵ In 1993-4 around 12% of Hospital and Community Health Services expenditure related to patients under 16 (excluding births).⁶ Hospital services are utilised extensively by children. Each year, one in four children will attend an A&E department, one in 16 will be admitted under the care of a paediatrician and approximately the same proportion is admitted for surgical care.⁷

1.1.1 *Children's needs*

- i. Children differ from adults in many ways including their physical, psychological, intellectual and emotional development and their social and legal status. Children may also be distinguished from adults in their physiology, the physical signs of illness, course of disease, indications for and impact of treatment.
- ii. The 1993 Audit Commission report⁴ on hospital services for children highlights two key respects in which children's health care needs differ from those of adults:
 - * Childhood is a period of rapid growth and development. Children of different ages have very different medical and surgical needs. Their care requires an approach which takes account of differences in their physical and emotional maturity.
 - * Children are part of a family and are dependent on their parents for physical and emotional care and support. Caring for a child means involving parents and siblings.

1.1.2 *Children's rights*

- i. The status of children as individuals with their own rights was first formally acknowledged internationally by the 1989 United Nations Convention on the Rights of the Child⁸ (which was ratified by the UK in 1991) and in the UK by the 1989 Children Act.⁹

- ii. The UN Convention recognises that children have a right:
 - * to take an active part in society
 - * to services which meet their needs
 - * to express their views and have them taken into consideration
 - * to be protected from harm

- iii. The Children Act set out the following principles to be observed in all services provided for children:
 - * the child has rights
 - * the welfare of the child is paramount and the state and parents have a duty to safeguard and promote their welfare
 - * services are provided in partnership with parents and carers
 - * all staff work with and support families
 - * the views of the child, parents and carers are taken into account

1.2 Development of policy on children's services in the NHS

1.2.1 Government recommendations

- i. The 1959 Platt Report² on the welfare of children in hospital was the first UK government report to acknowledge the special needs of children and their families. It identified six main principles of care for children which included the need for:
 - * child and family centred care,
 - * specially skilled staff
 - * separate facilities
 - * effective treatments
 - * appropriate hospitalisation
 - * strategic commissioning

- ii. Since that time, these principles have become widely accepted as fundamental to the provision of health care for children and continue to be used (for example by the Audit Commission⁴) as a basic template for assessing the quality of children's health services.

- iii. The Court report³ - a major study of child health services as a whole carried out in the early 1970s - recommended the need for a service "which is integrated in as much as it sees the child as a whole and as a continuously developing person".

- iv. The 1991 Department of Health report¹ on the welfare of children and young people in hospital contained the first comprehensive set of recommendations in this area since the Platt Report. It defined a good quality service for children as

being one which: "provides for the child as a whole, for his or her complete physical and emotional wellbeing and not simply for the condition for which treatment or care is required" and "is child and family centred, with children and their families experiencing a 'seamless web' of care, treatment and support, as they move through the constituent parts of the NHS". The 1991 report contained seven "cardinal principles" which were intended to underpin hospital services for children. These can be summarised as follows:

- * children should not be in hospital unless it is absolutely necessary
 - * children requiring admission should receive care of a high standard to facilitate speedy recovery and minimise complications and mortality
 - * hospital facilities for children should be as accessible as other similar amenities in terms of travelling distance for families
 - * children should be discharged as soon as socially and clinically appropriate and full support should be given for aftercare
 - * good child health care is shared with parents/carers
 - * accommodation, facilities and staffing should be appropriate to the needs of children and adolescents and separate from those provided for adults
 - * children have rights for their privacy to be respected, to be treated with tact and understanding, and to information appropriate to their age, understanding and specific circumstances
- v. In 1993, the Audit Commission undertook a major investigation of the care of children in hospitals.⁴ Its purpose was not to re-write the principles outlined above, which were by then well established, but rather to investigate the extent of their implementation in practice. The report looked at each of the Platt Report's principles in turn, identifying barriers to achieving good practice and suggesting how they might be overcome. The Audit Commission's findings and proposals have provided an important basis for subsequent policy development including, most recently, the 1997 recommendations of the Health Committee's inquiry into child health services.¹⁰
- vi. The 1996 Children's Charter¹¹ set out a number of additional standards pertaining to the rights and expectations of sick children and their parents. Those relating specifically to hospital care include rights:
- * to see the children's ward before admission
 - * to have a named qualified children's nurse
 - * for children to wear their own clothes, have some of their own things in hospital, play and meet with other children and have opportunities for appropriate education

1.2.2 *Development of paediatric specialties*

- i. Paediatrics was a late developing area of specialisation, both in medicine and nursing. In medicine, it was the last specialty to obtain a Royal College, with the

creation of the Royal College of Paediatrics and Child Health (RCPCH) in 1996. In nursing, similarly, paediatric nursing was the last branch of nursing to be formally recognised within the Royal College of Nursing (RCN). The first Paediatric Nurse Adviser was appointed by the RCN in 1984. Nevertheless, within these specialty areas there has been considerable activity and development over the past few years. For example, between 1986 and 1995, the RCPCH (previously the British Paediatric Association) produced over 60 documents setting out good-practice guidelines for a wide range of children's services.¹²

1.2.3 *Voluntary agencies*

- i. In addition to the development of government and professional interest in the particular requirements of children's health services, considerable energy has been invested in promoting children's interests by voluntary agencies such as Action for Sick Children (previously the National Association for the Welfare of Children in Hospital), which was launched soon after publication of the Platt Report to campaign for improved services.

2. THE PHILOSOPHY OF FAMILY-CENTRED CARE

This section:

- * looks at what is meant by family-centred care and identifies some of the uncertainties associated with its interpretation in practice
- * outlines recommendations and guidance aimed at promoting this philosophy of care and explores the evidence for their effective implementation

2.1 What is meant by family-centred care?

i. The issue of the detrimental effects of hospitalisation upon children was first raised over 50 years ago.¹³ Since then at least five governmental reports have reiterated the importance of involving parents with the care of their sick child and the concept of "family-centred care" has become an almost universal tenet of children's health services. The key components of family-centred care have been described as follows¹⁴:

- * The family must be viewed in its social, cultural and religious context
- * Roles of individual family members must be evaluated to provide support for their physical and emotional needs
- * The family needs clear information on the child's illness to enable participation
- * Care plans should be developed and evaluated with the family
- * The family's willingness to be involved in technical care should be assessed and accommodated
- * The child's normal routine and care should be promoted in hospital
- * The effect of the child's illness on the family should be assessed and support provided accordingly in hospital or home

ii. It has been pointed out by a number of authors^{15,16,17} that there is a lack of clarity over what family-centred care actually means in practice. Particular areas of uncertainty include:

- * The definition of "family", which tends to be interpreted as meaning parents, or even more narrowly as referring to the mother alone. Consequently, insufficient consideration has been given to the role of, and support for, fathers, siblings or members of extended families who may sometimes play key roles in caring.
- * The nature of the family's role in caring: whether this is negotiated with the family or predefined and delegated by professional staff; whether it is expected to extend beyond 'normal' caring into nursing and teaching functions and who should take the main responsibility for each of these.
- * Whether "family-centred care" requires professional staff to take account

of other family members' needs arising from the child's illness, or only to the extent that these have implications for the child's care.

The demands on and expectations of both families and professional staff vary considerably according to how these issues are interpreted, and uncertainty can lead to confusion and frustration on both sides about appropriate roles.

2.2 Government recommendations on family-centred care

2.2.1 Involving and supporting families

- i. The 1991 Department of Health report¹ on the welfare of children and young people in hospital contains recommendations to assist families to:

support and comfort their child

- * It should be recognised that parents and members of the immediate family are not visitors and should be encouraged and assisted to be with their child at all times, especially around stressful events such as during and after treatment and investigations.
- * Facilities (including accessible and appropriate sleeping accommodation at no cost, washing facilities, toilets, telephones, use of sitting rooms and kitchens) should be provided to enable members of the family to sustain the normal relationship to which the child is accustomed at home. Where necessary, families may need financial assistance for travel costs to visit the child in hospital.

help with their child's care

- * Parents should be helped to undertake many familiar tasks beneficial to the care of their child and to continue the care following the child's discharge

cope with life-threatening illness

- * In the case of life-threatening illness, staff should be sensitive to the needs of children and their families and be able to draw upon staff specifically trained in care and counselling. Parents should be informed in an appropriate manner and as soon as possible of their child's condition and given every opportunity to talk through their feelings. Care should be taken not to 'avoid' parents whose child is dying, while at the same time recognising the need for privacy. Parents should have the opportunity to return to the hospital to find out anything further they wish to know about any aspect of their child's illness, care or treatment.
- * When a child dies, a member of staff trained in care and counselling

should be designated to give families, including siblings, all necessary support and the family's GP should be informed as soon as possible.

- ii. The 1991 guidance also recommends that hospital routines should be sufficiently flexible to adapt to families' different cultural practices and that parents be encouraged to express their preferences for the care of their child in relation to diet and feeding, clothing, washing and bathing, and beliefs or traditions in respect of healing, treatment and care while dying.
- iii. The 1996 Children's Charter¹¹ contains a number of statements about the rights and expectations of sick children and their parents. These include rights:
 - * To be given an explanation of any treatment proposed, including the benefits, risks and alternatives, before deciding whether or not to agree to it. To take part in any discussions and decisions about the child's treatment and care and to be kept up to date with their progress. Discussions with the child should be at the right level for his or her age and understanding.
 - * For parents to stay in hospital with the child, participate in their care, accompany them to the anaesthetic room and be informed about pain relief.

2.2.2 *Play and education*

i. **Play**

The 1991 guidance¹ draws attention to advice from the Play in Hospital Liaison Committee¹⁸ and the Save the Children Fund¹⁹ on the provision of opportunities for play in hospital. Play is regarded as essential to the intellectual, social and emotional development of children. It is also seen as beneficial in helping them to resolve stressful situations encountered in hospital, reducing anxiety, facilitating communication and speeding recovery and rehabilitation. Play specialists in hospitals are seen as valuable in: contributing to clinical judgments through their observation and communication with children; helping to prepare children for tests and treatment; identifying children or relatives who are distressed; providing diversional therapy; and introducing some normality into a child's day by relieving boredom.

- ii. It is recommended that hospitals should:
 - * provide play facilities in all areas of the hospital in which children are cared for and ensure there is easy access for all children including those who are bedbound or have sensory or physical disabilities
 - * employ hospital play specialists to run play schemes; ensure effective and efficient management of this activity and facilitate close

collaboration with other specialist staff concerned with children's care and rehabilitation, such as physiotherapists

iii. **Education**

The 1991 guidance¹ describes education for children in hospital as necessary both to minimise the impact of the interruption in their schooling and to provide stimulation. Hospital schools are not formally required to provide the National Curriculum, but they are expected²⁰ to aim to meet its requirements in respect of both short- and long-stay patients.

Hospitals are expected to collaborate with local education authorities to provide and maintain facilities (including equipment and apparatus) for education of all school age children including those admitted to adult wards, and to maintain links with the child's own school to achieve continuity of education.

Specific guidance is given on the assessment and support of children with special educational needs and those with disabilities.

2.2.3 *Arrangements for adolescents*

i. The 1991 guidance¹ acknowledges that adolescents have distinctive and different needs from both child and adult patients. It identifies a range of good practices for the hospital care of adolescents including:

- * accommodation in a separate unit from children's and adult wards which can provide privacy, flexibility of regime and independence
- * space for socialising, hobbies, homework or just to be alone
- * freedom to wear and care for their own clothes and have visits from friends as well as family
- * access to kitchens, telephones and space for storage of personal belongings
- * involvement in their treatment and the opportunity to make decisions which affect their life-style and development
- * the use of nurses of both sexes

The guidance advises consideration of the needs of special groups of young people including those who are disabled or chronically ill, have mental health problems or mental handicap, or are in hospital for confinement or termination of pregnancy.

2.3 **Implementation of recommendations on family-centred care**

i. Despite the widespread consensus on the principles of family-centred care and extensive recommendations concerning their implications for care, there is some evidence that these are still not always implemented in practice.

- ii. The 1993 investigation by the Audit Commission⁴ identified the root problem as being that "clinicians, managers and other staff do not give sufficient attention to the needs of children and their families" and argued that this is manifest in a lack of written policies, management focus and poor communication between staff and patients. The report observed that written policies for family-centred care often do not exist, and those that do seldom state clearly the standards to be adopted or who should be responsible for co-ordinating and carrying them out. This is because the practices have been developed in an ad hoc way by enthusiastic staff, primarily paediatricians and nurses, with little or no input from senior management. Consequently, there is no consistency from one ward or department to another and parents and children find the differences confusing and unjustifiable.

2.3.1 *Communication and co-operation between staff and families*

The Audit Commission found that information leaflets rarely make it clear that parents are encouraged to stay and many parents felt their role on the ward was unclear and their experience in caring for their child was ignored. The research literature shows up some reasons why family-centred care may be difficult to implement in practice. These include:

- * nurses not always recognising parents' needs²¹ or not sharing their views about what issues matter²²
- * nurses being concerned that through sharing their knowledge and skills with parents they may be compromising their own professional roles²³
- * time spent with families not being seen as a legitimate nursing activity and therefore neither planned for nor adequately resourced²⁴
- * unequal treatment of mothers and fathers, whereby the latter feel marginalised or ignored²⁵

2.3.2 *Provision of accommodation and other facilities for parents*

- i. The Audit Commission⁴ found serious deficiencies in the provision of accommodation for parents in terms of distance from the ward, lack of facilities and lack of arrangements to monitor parents' satisfaction with the facilities. These findings are backed up by another study²⁶ undertaken in 1995 which suggests that, at least in the region studied, a large number of paediatric wards were providing poor and inadequate facilities (expensive and inaccessible food; lack of storage and laundry facilities; no concessions on parking costs) and accommodation for parents, and were not meeting Department of Health requirements.

2.3.3 *Adolescents*

Only 10% of sites visited by the Audit Commission in 1993⁴ had a separate ward for adolescents, though some did have separate areas for adolescents in children's wards. More recently, the 1997 Health Committee inquiry⁷ was told by the Chair of the RCN Paediatric Surgical Nurses group that adolescents are not well catered for and that there are very few adolescent units set up. One reason suggested for this was the lack of appropriate data to determine how many adolescent patients there are within any particular Trust and consequent difficulty in knowing whether it is worthwhile setting up a special service for them.

3. STAFFING CHILDREN'S SERVICES IN THE NHS

This section:

- * outlines principles and policy with regard to the training, numbers and skill mix required for health professionals working with children
- * looks at how far these principles have been met in practice

3.1 Skills required of staff providing health care for children

- i. The 1993 Audit Commission report⁴ states that the special needs of children and their families cannot be met without staff who have the right skills a) to provide care and support for the whole family and b) to deal with the highly specific problems of childhood illness.

3.1.1 *Policy on training and provision of medical staff*

- i. The 1991 Department of Health guidance¹ recommends that:
 - * every child admitted to a hospital children's department should be supervised by a children's physician or surgeon
 - * if a child is admitted to another department, a named paediatric consultant should be responsible for advising the consultant concerned for the care of the child
 - * a consultant paediatrician should be responsible for advice on care and treatment policies in maternity and A&E units and such departments should have cover from a senior paediatrician at all times
 - * there should be adequate safety net cover in all departments where paediatric support is required (The British Paediatric Association and the Royal College of Physicians recommend that junior doctors providing safety net cover should have at least a year's experience of working in paediatrics.)
 - * facilities and appropriate protected time should be available for training of paediatric staff
 - * in other specialties regularly involved with the care of children there should be consultants trained and experienced in the treatment of children available to participate in and advise on treatment
 - * the child psychiatric department should have a close relationship with the children's department to ensure that both the physical and emotional

needs of all children receiving hospital care are met

ii. **Paediatric specialties**

The 1989 National Confidential Enquiry into Perioperative Deaths²⁷ (NCEPOD) recommended that:

- * surgeons and anaesthetists should not undertake occasional paediatric practice
- * consultants who take responsibility for the care of children must keep up to date and competent in the management of children
- * no trainee should undertake any anaesthetic or surgical operation on a child of any age without consultation with their consultant

iii. The British Association of Paediatric Surgeons²⁸ recommends that there should be one specialist paediatric surgeon per 500,000 population. The British Cardiac Society and Royal College of Physicians of London recommended in 1992 that there should be a minimum of one consultant paediatric cardiologist per million population, and no unit should have fewer than three consultants.²⁹ The British Paediatric Association has defined targets for specialist consultant paediatricians in each other specialty area.³⁰

iv. The Royal College of Paediatrics and Child Health³¹ proposes the following principles which should form the basis for planning and provision of surgical services for children:

- * children, both as in-patients and day cases, should be treated in facilities appropriate to their age and should not be admitted to adult wards
- * in every hospital which offers a surgical service for children there should be an appropriately trained consultant responsible for that service. All surgeons who operate on children should be suitably trained and have sufficient workload to maintain their skills
- * a nominated consultant anaesthetist trained in paediatric anaesthesia should be responsible for services for children and the service should be led at all times by consultants who anaesthetise children regularly (at least one full list per week)
- * assistance from nurses with paediatric training and skills should be available to the anaesthetist at all times
- * day-case surgery on children should only occur where there is skilled paediatric cover present on site both during and after the operation
- * in-patient children's surgery should only occur in a hospital with a fully staffed paediatrics department

- v. The report of the National Coordinating Group on Paediatric Intensive Care³² recommended that:

- * facilities must be physically sited where there is immediate availability of medical staff who have paediatric airways skills, supported at all times by consultant paediatricians and anaesthetists

3.1.2 *Actual provision of paediatric medical staff*

- i. In the sample of surgeons and anaesthetists studied by NCEPOD²⁷ in 1989, 87% of surgeons said they operated on children but 83% of these did fewer than 20 operations per year on children under six months. Similarly, almost all the anaesthetists studied anaesthetised children but 76% anaesthetised fewer than 20 children under six months each year.
- ii. Between 1990 and 1995 there was a 42% increase in the numbers of doctors training in paediatrics and a 54% increase in those working in the specialty. However, in the view of the RCPHC there remains a continuing need for more training posts in paediatrics.⁷
- iii. There is little published information on how adequately other standards for specialist paediatric provision are currently being met.

3.1.3 *Policy on training and provision of nursing staff*

- i. The basic qualification for nursing children is the Registered Sick Children's Nurse (RSCN). According to the Health Committee⁷, only 1 in 33 nurses have such a qualification. The ENB recommended in 1991 that 70% of all nursing staff on children's wards should be qualified in the specialty. Similarly, the Working Party on Paediatric Intensive Care³³ proposed that within paediatric intensive care units, at least 70% of nurses should hold a paediatric qualification (RSCN or the equivalent Project 2000 qualification) and the same proportion should hold an intensive care qualification, ideally in paediatric intensive care. The Working Party identified a need to increase the number of places available and the funding for nurses to undertake appropriate post registration courses in intensive care of children.
- ii. The 1991 Department of Health recommendations¹ set the following target standards for nurse staffing of children's hospital services. There should be:
 - * at least two RSCNs (or nurses with the relevant Project 2000 qualification) on duty 24 hours a day in all hospital children's departments and wards
 - * an RSCN available 24 hours a day to advise on the nursing of children in other departments
 - * sufficient RSCNs to supervise the training of student nurses

- * the RSCN/child ratio, staff numbers and skill mix should be commensurate with patient needs and determined by a systematic method of manpower demand assessment which is regularly reviewed

3.1.4 *Actual provision of paediatric nursing staff*

- i. In their 1991 audit, the Audit Commission⁴ found that most children's wards in their sample had only one RSCN on duty at some times during the day, and occasionally none at all. Almost 50% of the wards failed to meet the standard of two RSCNs on any shift at night.
- ii. A 1994 *Which? Way to Health* magazine survey³⁴ of non-specialist NHS hospitals found that, of the 285 hospitals responding which had children's wards, only one third had two RSCNs on duty on those wards at all times.
- iii. A 1996 survey of members of the RCN Paediatric Nurse Managers Forum³⁵ found that the recommended standard of two RSCN nurses at all times on children's wards was consistently being achieved in only 72% of the organisations studied. In areas where children were admitted outside the designated children's unit, the picture was much bleaker, with only 5% of organisations achieving this standard (with rotation of staff or cover from a children's ward).

4. ORGANISATION AND COMMISSIONING OF CHILDREN'S SERVICES

This section:

- * summarises the policy recommendations on the organisation and commissioning of children's services
- * looks at how far these recommendations have been met in practice

4.1 Policy recommendations on organisation and location

The basic principles concerning the organisation of children's hospital services in the NHS are that they should be grouped together in a comprehensive unit and separately provided from those for adults.

4.1.1 *Comprehensive services*

- i. The benefits of grouping children's services together within a children's department or hospital are well recognised. Such a grouping enables¹:
 - * participation of a paediatric clinician in the general management and professional oversight of the department
 - * provision of specialist nursing services managed, supervised by and professionally accountable to a senior paediatric nurse
 - * a comprehensive commitment to providing child-centred care with appropriate facilities and equipment for play, education, parental involvement and support
- ii. The 1991 Department of Health guidance¹ advised districts and provider hospitals to consider the extent to which the children's department can be located on one site within the curtilage of the district general hospital.
- iii. **A&E services**

One-third of all patients seen in A&E departments are children and there is a range of special provisions which have become widely accepted as necessary for the successful treatment of children in A&E¹. These include:

- * appropriate appliances and equipment (eg child sized resuscitation equipment)
- * separate and appropriate space for waiting, playing, examination, treatment and recovery
- * access for parents and carers to examination, x-ray and anaesthetic rooms
- * procedures to prioritise children and ensure they are seen promptly

- * 24 hour availability of specialist paediatric medical and nursing staff
- * training for non-paediatric staff in caring for children

iv. **Outpatients**

The 1991 guidance¹ recommends that, wherever possible, separate children's out-patients with appropriate facilities for families and children should be provided in close proximity to the children's department.

v. **Day patients**

Around 35% of surgical procedures on children are carried out on a day-case basis.⁷ The 1991 guidance¹ recommends that children receiving day care should not be admitted or treated alongside adult patients. Medical, nursing and other staff should be trained and experienced in the treatment of children as day cases and the patient management system should be designed for every child to be discharged within the day (except where complications make this impracticable).

vi. **Intensive care**

The National Coordinating Group on Paediatric Intensive Care³² suggests that the treatment of a critically ill child requires:

- * availability of other tertiary services on site
- * child-friendly accommodation and facilities
- * facilities for the family to visit and stay with the child
- * specialist equipment for children of differing ages
- * support services, such as paediatric pathology, laboratory services and paediatric radiology
- * provision of safe transport to other appropriate facilities if needed

vii. **Tertiary services**

Because tertiary services have evolved from local initiatives, they are not evenly distributed and access to these facilities is inequitable. In general, equivalent services for adults are more highly developed, for example children's intensive care is not available in all regions, whereas for adults it is routinely available. Children needing intensive care are frequently treated in adult facilities or have to be transferred outside their local region.³⁶

viii. Where highly specialised services are provided at regional and supra-regional centres, the 1991 guidance¹ recommends that:

- * wherever possible, children are referred to the centre most accessible to their home and family and adequate transport arrangements are made for children and parents/carers, including provision for appropriate

specialist staff to go with them

- * regional specialists are encouraged to develop peripatetic clinics in DGHs so that their expertise can be made available to children nearer their homes
- ix. The British Paediatric Association's 1995 review³⁶ of tertiary services for children and young people recommends that children's tertiary services should be situated on hospital sites containing a comprehensive range of facilities for children and adults, including A&E and obstetrics, so that they can benefit from the expertise of general paediatricians and adult specialists and share equipment.

4.1.2 *Actual practice*

- i. The Audit Commission⁴ identified problems both with a lack of separate facilities and under use of those that do exist. Most hospitals treating children did have separate children's wards, but separate outpatient and A&E facilities were much rarer. A survey of 174 health authorities and trusts undertaken by the ENB³⁷ in 1992 found that 55% of out-patient departments and 43% of A&E departments were caring for children "in non-designated paediatric areas". Some hospitals did have a separate waiting area and a separate treatment room, but these were not always available for use. The 1996 RCN survey³⁵ found that 23% of the 258 organisations studied had neither separate waiting nor treatment areas in their A&E departments specifically for children.
- ii. In the RCN survey³⁵, 60% of respondents reported children being admitted to non-paediatric ward areas, with some stating that up to 50% of children under 16 were admitted to over 35 different adult in-patient areas. The Audit Commission, in follow-up audits to the 1993 report, found that in almost half the hospitals studied, children having surgery were being admitted to wards where they were mixed with adults.⁷ Even where separate facilities were available, the Audit Commission found that they were not necessarily used for the care of all children. This was particularly the case in surgical specialties such as ophthalmology and ENT. The 1993 report¹ suggests that surgeons may prefer to treat children in adult wards dedicated to their particular specialty because:
- * they have less control over bed use in children's wards
 - * some fear that any reduction in their use of designated beds might threaten the viability of their specialty in the hospital
 - * they perceive a need for nurses trained specifically to deal with the procedures carried out in their particular specialty. Over 25% of those surveyed by the ENB³⁷ were providing ENT and ophthalmic services without RSCNs.
- iii. In respect of paediatric intensive care, oral evidence given to the Health Committee⁷ identified concerns over: the number of children needing intensive

care who are admitted to adult units or to other facilities that are not paediatric intensive care units; the question of whether there should be fewer but larger intensive care units for children; and whether there were sufficient numbers of specially trained nurses to staff the increased number of PICU beds currently planned.

4.2 Commissioning children's health services

- i. The *UK Agenda for Children*³⁸ states that: "Efficient, effective and child centred services for sick children and young people depend as much on having a clear and consistent strategy for purchasing services as on having a strategy to deliver them". It recommends that all purchasing authorities should designate a senior officer, experienced in children's issues, to be responsible for purchasing all services for children. The Audit Commission⁴ has also highlighted the key role of commissioners in leading the development of strategies for children. Despite this there is no central guidance on planning or commissioning for children's services. (The 1991 Department of Health recommendations¹ contain advice and good practice guidance for health authorities and provider hospitals, but is not directly concerned with the commissioning process.)
- ii. Local audits of child health commissioning carried out by the Audit Commission across England and Wales in 1994 showed that many commissioning agencies had not begun to address children's services as such. Child health services continued to be commissioned in block contracts, with no co-ordinated planning, no quality assurance and no identified outcome measures.
- iii. In 1994 a national study³⁹ was undertaken to examine patterns of child health commissioning across the UK. Of the 118 local health authorities responding to the survey, 58% had a specific named person with overall responsibility for commissioning children's services. Of these individuals, 32% had experience in child health, but mostly not in senior posts, and 15% had postgraduate qualifications in child health. Only 5% worked exclusively in the area of child health commissioning. Fifty per cent of the health authorities that replied said they had a team for planning and commissioning of children's services, but it was clear that many had confused this with local multi-agency groups involved in joint planning and/or commissioning. Only about one third of the authorities treated children's services as something to be planned and commissioned in their entirety. In most cases, such services were planned and commissioned within specific areas (such as mental health or oncology) in the context of related adult services.
- iv. The findings of this study support the widespread view that children's health services in the mid 1990s were not being given priority by commissioners. The authors comment that, with a few notable exceptions, strategies were not in place that would allow the the provision or maintenance of a child-centred service across all provider sectors. The danger this presents is that "the disease, the service, or the institution becomes the focus instead of the child".

5. CONTINUING PROBLEMS WITH CHILDREN'S SERVICES

The Audit Commission's 1993 report⁴ concluded that "although the principles which should underlie health care for children are agreed by national bodies, there is a lack of awareness of them and of their importance at local level, resulting in poor implementation in some hospitals". Four years later, in 1997, the Health Committee⁷ came to a similar conclusion that, despite the wealth of advice and guidance now available on the delivery of health services to children, it often is not implemented.

A number of reasons have been identified as helping to explain the continuing failure to translate the policy consensus into consistently good practice. These include:

* *Weak guidance*

While there is considerable consensus on what constitutes good practice and a plethora of guidance on appropriate standards, the recommendations tend to be advisory rather than requiring compliance, and therefore can more easily be ignored. In addition, there is currently no system of proactive monitoring of standards. For example, although there are plans to do so in the future⁷, the Department of Health has not so far collected data on the extent to which children are still being admitted to adult wards, even though admission to a children's ward is not only a Patient's Charter requirement but also a baseline requirement in respect of children's services in the Department's Priorities and Planning Guidance for the NHS: 1997/98.

* *Lack of commitment and expertise*

There continues to be insufficient focus and emphasis on meeting the specific needs of children (and particularly of adolescents). Purchasers still do not have the necessary commitment to, or expertise in, purchasing services which focus on the specific needs of children. Clinics are not planned round the needs of children but continue to follow traditional patterns or professional self-interest.

* *Limited voice of paediatric specialists*

The 1996 RCN survey³⁵ of paediatric nurse managers found that 84% of respondents were responsible for the implementation of consistent policies for children throughout their organisation. However, due to the nature of the management structure, where many postholders were accountable to non-nurses, they were unable to substantially influence areas outside the designated children's unit and many of them were not involved in decisions regarding service developments or in negotiating contracts for the provision of children's services.

* *Inadequate information*

The information necessary to plan, provide and evaluate child-centred, cost-

effective services is often not available. National and local data on health care outcomes which incorporates the views of consumers and staff working with children is required in order to plan, provide and evaluate services.

* *Fragmentation*

The way contracts are drafted can lead to the fragmentation of services and confusion about who is responsible for paying for and providing individual components of a paediatric care package.

* *Staff shortages*

A continuing insufficiency of specialist paediatric staff makes it difficult to achieve recommended staffing levels.

* *Poorly defined concepts*

Lack of clarity about the operational meaning of family-centred care leads to inconsistencies, confusion and uncertainty for families and staff and an underestimation of its implications for resources and family-professional relationships on the ward.

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