

Specialist Health Services for Children and Young People

A Guide for Primary Care
Organisations

January 2003

Royal College of Paediatrics
and Child Health



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www.rcpch.ac.uk

We hope that this document will be helpful to health professionals and managers in all four countries in the UK. However, there is inevitably a particular focus on England because of the rapid pace of handover of budgets to Primary Care Trusts. We acknowledge the differing situations in the four countries of the UK by using the term "Primary Care Organisation" throughout, to encompass the varying structures in each country, and believe that most of the issues are relevant to all four countries.

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FOREWORD

The publication in 2002 of *Shifting the Balance of Power* set out the direction in which health care would evolve and emphasised the central role of Primary Care Trusts (PCTs). Many health professionals recognised the potential benefits in improving local health care but at the same time were concerned about the impact of these far reaching changes on more specialised services. Paediatricians and children's nurses shared these anxieties. Consultation with managers suggested that a summary of the key elements involved in children's services would be very helpful to the newly established PCTs. This review is our response. It has been produced by the RCPCH in conjunction with the Royal College of Nursing, with input from many individuals from different organisations and backgrounds including PCTs, members of the Faculty of Public Health Medicine and lay groups. It details the various elements of children's services that are now the responsibility of PCTs. Many are self-evident, some are statutory duties, and some represent current best practice. Where we felt this would be helpful, we have indicated areas of service that are in need of improvement. Published standards and guidelines are referred to where appropriate.

We have been particularly concerned that this document should not in any way appear to pre-empt or over-ride the National Service Framework (NSF). The NSF is a much more ambitious undertaking that aims to set the philosophy and the health care agenda for children, for the next decade or more. This review in contrast is compiled from the perspective of professionals in the field of child health. Our intention is more modest - simply to list, in easily accessible format, the tasks and responsibilities that PCTs need to address now, in collaboration with service providers and users. However, over the past year we have heard repeatedly that services are vulnerable to planning blight while awaiting publication of the NSF and other major reviews. Implementation of the NSF will depend on the planning and commissioning capacity of PCOs and we hope this review will facilitate that process.

We have not addressed the provision of primary care, which is the responsibility of general practitioners and many other professionals, except to emphasise good communication and continuity of care. The focus is on secondary and tertiary children's health services since PCOs are responsible for ensuring that children and young people have access to a comprehensive range of specialist health services - regardless of whether these are provided or commissioned by the PCO.

The RCPCH and RCN are grateful to Dr Patricia Hamilton for leading this project and compiling the review. As Honorary Secretary of the RCPCH, a practising neonatologist, and clinical director of maternity and children's services at St George's Hospital, London, she has an unrivalled knowledge of UK paediatrics and we are confident that the guidance presented in the following pages will be both useful and reliable.

David Hall, President RCPCH
December 9th 2002.

Acknowledgments

This document was compiled and written by Dr Patricia Hamilton, Honorary Secretary. She and the RCPCH are extremely grateful to all those who offered comments on the document during its consultation period.

PART ONE

Introduction

" During 2002.... each PCG and PCT will ensure that a senior member of staff has designated responsibility for commissioning children's services. Strategic Health Authorities will need to have monitoring arrangements to ensure that appropriate commissioning of services for children is in place."

The Government's response to the Kennedy report.

The health needs of children are wide ranging and include promotion of well being as well as prevention and treatment of disorders arising from social and environmental hazards existing in family, community and society. Many agencies are involved including those with responsibilities for health, social care, education, and the environment.

The Context

Children's services are potentially vulnerable, partly because of their complexity, and partly because waiting lists, cancelled operations and acute hospital overspends will initially be higher priority for these organisations.

There are several Government initiatives designed to improve looking at the well being of children and young people. These include:

The National Service Framework (NSF) for Children

The Children's NSF will be published at the end of 2003. The Acute module will now be delivered in two phases. The first phase will be specifically focused on standards around hospital services and is due to be published in January 2003. The second phase will be focused on the patient journey of the ill child i.e. the management of illness in the community. This will be published during 2003 with the rest of the NSF.

The external working groups of the children's NSF are addressing the following:

1. Children needing acute and hospital services
2. Maternity services
3. Mental health and psychological wellbeing of children and young people
4. Children in special circumstances
5. Disabled children and young people
6. Healthy children and young people

There are also working groups on medicines, workforce, information strategy, research and development and patient participation.

The Children and Young People's Unit

The CYP Unit supports the development of the Government's strategy for children and young people, including reducing child poverty and youth disadvantage, looking across the full 0-19-age range. They promote active partnership with children and young people, and with the voluntary sector. They are also responsible for the administration of the Children's Fund, which aims to prevent poverty and social exclusion amongst children and young people.

Other recent government initiatives relevant to children

The "Quality Protects" Programme is a key part of the Government's wider strategy for tackling social exclusion. The Sure Start programme is aimed at supporting the needs of disadvantaged pre-school children, *Safeguarding Children* and the Climbie enquiry address important child protection issues. *Health for all children* 4th edition OUP 2003 provides a detailed review of these initiatives.

References:

- <http://www.doh.gov.uk/nsf/children.htm>
- <http://www.cypu.gov.uk>
- <http://www.doh.gov.uk/qualityprotects/>
- <http://www.surestart.gov.uk/home.cfm>
- <http://www.victoria-climbie-inquiry.org.uk/>
- <http://www.doh.gov.uk/scg/safeguardingchildren.htm>
- <http://www.healthforallchildren.co.uk>

Education

All children have a right to education and this includes those who are in hospital. Local Education Authorities (LEAS) have to ensure that education is provided for children in hospital or at home as far as the medical condition allows. This includes children and young people with mental health needs. PCOs will need to liaise closely with LEAS to ensure that, for example, appropriate accommodation is available for education to take place.

Reference

- *Access to Education for Children and Young People with Medical Needs: Statutory Guidance* DfES/DH <http://www.dfes.gov.uk/sickchildren/Pdfs/Accessstoed.pdf>

Philosophy

1. Children have rights, which should be respected and promoted and include a safe and healthy environment, good education, good nutrition and a secure family life.
2. Children should be seen as children first recognising their changing needs and abilities as they become older, rather than as a disease or problem.
3. Parents and children should be actively involved in the services provided.
4. Each child is a unique individual and racial, linguistic, religious and cultural background should be respected.

Principles

1. Service standards should be evidence based and balance both the quantity and quality of provision.
2. Services should be both accessible and child friendly.
3. Services should promote and protect the rights of children and families and be advocates for their needs.
4. Services should be well co-ordinated with continuity over time between the agencies/ services involved.
5. Services should be evaluated regularly to ensure they are meeting the evolving needs of the child population.

6. Services should work within the available resources taking account of financial, political and environmental factors.
7. Services should be delivered as close to home as resources and expertise allow.

Cross-cutting themes

A number of themes are applicable across all forms of service provision:

1. Children's rights
2. Participation and partnership with children, young people and their carers.
3. Health outcome monitoring and information technology
4. Workforce issues and clinical governance
5. Partnership with Government, and inter-agency and multidisciplinary working
6. Inequalities in health status and access to care

Reference

- *UN Convention on the Rights of the Child*
<http://www.unhcr.ch/html/menu3/b/k2crc.htm>

Thus a health service for children and young people:

- 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.
- Is child and family centred with children, their siblings and their parents or carers experiencing a “seamless web” of care, treatment and support, as they move through the constituent parts of the NHS.
- Considers care pathways which, where appropriate, include:
 1. prevention (protection and health promotion)
 2. identification (concern, screening)
 3. assessment
 4. management (short and long-term)
 5. rehabilitation
 6. palliation

References

- DoH *Welfare of Children and Young People in Hospital* HMSO 1991
- *Children in Hospital*, The Scottish office
<http://www.scotland.gov.uk/library/documents6/chilpol-04p...>
- Children in Wales <http://www.childreninwales.org.uk>
- A Commissioner for Children in Northern Ireland
<http://www.childpolicy.org.uk/dir/index.cfm?ccs=1043&cs=671>
- Action for Sick Children <http://www.actionforsickchildren.org> Publishes: *Health Services for Children and Young People* 1996

Health service responsibilities include

- Health promotion - the role of health professionals in relation to the promotion of a healthy lifestyle, promoting mental health and the provision of support to parents; these services need to be provided throughout childhood
- Prevention of illness, injury, disability throughout childhood - including specific programmes such as immunisation
- Protection of children and young people from violence, bullying, abuse and accidents
- Detection of health problems - including screening and surveillance programmes, and diagnostic services
- Management of acute illness and injury - including babies who develop problems in the newborn period; the role of parents in the management of self-limiting illness; the role of primary care services in the management of more serious illness, including GPs and other members of the primary health care team, NHS Direct, walk-in centres, ambulance services, A&E services, etc; specialist paediatric services, including the provision of assessment services, inpatient services and the need for paediatric intensive care services
- Management of chronic diseases
- Management of mental health problems
- Management of children with disabilities - including diagnostic services, multidisciplinary child development services and the interface with education and social services
- Management of vulnerable children - including the role of health services in the management of children at risk of or subject to abuse; looked after children; and other children in need.

Commissioning Specialist Services for Children

In the UK, primary health care for children is provided by general practitioners, health visitors and their teams of colleagues. Primary care is not addressed in this document, except to emphasise collaboration and communication. The focus is on services provided by paediatricians - doctors trained as specialists in paediatrics. Paediatricians provide a consultant-led service for children who are seriously ill or who have problems that cannot be managed solely by primary care teams. They may work either mainly in hospital or mainly in the community, but these boundaries are becoming increasingly irrelevant. At local or district level, most paediatricians are generalists and provide secondary care, although many have developed a particular interest and expertise, such as diabetes or child protection.

Tertiary specialists are paediatricians who spend all or most of their time in a highly specialised area of practice such as neurology or rheumatology. They are generally based in a regional or teaching centre, and usually work in multi-disciplinary teams which can provide both in-patient care and outreach services to districts.

Collaboration with other agencies will be needed for children whose care crosses health service boundaries of primary and specialist care and those where multi-agency services are needed, such as social and education services.

References

- *The Next Ten Years*, RCPCH, 2002. <http://www.rcpch.ac.uk/news/index.html>
- *Strengthening the Care of Children in the Community*, RCPCH, 2002. http://www.rcpch.ac.uk/publications/recent_publications.html
- Children Act: http://www.hmsso.gov.uk/acts/acts1989/Ukpga_19890041_en_1.htm
- Education Act: <http://www.hmsso.gov.uk/acts/acts1996/1996056.htm>

Securing local access to a range of health services – the responsibility of the Primary Care Organisation

To what range of health services should the Primary Care Organisation ensure local children and families have access?

Although the mechanisms for organising health care provision are still evolving, the PCO should assume responsibility for *all* the children within its boundaries, including those who are vulnerable or hard to reach. The definition of its boundaries should be made clear and provision made for children for whom services might cross boundaries, for those whose families move frequently and for those who may not be registered with a general practitioner. The range of services

provided directly by the PCO will vary from one PCO to another, but the principles remain the same.

PCOs take a public health overview of health care needs of their population and include multi-professional group involvement through links with other agencies. There should be consumer involvement and mechanisms for audit and monitoring of progress. Close relationships with Strategic Health Authorities (StHAs) or Unified Health Boards (Scotland) and well-planned specialty commissioning will be vitally important. Care Trusts and Local Health Care Cooperatives may play a major role in the future, bringing together health care and social services and developing closer links with education.

What do families, children and young people want, need and benefit from the NHS?

1. Equitable access to specialist obstetric advice for pre-pregnancy counselling and for women with problems during pregnancy. Screening in pregnancy and infancy.
2. Care during pregnancy, labour and at birth, including resuscitation, identification of abnormality and illness, and transfer to specialist care.
3. Special, high dependency and intensive care of the newborn baby.
4. A programme of immunisation, health promotion, parent support, screening and surveillance for pre-school and school age children and young people.
5. Protection against neglect and abuse of all kinds, including violence at home and bullying at school.
6. Consultation, advice and management for non-acute problems.
7. Integrated multi-disciplinary care for those with disabilities and long-term problems, including care pathways and key workers.
8. Early identification and intervention for children with signs of educational failure.
9. Identification and treatment of mental health problems. Prevention by promoting early intervention e.g. parenting skills, parent support, promoting emotional literacy at school.
10. Assessment and management of acute illness or injury.
11. Easy access to secondary and tertiary level expertise.
12. Support and advice regarding adoption and fostering.

13. Health care, physical, emotional and psychological, for those who are vulnerable, including looked after and refugee children.
14. Clear information for children and parents.
15. Involvement of children, young people and parents in decision-making processes.
16. Seamless links with social and educational services and other health authorities or boards
17. A reduction in inequalities of health status and health provision
18. Health care monitoring and planning.

Principles for a paediatric and child health service fulfilling these needs

1. Prevention of illness and health promotion should receive as much attention as treatment of ill health.
2. Services should be provided by staff whose training is appropriate for their duties.
3. No paediatrician or other health professional should work in isolation.
4. Children should have ready access to expertise that is relevant to their age and their needs.
5. Care should be provided close to the child's home so long as this is compatible with the expertise and facilities required.
6. Children should only be admitted to hospital if the care they require cannot be provided at home or on a day care basis. Community children's nursing services should be provided to ensure that children can remain at home wherever possible.
7. The principles of equity should apply in all service planning. Problems related to local geography, transport, or financial situations should not be allowed to exclude any child from the health care they need. Pathways of care ought to be the same *in principle* wherever a child lives.
8. There should be clear pathways and programmes of care from primary care, through a local paediatrician to a tertiary specialist; increasingly, this will be through managed clinical networks.

9. Each local area should ensure that it has a full range of skills available or accessible, to deal with all aspects of child health.

10. Risk management systems should be in place to ensure that adverse incidents are reported and necessary changes implemented.

11. Research and critical review of evidence should continue across the spectrum of children's health care, to develop improved methods of treatment, maintain quality and to avoid perpetuation of outdated or ineffective practice.

12. There should be high quality information systems and expertise to maintain efficient and effective databases.

References

- *Old Problems, New Solutions: 21st Century Children's Healthcare*, RCPCH. http://www.rcpch.ac.uk/publications/recent_publications.html
- *Paediatrics In 2010* RCPCH (in preparation).
- Action for Sick Children <http://www.actionforsickchildren.org/>

PART TWO: Specific Services

1 Commissioning Child Health Promotion

1.1 General Principles

- Individuals, disciplines and agencies need to be involved in planning child health promotion services. There should be effective Child Health Promotion and Surveillance programmes in place with clear roles and responsibilities.
- There should be a district child health promotion coordinator to ascertain who is taking the lead responsibility for each aspect of preventive care and each area of staff training.
- All parents should be given a Personal Child Health Record for their child.
- Surveillance should be provided as set out in *Health for All Children 4th edition 2003*.
- There should be coordinated planning and management of databases. New database projects should include the core dataset developed by the Child Health Informatics Consortium.
- Health Visitors, school nurses and community child health nurses are key in health promotion through giving advice on good parenting, healthy diets and the dangers of smoking etc.
- School nurses also play an important role in advising on emotional and sexual problems and supporting the Healthy Schools initiative

References:

- Child Health Informatics Consortium <http://www.chiconsortium.org.uk/>
- Health for all Children 4th Edition <http://www.healthforallchildren.co.uk>
- National Healthy School Standard: <http://www.wiredforhealth.gov.uk/healthy/healsch.html>

1.2 Screening and Surveillance Programmes

- Effective screening programmes need collaborative working with a range of clinicians, managers and public health professionals. The National Screening Committee Children's sub-group oversees screening programmes.

- Written policies should be available and effectively practised for early detection and referral pathways of:
 - Hepatitis B and HIV in pregnancy
 - Phenylketonuria
 - Developmental dysplasia of the hip
 - Congenital hypothyroidism
 - Hearing loss
 - Other conditions as recommended by the National Screening Committee
 - Neonatal screening for cystic fibrosis and haemoglobinopathies is being introduced.
- There should be clear care pathways from surveillance and screening programmes to diagnostic assessment.
- Screening and surveillance programmes should be audited.

References

- *Health for All Children* 4th edition <http://www.health-for-all-children.co.uk>
- *Strengthening the Care of Children in the Community* RCPCH 2002
http://www.rcpch.ac.uk/publications/recent_publications.html
- UK National Screening Committee Programme Director's Report 2002
<http://www.nelh.nhs.uk/screening>

1.3 Infectious disease and immunisation programmes

- Effective immunisation programmes must be maintained. There must be one individual designated as immunisation coordinator, central computerised immunisation records and an immunisation advice service.
- The coordinator and the services should work closely with health visitors.
- Other immunisations should be delivered to at-risk groups. These include vaccinations to provide protection from tuberculosis, hepatitis B, pneumococcus and influenza, plus arrangements for intensive community-wide catch-up programmes such as the meningococcal vaccine programme.
- There should be a named individual and agreed reporting arrangements for paediatric infectious diseases. There should be policies in place for antibiotic usage and minimisation of cross infection risks.
- There should be policies in place for the care of children who have or are at risk of HIV infection and AIDS.

- The role of school nurses for recognition of ill health and promoting health in schools should be supported.

References

- RCPCH <http://www.rcpch.ac.uk>
- DoH immunisation publications <http://www.immunisation.org.uk/>
- CMO: *Getting ahead of the Curve* <http://www.doh.gov.uk/cmo/idstrategy/>
- The concept of Immunisation co-ordinator was introduced by Department of Health (HN/85/10).

2 Commissioning services for child protection

- Section 27 of the Children Act requires that there is a Child Protection Service Specification and PCOs should ensure that child protection is reflected in each contract.
- All paediatricians have a duty to be familiar with the necessary procedures. Rigorous systems are needed to protect both children and doctors in this field.
- Each NHS Trust commissioning or providing child health services must have a named doctor and nurse for child protection. There should also be a designated doctor and nurse for each district.
- There must be appropriate representation on the Area Child Protection Committee and close working with other agencies including social services and the police.
- Protocols in line with national guidance must be in place and there must be arrangements for training and continuing professional development in child protection for all professionals involved with children.
- There should be an adequately resourced service for the examination, treatment and follow-up of children and young people who have been abused. This should include the appropriate provision of therapeutic services and appropriate medical advice should be available to statutory agencies.
- There must be collaboration with local authorities to meet the Government “Quality Protects” targets for children in need and looked after children.

References

- *The Quality Protects Programme: transforming children's services* DoH 1998
<http://www.doh.gov.uk/qualityprotects/>
- *Framework for the assessment of children in need & their families* DoH 2000
- *Duties of the designated doctor in child protection* (RCPCH 2001). <http://www.rcpch.ac.uk>
- *Carlile Report* (report to the Welsh Assembly):
<http://www.childpolicy.org.uk/dir/index.cfm?ccs=1277&cs=518>
- *Safeguarding Children*: <http://www.doh.gov.uk/scg/safeguardingchildren.htm>
- *The Climbié inquiry* <http://www.victoria-climbié-inquiry.org.uk/>

3 Commissioning acute and emergency services

3.1 The newborn

- There should be appropriately trained and experienced staff immediately available for resuscitation of the newborn.
- Managed clinical networks of maternity and paediatric services should be set up so that high risk pregnancies and babies can be managed in units with appropriate numbers of trained and experienced staff.
- There should be clear information for women so that they are aware of what can and cannot be offered in the unit in which they will be delivered.
- Newborn babies should be examined within 24 hours of birth by a professional trained to carry out this examination. There should be clear lines of referral for the management of any abnormality found.
- Retrieval arrangements should be in place so that sick newborn babies can be collected by a trained team on behalf of the receiving unit.
- Neonatal units should work towards delivery of intensive and high dependency care in accordance with standards and guidelines laid down by the British Association for Perinatal Medicine.
- Prevention of haemolytic and haemorrhagic disease of the newborn must be assured through programmes for administration of routine anti-D prophylaxis to mothers in pregnancy and vitamin K to babies at birth. Information should be available to parents so that informed choices can be made.
- There should be active promotion of and support for breast-feeding and hospitals should work towards achieving “Baby-Friendly” status.

References

- NICE guideline on routine antenatal anti-D prophylaxis for Rh-negative women <http://www.nice.org.uk/article.asp?a=31696>
- DoH guidelines on vitamin K <http://www.doh.gov.uk/pdfs/vitamink.pdf>
- BAPM Standards for hospitals providing neonatal intensive and high dependency care (2nd Edition 2001) <http://www.bapm-london.org/>
- “Resuscitation of Babies at Birth” *Current Paediatrics* 1998 8 225-30
- *Examination of the Newborn* RCPCH (in preparation)
- Baby Friendly Initiative <http://www.babyfriendly.org.uk/home.asp>
- DoH Neonatal Services Review 2002 (in final draft)

3.2 Accident & Emergency Services

- Parents may access the health care system not just through their general practitioner but via NHS Direct, Walk-in centres or the A and E department. All should have specific facilities for children.
- Changes in parents' perceptions of illness and increased expectations of seeing a paediatrician mean that these routes of access are not confined to emergency and out of hours care.
- A and E departments must have appropriate facilities for children which are separated from those for adult patients.
- The paediatric part of the A and E unit must have at least one registered children's nurse on duty at all times and paediatric medical staff should be rapidly available from inpatient paediatric facilities.
- The services should be led by a consultant with expertise and experience in the care of children in A & E and there should be a designated liaison consultant paediatrician. There should also be a liaison Health Visitor.
- Ambulatory or short stay emergency assessment and day case units may provide a facility for longer-term assessment than can be provided in A and E but still obviate admission to inpatient services.
- Minor injury units should meet the criteria laid down by the Intercollegiate Group on A and E medicine for children.
- Where the above standards cannot be met immediately, there should be interim arrangements for top-up training for all nurses and doctors who deal with paediatric emergency and out-of-hours care.
- A and E information systems should allow child attendances and accident statistics to be recorded and analysed to help preventive programmes. There must be effective links to the child protection register.

References

- *Accident & Emergency Services for Children* (RCPCH 1999)
- *Duties of the Liaison A & E Paediatrician* (RCPCH 2001)
- *Old Problems, New Solutions* (RCPCH 2002) <http://www.rcpch.ac.uk>
- *Nursing Children in Accident and Emergency Departments* (RCN 1998)
- *Children's attendance at a minor injury service* <http://www.rcpch.ac.uk>
- *Emergency Services for Children and Young People* <http://www.actionforsickchildren.org>

3.3 General acute paediatrics

- About 1 in 10 children aged under 4 are admitted to hospital, usually for periods of less than 24 hours. Services should be designed to cope with short stay and rapid discharges.
- The relatively small number of more complex disorders justifies care in tertiary centres. Services should balance access to expertise with geographical considerations.
- Where there are in-patient facilities, personnel able to cope with emergencies should be immediately available at all times.
- Infections make up about half of all paediatric admissions to district general hospitals. Staff should be trained in the assessment and management of acute viral and bacterial infections.
- About 1 in 10 children admitted receive high dependency care, e.g. for oxygen dependent respiratory disorders. Plans should be made for access to high-dependency facilities.
- About 1 in 20 children is referred to a paediatrician as a new outpatient each year. There should be facilities and time available for paediatricians to manage outpatients properly.
- There should be liaison with Local Education Authorities (LEAS) to ensure that education is provided for children in hospital.

References

- *Welfare of Children & Young People in Hospital*. Dept of Health 1991
- *Ambulatory Paediatrics* RCPCH 1998
- Action for Sick Children <http://www.actionforsickchildren.org/>
Publishes: *Health Services for Children and Young People* 1996
- Child Advocacy International <http://www.childfriendlyhealthcare.org/>
- *A Charter for Paediatricians* RCPCH 2000. <http://www.rcpch.ac.uk>

3.4 Adolescent health

- Adolescents should have dedicated space and facilities within paediatric units.
- Staff should be trained in working with adolescents.
- There should be joint working at commissioning level with Child and Adolescent Mental Health services, educational and social services.
- There should be clear and seamless transition for those with long-term conditions from paediatrics into appropriate adult medical, surgical and psychiatric services.

- There should also be a smooth transition from community children's nursing services to continuing care nursing services for adolescents with chronic diseases.

References

- *Health Services for Adolescents* RCPCH in press
- Action for Sick Children <http://www.actionforsickchildren.org/>
Publishes: *Setting standards for Adolescents in Hospital* 1990
Youth Matters 1998
- *RCN Issues in Nursing and Health* 33 -caring for adolescents (2002)

3.5 Paediatric Surgery and Anaesthesia

- Safe services must be provided as set out in the reports of the Royal Colleges of Surgeons and of Anaesthetists.
- Surgeons and anaesthetists must undertake sufficient work with children to maintain their skills.
- Surgery on newborn babies within 44 weeks of conceptual age, and specialised surgery, should be performed by paediatric surgeons at specialist centres.
- It is not currently feasible and may not be desirable to undertake all children's surgery at tertiary centres. District hospitals should establish a policy that specifies how access to children's acute and elective surgery will be maintained.
- Arrangements should be made for paediatric orthopaedic surgery, ENT surgery etc to be carried out by suitably trained staff in conditions that are suitable for children.

References:

- *Children's Surgery: A First Class Service* RCS 2000
<http://www.rcseng.ac.uk/services/publications/>
- *Paediatric Surgery: Standards of Care*. British Association of Paediatric Surgeons, 2002 <http://www.baps.org.uk/standards%20of%20care-aug02.htm>
- *Just for the Day Just for the day: children admitted to hospital for day treatment*. Thornes, Rosemary.- London: NAWCH on behalf of Caring for Children in the Health Services, 1991
- Action for Sick Children <http://www.actionforsickchildren.org/>
Publishes: *Setting standards for children undergoing surgery* 1994

4. Commissioning child mental health

- Child and Adolescent Mental Health Services (CAMHS) are often provided in different trusts from acute or community services; whatever the managerial arrangements, a close working relationship between CAMHS and other children's services is vital.
- There has been a marked increase in the incidence of behavioural disorders in childhood. There is a shortage of child psychiatrists and psychologists to provide the services that are needed.
- Many cases and much preventive work can be managed in the community. Service delivery at primary and secondary care level requires recruitment of primary child mental health workers and community CAMHS nurses.
- Provision should be made for the psychological assessment and support of children and young people presenting with medical disorders.
- Early intervention and promotion of parenting skills and parent support may prevent some behavioural and mental health problems. There should be liaison with parenting schemes and initiatives such as Sure Start.
- Provision should be made for the assessment and care of young people with depression, self-harm, eating disorders and drug and alcohol abuse.
- Protocols for management of children and young people with mental health and behavioural problems should be prepared in line with national guidance.
- There should be multi-agency management plans for children and young people with high levels of distress and for those at high risk of harming themselves or others.
- Education should be provided for children and young people with mental health needs as far as the medical condition allows.

References:

- SIGN guideline on Attention Deficit/Hyperactivity Disorder (ADHD) in children and young people <http://www.sign.ac.uk/guidelines/fulltext/52/index.html>
- *Helpful Parenting* RCPCH 2002
- *Encouraging better behaviour* NSPCC 2002 <http://www.nspcc.org.uk/html/home/home.htm>
- Mental Health Information Royal College Psychiatrists <http://www.rcpsych.ac.uk/info>
- *Child in Mind* RCPCH in progress
- *Handbook on Child & Adolescent Mental Health*. Health of the Nation DoH 1995

5. Commissioning Long-Term Care

- Provision for long term management in programmes of care for children with chronic illness, disability and social disadvantage involves hospital and community based child health services working with GPs and primary care colleagues, social services, education departments and the voluntary sector.
- In every locality there should be designated facilities and trained staff in all relevant disciplines and therapies for providing assessment and care of children with developmental problems and disabilities.
- There should be screening, diagnostic and tertiary audiological and vision impairment services for children.
- There should be a designated doctor for educational liaison and health care support for children with chronic medical problems in school. There must be a designated medical officer for Special Educational Needs and transition to adult care services must be planned as required by the Education Act 1996.
- There should be a specific health care plan for children looked after with medical support for local adoption and fostering panels and provision of advice to Local Authorities.
- The needs of looked after children also include nurse specialists and social services as set out in the Quality Protects programme.
- There should be respite facilities for children with severe long-term physical and mental problems who are mainly cared for by their families.
- There should be provision for the assessment and care of children with attention deficit disorders, autism spectrum disorders and behavioural disorders.
- There should be local facilities for the on-going care of children with long-term conditions such as asthma, diabetes, epilepsy, cerebral palsy and cystic fibrosis. These should include community children's nurses, therapists, nurse specialists and access to tertiary specialists where appropriate. Key workers have an important role.
- A 24hour/7day (interim target 12/7) community children's nursing service, supported by a multi-disciplinary team, should be provided to prevent unnecessary admission of children to hospital and to facilitate early discharge. They need access to medical staff in primary and secondary care sectors.
- There should be access to palliative care services for children.

- Children with disabilities and their families should have access to CAMHS services and to specialized expertise for complex behavioral and psychological problems.

References:

- *Children's Community Nursing: Promoting effective teamworking for children and their families*. RCN 2000
- *Services to Disabled Children and their Families* Social Services Inspectorate 1994 HMSO
- *Essentials of Effective Community Health Services for Children and Young People* 1997
<http://www.show.scot.nhs.uk/crag/committees>
- *Promoting Health for Looked After Children* DoH 2000
http://www.dfes.gov.uk/a-z/LOOKED_AFTER_CHILDREN.html
- British Association of Adoption and Fostering standards <http://www.baaf.org.uk/>
- The Health of Refugee Children - Guidelines for Paediatricians
http://www.rcpch.ac.uk/publications/past_publications/refugee.pdf

6. Commissioning Specialised and Tertiary Services

- Paediatric tertiary services deal with conditions of low incidence (in contrast to their adult equivalents) and high cost. There is considerable variation in demand and geographical access. A small minority of children for whom specialist care is needed will travel to distant units for this care but wherever possible the tertiary service should deliver its care locally to children by networking with local specialist services and primary care.
- Specialised services defined in the National Specialist Service Definitions Set are currently commissioned by Regional Specialised Commissioning Groups. The four countries of the UK may approach specialised commissioning in various ways but PCOs will need to ensure high standards, coordination and equity of access and quality.
- There are a number of recognised medical subspecialties of paediatrics and divisions of surgery, some of which have specialised sub-divisions. Paediatric cardiology, paediatric intensive care and neonatal intensive care are already the subjects of high level planning but as yet many other specialties are not.
- Most subspecialties have their own Specialty Group and each is represented by a Royal College Specialty Advisory Committee. These set standards for education, training and service. They are too detailed to be included here but are available from Specialty Group and the College websites. The College website lists the convenor of each specialty group.
- PCOs will recognise that collaborative commissioning groups will be needed for specialised services. Criteria for treatment are complex and some are controversial. It would be more efficient to have a small number of commissioners who have to become proficient in each field. Some very specialised services will need to be commissioned above local or regional levels or by the National Specialist Commissioning Advisory Group (NSCAG).
- Services should be commissioned from centres that can provide a multi-disciplinary team and be part of appropriate specialist-led networks of doctors, nurses and other staff.
- Resources should be invested in training specialist nurses, advanced nurse practitioners and professionals allied to medicine, such as children's physiotherapists, occupational therapists, speech and language therapists, dieticians and pharmacists.
- There are significant workforce shortages in most paediatric specialties and it makes sense to develop expert teams who can provide a high quality 24/7 in-patient service together with an outreach programme. This may mean fewer in-patient centres for each specialty.
- Resources should enable specialist services to comply with NICE, SIGN and other national guidelines as set by the specialty groups.

- Accurate databases, preferably as part of national databases, will be needed to gather information for monitoring patterns and health outcomes.
- Research and academic medicine are essential to the continuing improvement of children's health care. Clinical care should not be dependent on University or research-funded posts.

References

- http://www.rcpch.ac.uk/committees/specialty_group_contacts.html
- National Institute of Clinical Excellence <http://www.nice.org.uk>
- Scottish Intercollegiate Guideline Network <http://www.sign.ac.uk>

7 Workforce issues

- The NHS Plan is clear that in future care will be consultant delivered. Many staff currently are working well over 48 hours and increasing numbers of doctors wish to work flexibly or part-time. A significant expansion of consultant numbers is urgently required.
- No service should be planned to be dependent on trainees working without supervision. The New Deal for junior doctors and the European Working Hours Directive mean that, in order to provide 24/7 cover for high intensity and emergency services, a shift system may be the only realistic solution. This will need at least 7 and in some cases up to 10 individuals per shift.
- Issues of cost, staff shortages and skill maintenance in small units suggest that services of high intensity may have to be delivered in fewer centres in order to provide safe cover. Inter-disciplinary working and multi-skilling should be encouraged in order to deliver services as effectively and efficiently as possible.
- Other models of care offer the opportunity to sustain children's services at local levels but will need early user involvement and collaboration between several districts.
- In future nurses may undertake enhanced roles that will encompass aspects of assessment, care and treatment previously undertaken by doctors. Nurses who wish to take on these roles should be encouraged to benefit from nationally recognised education and training programmes.

References:

- *Paediatrics in 2010* RCPCH 2002 <http://www.rcpch.ac.uk>
- *Making a Difference; Strengthening the nursing, midwifery and health visiting contribution to health and health care.* 1999 DoH <http://www.nhs-nwmad.org.uk/>
- *A Charter for Paediatricians* http://www.rcpch.ac.uk/publications/recent_publications.html

8 Commissioning Training

- PCOs are likely to have input into funding for training.
- PCOs should engage with the workforce confederations in accurate workforce planning for doctors, nurses and other key disciplines.
- They should commission registered children's nursing programme places at both pre-registration and post-registration level.
- There are many changes occurring in the training of junior doctors. The CMO's proposals for modernising the SHO grade will alter the nature and duration of time spent in that grade.
- Non-standard posts should only be approved if they include career development and methods of assessing competence.
- In future it is likely that junior doctors' progression to CCST will be based on competency assessment as well as examinations and time served. This will mean that some may be assessed as fit for a consultant post in less time than the current Calman training. This in turn means that some specialist training may take place post-CCST.

References:

- *Medical, Health Care and Associated Professions: Postgraduate medical education and training 2002* <http://www.doh.gov.uk/medicaltrainingintheuk>
- *Unfinished Business*; Report on SHO modernisation <http://www.doh.gov.uk/shoconsult/>

9. Clinical Governance

- All services need guidelines, quality assurance, benchmarking, audit and risk management.
- Delivery and outcome monitoring need good quality information that is collected on local databases that can communicate with those in neighbouring localities as well as with national databases.
- Good critical incident reporting depends on ease of access to the system, anonymity and a no-blame culture.
- There is a need for high quality mutually compatible IT systems and personnel with appropriate expertise.
- Job plans should include time set aside for clinical governance.
- Guideline development will identify research needs and these issues will need to be addressed, along with the needs of academic doctors and trainees.

References:

- *Essence of Care: patient-focussed benchmarking for healthcare practitioners*
<http://www.doh.gov.uk/essenceofcare/>
- *Good Medical Practice in Paediatrics and Child Health* RCPCH 2001
http://www.rcpch.ac.uk/publications/recent_publications.html

10. PCOs that manage acute and/or community paediatric services

There are a variety of service models currently in existence. Some children's services are entirely within an acute trust; some entirely within a community trust and others have acute services in one and community in another. The impact of any change in management structure on the rest of the service should be carefully considered. If the service is working well then caution is needed before altering the structure. Any changes should network properly and if a PCO takes over any part of the service the following should be noted.

10.1 General responsibilities of PCOs

PCO leaders should support and facilitate reduction of barriers between hospital and community care, between CAMHS and paediatric services, between primary and secondary care and between NHS and other agencies. More specifically, they will need to consider the following:

1. Appropriate lines of accountability within the professions - in particular a medical director, director of nursing and clinical directors or their equivalents on the Board
2. Detailed job descriptions and job plans for all staff.
3. Systems for clinical governance involving multi-disciplinary teams.
4. Standardised guidelines across the services and between primary, secondary and tertiary care.
5. Annual peer appraisal, including review of job plan and personal development plan by a practitioner on the GMC register for Consultant and career-grade doctors.
6. Facilities for training and continuing professional development of doctors, nurses and those professionals allied to medicine.
7. Extension of skill-mix where appropriate in order to maximise use of staff potential.
8. Professional leave for doctors, nurses and professionals allied to medicine to take part in College, BMA and other professional duties
9. Management support for clinical leaders
10. IT facilities and means for audit
11. Facilitation of movement of staff and patients across trust boundaries for training and service requirements

References

- A Charter for Paediatricians RCPCH 2000
- Checklist for job descriptions for Paediatricians RCPCH

Both on: http://www.rcpch.ac.uk/publications/recent_publications.html

PART THREE: Checklists

General

The NSF modules

The external working groups of the NSF are addressing the following:

1. Children needing acute and hospital services
2. Maternity services
3. Mental health and psychological wellbeing of children and young people
4. Children in special circumstances
5. Disabled children and young people
6. Healthy children and young people

General Principles

- ❑ A senior member of the PCO has responsibility for children's services.
- ❑ A senior Strategic Health Authority member is responsible for children's services.
- ❑ The StHA monitors commissioning of services for children.
- ❑ Parents and children are actively involved in the services provided.
- ❑ Racial, linguistic, religious and cultural backgrounds are respected.
- ❑ Services are delivered as close to home as resources and expertise allow.
- ❑ Facilities in child health services are child friendly.
- ❑ Services are evaluated regularly to ensure they are meeting evolving needs.

- ❑ Health outcome information and technology systems are in place.

Families, children and young people need from the NHS:

- ❑ Access to pre-pregnancy counselling
- ❑ Screening in pregnancy and infancy
- ❑ Care during pregnancy and delivery
- ❑ Care at birth, including resuscitation, identification of abnormality and illness.
- ❑ Special, high dependency and intensive care of the newborn baby.
- ❑ A programme of immunisation
- ❑ A programme of health promotion
- ❑ Resources for parent support
- ❑ Screening and surveillance for pre-school and school age children and young people
- ❑ Protection against neglect and abuse of all kinds, at home and at school.
- ❑ Arrangements for consultation, advice and management for non-acute problems.
- ❑ Integrated multi-disciplinary care for those with disabilities and long-term problems.
- ❑ Early identification and intervention for children with signs of educational failure.
- ❑ Prevention, identification and treatment of mental health problems.
- ❑ Assessment and management plans for acute illness or injury.
- ❑ Care when sick or injured.
- ❑ Easy access to secondary and tertiary level expertise.
- ❑ Support and advice regarding adoption and fostering.
- ❑ Health care, both physical and psychological, for looked after and refugee children.
- ❑ Clear information.
- ❑ Involvement in decision-making processes.

- ❑ Seamless links with social and educational services and other health boards
- ❑ Reduction in inequalities of health status
- ❑ Health care monitoring and planning

A paediatric and child health service has:

- ❑ Services provided by staff whose training is appropriate for their duties.
- ❑ No paediatrician or other health professional working in isolation.
- ❑ Ready access for children to expertise that is relevant to their age and their needs.
- ❑ Children not admitted to hospital if their needs could be provided at home.
- ❑ Community children's nursing services.
- ❑ Clear pathways and programmes of care.
- ❑ Full range of skills accessible to deal with all aspects of paediatrics and child health.
- ❑ Risk management systems in place and necessary changes implemented.
- ❑ Research and critical review of evidence across all children's health care.
- ❑ High quality information systems and expertise to maintain databases.

Specific services

1. Commissioning health promotion

1.1 General principles

- There is a district child health promotion coordinator
- All parents have a Personal Child Health Record for their child.
- Other surveillance is provided as set out in *Health for All Children*.
- There is coordinated planning and management of statistical databases.
- Health Visitors and school nurses are involved in health promotion.

1.2 Screening and Surveillance Programmes

- There are effective screening programmes for the population.
- Written policies are available and effectively practiced for detection and referral of:
 - Hepatitis B and HIV in pregnancy
 - Phenylketonuria
 - Developmental dysplasia of the hip
 - Congenital hypothyroidism
 - Hearing loss
 - Other conditions as recommended by the National Screening Committee
- There are care pathways from surveillance and screening to diagnostic assessment.
- Screening and surveillance programmes are audited.

1.3 Infectious disease and immunisation Programmes

- ❑ There is a doctor designated as immunisation coordinator
- ❑ There is an immunisation advice service.
- ❑ These services work closely with the health visitors and school nurses.
- ❑ Immunisations are delivered to at-risk groups to provide protection from:
 - ❑ Tuberculosis,
 - ❑ Hepatitis B
 - ❑ Pneumococcus
 - ❑ Influenza
 - ❑ Meningococcus
- ❑ There is a named individual and reporting arrangements for infectious diseases.
- ❑ There are arrangements for the care of children who have HIV infection

2 Commissioning services for child protection

- ❑ There is a Child Protection Service Specification
- ❑ All paediatricians and nurses are familiar with the necessary procedures.
- ❑ Rigorous systems protect both children and doctors.
- ❑ Each Trust has a named doctor and nurse for child protection.
- ❑ There is a designated doctor and nurse for each district.
- ❑ There is appropriate representation on the Area Child Protection Committee
- ❑ There is close working with other agencies including social services and the police.
- ❑ There are proper protocols in line with national guidance and “Quality Protects”.
- ❑ There is training and continuing professional development in child protection.

3 Commissioning acute and emergency services

3.1 The newborn

- ❑ There are appropriate staff immediately available for resuscitation of the newborn.
- ❑ The levels of skills and numbers of personnel meet the standards for the size of unit.
- ❑ Managed clinical networks of maternity and paediatric services are being set up.
- ❑ There is clear information for mothers about the unit in which they will be delivered.
- ❑ Newborn babies are examined within 24 hours of birth by a trained professional.
- ❑ Retrieval arrangements for sick babies are being put in place.
- ❑ Neonatal units are working to meet national standards.
- ❑ Anti-D prophylaxis is given to mothers in pregnancy according to guidelines.
- ❑ Vitamin K is given to babies at birth.
- ❑ Information is available to parents so that informed choices can be made.
- ❑ Breast-feeding is promoted.

3.2 Accident & Emergency Services

- ❑ A and E departments have facilities for children separated from those for adults.
- ❑ The paediatric A and E unit has at least one registered children's nurse on duty
- ❑ Paediatric medical staff are rapidly available from inpatient paediatric facilities.
- ❑ Services are led by a consultant with expertise in the care of children in A & E
- ❑ There is a designated liaison consultant paediatrician.
- ❑ There may be ambulatory or short stay emergency assessment and day case units.
- ❑ Minor injury units meet national standards
- ❑ There is training for all nurses and doctors who deal with paediatric emergencies
- ❑ Information systems are effective and link to the child protection register.

3.3 General acute paediatrics

- ❑ Services are designed to cope with short stay and rapid discharges.
- ❑ Services balance access to tertiary specialist expertise with geography.
- ❑ Trained personnel are available to cope with emergencies at all times.
- ❑ Staff are trained in the assessment and management of acute infections.
- ❑ Plans are in place for high-dependency care.
- ❑ Facilities and time are available for paediatricians to manage outpatients.
- ❑ Education is provided for children in hospital.

3.4 Adolescent health

- ❑ Adolescents have dedicated facilities within paediatric units
- ❑ Staff are trained in working with adolescents.
- ❑ There is joint commissioning with Child and Adolescent Mental Health services.
- ❑ There is seamless transition for those with long-term conditions into adult services.
- ❑ There is good transition from community children's nurses to continuing care nurses.

3.5 Paediatric Surgery and Anaesthesia

- ❑ Services meet standards of the Royal Colleges of Surgeons and of Anaesthetists.
- ❑ Surgeons and anaesthetists undertake sufficient work with children to maintain skills.
- ❑ Specialist surgery is done by paediatric surgeons at specialist centres.
- ❑ District hospitals provide some surgical services, provided standards are met.

4 Commissioning child mental health

- ❑ There is a close working relationship between CAMHS and other children's services.
- ❑ There are resources for the management of behavioural disorders in childhood.
- ❑ Primary child mental health workers are involved in service delivery.
- ❑ There is psychological assessment and support of children with medical disorders.
- ❑ Provision is made for the assessment and care of children with:
 - ❑ attention deficit disorders
 - ❑ autistic spectrum disorders
 - ❑ behavioural disorders
- ❑ There is liaison with parenting schemes and Sure Start.
- ❑ Provision is made for the assessment and care of young people with:
 - ❑ depression
 - ❑ self-harm
 - ❑ eating disorders
 - ❑ drug and alcohol abuse.
- ❑ Protocols for management of mental health problems meet national guidance.
- ❑ There are multi-agency plans for those at risk of harming themselves or others.
- ❑ Education is provided for children and young people with mental health needs.

5 Commissioning long-term care

- ❑ Services are commissioned on a multi-agency basis.
- ❑ There are designated facilities and staff for children with developmental problems.
- ❑ There are audiological and visual services for children.
- ❑ There are designated doctors for educational liaison and Special Educational Needs.
- ❑ There is health care support for children with chronic medical problems in school.
- ❑ There is a specific health care plan for children looked after.
- ❑ There is medical support for local adoption and fostering panels.
- ❑ There are respite facilities for children with severe long-term problems.
- ❑ There are local facilities for the on-going care of children with long-term conditions.
- ❑ A 24hour/7day community children's nursing service is available.
- ❑ There is access to palliative care services for children.
- ❑ There are psychological and counselling services.

6 Commissioning specialised and tertiary services

- ❑ There is access to specialists in all recognised specialties of paediatrics.
- ❑ Collaborative commissioning groups exist for specialised services.
- ❑ There are no single-handed specialists.
- ❑ Services are provided in centres with a multi-disciplinary team as part of networks.
- ❑ There are provisions for specialist nurses and advanced nurse practitioners.
- ❑ There are children's therapists and dieticians.
- ❑ Resources enable specialist services to comply with national guidelines.
- ❑ Specialist services meet Specialty Group and Royal College standards.
- ❑ Accurate databases, preferably as part of national databases, are in place.
- ❑ Research and academic medicine are seen as essential to children's health.
- ❑ Clinical care is not dependent on University or research-funded posts.

7 Workforce issues

- ❑ The service does not depend on trainees working without supervision.
- ❑ Junior doctors' hours comply with the New Deal
- ❑ Consultants' and non-career grade doctors' hours meet the EWT Directive
- ❑ Inter-disciplinary working and multi-skilling is actively encouraged.
- ❑ Nurses who wish to take on enhanced roles benefit from training programmes.

8 Commissioning Training

- ❑ There is liaison with the workforce confederations in workforce planning.
- ❑ Registered children's nursing programme places are commissioned.
- ❑ Nonstandard posts include career development and methods of assessing competence.

9 Clinical Governance

- ❑ Arrangements are in place for quality assurance, audit and risk management.
- ❑ Good quality information is collected on local databases and national databases.
- ❑ There is easy, blame-free, access to the critical incident reporting system.
- ❑ There are high quality IT systems and personnel with appropriate expertise.
- ❑ Job plans include time set aside for clinical governance.
- ❑ Guideline development identifies research needs and these are addressed.

10. PCOs that manage acute and/or community paediatric services:

General responsibilities of PCOs to ensure:

- ❑ Appropriate lines of accountability within the professions.
- ❑ Detailed job descriptions and job plans for all staff.
- ❑ Systems for clinical governance involving multi-disciplinary teams.
- ❑ Standardised guidelines across the services.
- ❑ Annual appraisal and review of job plan for doctors by a medical practitioner.
- ❑ Facilities for training and continuing professional development of all staff.
- ❑ Extension of skill-mix to maximise use of staff potential.
- ❑ Professional leave for doctors, nurses and professionals allied to medicine.
- ❑ Management support for clinical leaders.
- ❑ IT facilities and means for audit.
- ❑ Facilitation of movement of staff and patients across trust boundaries.

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