

Modelling the Future

A consultation paper on the future of
children's health services

September 2007

Royal College of Paediatrics
and Child Health



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Visit the RCPCH website (www.rcpch.ac.uk/modellingthefuture) for:

- references
- PowerPoint presentation
- scenarios for discussion

The website also provides you the opportunity to respond to the questions set out in this report. The consultation on these questions closes on December 14, 2007.

Acknowledgements

This report is the culmination of 18 months of work. The project has been led by Dr Simon Lenton, Vice President for Health Services, working with Dr Ingrid Wolfe and Susan Mitchell. In particular the contribution of the six working groups and their chairs must be acknowledged:

- Acute and urgent care services, chaired by Dr Geoff Lawson
- Neonatal services, chaired by Professor Kate Costeloe
- Services for behavioural disorders, chaired by Dr Daphne Keen
- Services for disadvantaged and vulnerable children, chaired by Dr Helen Hammond.
- Long-term conditions services, chaired by Dr Hilary Cass
- Specialist services, chaired by Professor Andy Cant

In addition members of RCPCH Council have contributed ideas and feedback throughout the project.

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Foreword

It gives me great pleasure to introduce this landmark document. The future delivery of child health services is one of the most pressing and important issues facing paediatricians and commissioners today.

The aim is to achieve quality paediatric services of an agreed standard in a way that is safe and sustainable. These services should be provided close to home where possible and in a networked specialist centre where necessary.

Modelling the Future starts a series of publications on this theme planned by the College. This one sets the standards and opens the debate on how paediatric services should be delivered, the drivers, the principles and the possible models. It will form the basis for pieces of work that look at providing guidance as to how these models can be put in place locally.

The delivery of this document is thanks to an enormous amount of work by our VP for Health Services, Simon Lenton. He has brought to it his vision and encyclopaedic knowledge of health service issues together with his ability to combine public health principles to the practicalities of paediatrics. He has drafted, consulted, and redrafted many times with patience and painstaking effort and we are very grateful to him.

We are also grateful to the Health Services team – paediatricians and College staff – as well as those who have responded to consultations and made comments on earlier drafts.

Council commends this document to you, as do I, and we all look forward to a brighter future for paediatric services.

Dr Patricia Hamilton

President, RCPCH

August 2007

Executive Summary

The RCPCH aims to contribute to the health and well-being of children in the UK largely through improving the training, assessment and continuing professional development of paediatricians. However, the College recognises that paediatricians need to work in safe systems if their skills are to have maximum benefit for children and their families. This paper proposes options for better health service delivery in a variety of settings and is designed to stimulate local discussion and to generate national solutions particularly around service configuration and workforce planning.

Meeting the changing needs of children and families in a rapidly evolving health service will always be challenging. This is difficult now and will be for the next few years particularly because by 2009 we need to reconcile the expectations for high quality care with the limited numbers of paediatricians that are available under the European Working Time Directive (EWTD). The situation is further complicated by the impact of other NHS management changes including payment by results, choice, plurality and contestability, the changes in out of hours and urgent care provision, and the fragmentation of commissioning within the health sector and between other agencies providing children's services.

Modelling the Future started by reviewing NHS policy over the last decade and extracted two essential themes that are the essential foundations for the development of all children's services; these are clarity of *purpose* and *values*. These then underpin a *practical framework* to guide the future development of all children's services.

The *purpose* of the health service is to

1. Improve health.
2. Reduce inequalities.
3. Use resources wisely and be sustainable.

The *values* are based on the United Nations Convention on the Rights of the Child which are all about ensuring adequate provision of health services, protection of children from threats to their health and wellbeing and participation in decision making. From a health service perspective these can be further distilled down to the concepts of being family friendly, pathway based and continually improving :-

1. Family friendly means:

- Involving the child and family in the management of the child's condition.
- Assessment and management of the impact of the condition on the child.
- Assessment and support to address the consequences for the whole family.
- Consideration of the wider public health issues that impact on the child and family.

2. Pathway based means both basing services around the patient journey and taking a whole system approach to the commissioning, delivery and regulation of services. The starting point should be needs driven and end point outcome-orientated. To varying degrees there are five components to each pathway:

- Prevention.
- Identification.
- Assessment.
- Interventions.
- Long-term support.

Groups of pathways should be delivered by teams working within a managed clinical network.

3. Continually improving means that there is a system to constantly reflect, learn and improve. The improvement processes need to engage patients, clinicians, managers and policymakers so that they all pull in the same direction. To achieve this there need to be:

- Standards for the components and outcomes of the pathway.
- Measures that reflect those standards.
- Relevant and timely feedback to those using, providing and commissioning the service.
- Commitment and improvement processes to rectify any identified problems.

The purposes and values described here should be the bedrock for all of children's healthcare and they should guide both clinical practice and the development of services. From the perspective of the family the result is an accessible, effective and safe, seamless service and from a commissioning perspective the service is also sustainable, efficient and equitable.

The implications of this approach will challenge traditional professional organisational and management boundaries as it asks first what needs to be done, then who has the competency to do this well, then where can it be delivered conveniently and safely, and finally what support services are needed. The sustainability and equity of the chosen option has to be considered before a final decision is made.

This report examines how well the six major components of children's health services (acute, neonatal, long-term conditions, child behaviour services, vulnerable children's services and specialist services) fit with the purpose and values outlined. It then considers the major challenges currently facing those services and identifies possible solutions. The report is presented as a consultation to allow feedback in order to reach a consensus about ideal configurations for a variety of settings.

Key points

There is widespread support amongst paediatricians for greater cooperation between teams and organisations working in a geographical area. It is clear that greater cooperation between different

professional groups will play an increasingly important role in service design and delivery. This includes sharing clinical protocols, working in managed networks, rotating staff between services, and joint training. A whole-systems approach to planning change will help to ensure that unintended consequences are avoided.

Reconfiguration and local innovation are two ends of an improvement continuum and both have their roles to play in developing better services. Reconfiguration is usually large-scale involving changes in organisational capacity such as closing or moving hospital services. Reconfiguration can also mean changing clinical activity or roles (skill mixing). It usually involves multiple stakeholders, often has significant financial implications, and may be controversial. Innovation on the other hand, generally involves small-scale incremental changes in how services are delivered - in a different venue, at a more convenient time, a substitution of clinical roles, or an improvement in clinical practice.

Universal points

Challenges

- Improving the coordination and continuity of services from the patient perspective.
- Responding to changing epidemiology, by evolving from a focus on acute care to managing long-term conditions, in a model which focuses on delivering care closer to home.
- A greater emphasis on preventing the preventable.
- Addressing the issue of disjointed commissioning.
- Reducing unnecessary variations in health and health service outcomes.
- Improving transition to adult services.

Solutions

- Plan, deliver, inspect and regulate services along pathways and networks of care.
- Work more closely with Local Authority services and public health departments to promote health and reduce inequalities.
- Strengthen the commissioning capacity and function.
- Invest more in health services research.
- Design systems to continually improve services.

Acute and urgent care services

Challenges

- Increasing demand on emergency department services as a result of changes to General Practice services out of hours.
- Emergency departments not meeting current national standards
- Inadequate numbers of paediatricians to cover the current number of acute paediatric units.

Solutions

- Integrate urgent, emergency, and hospital paediatric services into managed networks.
- Recruit and retain children's nurses and develop their roles.
- Develop the competence of the first-line urgent care workforce.
- Implement 2007 guidance on standards for emergency departments.
- Reduce the number of acute inpatient paediatric units where units are small and in close proximity to each other.

Neonatal services

Challenges

- Insufficient number of paediatricians and neonatal nurses to provide safe high quality neonatal care services.
- Inadequate level 3 neonatal capacity.
- Insufficient capacity to retrieve babies and safely transfer them between units.

Solutions

- Strengthen specialist commissioning to promote neonatal network development.
- Address recruitment/retention of neonatal nurse practitioners and invest in their training and development.
- Review the medical and nursing skill mix in neonatal units.
- Develop better telemedicine and retrieval services.

Child behaviour services

Challenges

- Rising incidence and prevalence of child mental health and neurodevelopmental problems.
- Inadequate access to services to meet the demand.
- Insufficient access to child mental health services in homes and schools.
- Poor integration between health and education-based behaviour services.

Solutions

- Improve access to support in homes and schools by training parents and school staff.
- Develop the role of the school nurse.
- Integrate health, education, and social care provision into a managed network.
- Delineate roles of paediatricians, child psychiatrists and child psychologists.

Disadvantaged and vulnerable children's services

Challenges

- Increasing inequalities.
- A disjointed system for investigation, examination and care for vulnerable children.
- Insufficient numbers of paediatricians with forensic skills to maintain safe high quality care available 24/7.
- Poorly developed support services for abused and looked after children.

Solutions

- Improve the identification of families at risk and their access to support programmes.
- Improve access to specialist child protection services within a managed network over wide geographical areas.
- Develop units to integrate the elements of child protection work.
- Reduce the number of people involved with investigation, examination and long-term support and enhance their expertise.
- Improve support services to vulnerable children, especially looked-after children.

Long-term condition services

Challenges

- Increasing prevalence of disabling and long-term conditions.
- Poor continuity and coordination between services including the transition to adult services.
- Poor access to interventions such as support and therapy services.
- Paucity of research effort and lack of evidence on effective interventions for many long term disabling conditions and their effects on children and families.

Solutions

- Develop and roll out the expert patient model.
- Continue to develop community children's nursing and multidisciplinary teams.
- Improve the quality of the initial assessment and link to decision-support tools and protocols for referral.
- Invest more in support services.
- Invest in research for prevention of long-term conditions and interventions for management and support.

Specialist services

Challenges

- Access to tertiary hospital-based specialist services may be inconvenient for patients.

- The capacity of specialist services often does not match need.
- Fragmented commissioning of specialist services together with inadequate and poorly coordinated funding streams.
- Affording increasingly complex and expensive specialist interventions.

Solutions

- Develop managed networks so specialist services are available closer to patients' homes, where it is safe to do so.
- Improve the capacity and competence of those commissioning specialist services.
- Define the specialist component within care pathways.
- Reduce the number of centres providing tertiary care to enable EWTD compliance.
- Define the specialties that need 24/7 hands-on consultant delivered service.
- Develop better on-call consultation services.
- Develop the role of specialist children's nurses.

Implications for configuration and workforce

In remote and isolated places inpatient provision needs to be maintained so all paediatricians will need to participate in the on-call rota and also provide non-urgent (planned) services. Active links with larger centres for consultations, using telemedicine, for example, and rotating staff between remote units and larger hospitals should help to develop and to maintain local safety and competence.

Acute provision in hospitals that are small but close to another often larger hospital still requires further evaluation. However, a combined urgent care centre and emergency department linked with an observation and assessment unit, open for peak hours, appears to be a viable option. Paediatricians could cover such a unit, either locally or from the larger centre.

In large and medium-sized places, two models of service provision are emerging. One model is a team of paediatricians offering acute and urgent care across an inpatient unit, an assessment unit and an emergency department, working closely with a second team of paediatricians providing non-urgent care in community settings. The alternative model is that all paediatricians provide acute care as consultant-of-the-week and all provide non-urgent care in the community at other times.

Whether a separate neonatal on-call rota is required in such places depends on the designation of the neonatal unit. A separate rota is required for a Level 3 unit, but a Level 2 unit should be cross-covered at night from the general paediatric rota. The issue of adequate Level 3 neonatal capacity and retrieval teams still needs to be resolved.

In large tertiary centres there could be a separate general acute on-call rota generally not involving specialists. Some specialists will need to be available for hands-on clinical work 24 hours a day, though this may mean reducing these specialist services in some centres. Specialists not providing 24 hours a day hands-on clinical work should be available to provide telephone consultation for on-call paediatricians, so when on-call, this may involve working in a network covering more than one tertiary centre.

Finally, at this stage these proposals are for discussion and consultation. Key questions for discussion at a Regional level are included throughout this document to help structure feedback, collect good practice and so shape the future of children's services.

Introduction

Why has this report been written?

“You can and should shape your own future; because if you don’t somebody else surely will.”

Joel Barker

David Nicholson, as NHS Chief Executive, has clearly signalled that there needs to be a reconfiguration of services in England and the many issues driving change are equally applicable to the other nations in the UK. Large-scale reconfiguration is often an expensive and time-consuming process which then sometimes falls at the last hurdle due to public and political concerns over the closure of local services. Children’s services are often overlooked in these large-scale reconfigurations, so this report has been written in order to openly discuss the strengths and weaknesses of children’s services. The intent is to stimulate a debate and generate ideas about the future design of children’s services.

It is hoped that this piece of work will then influence plans for reconfiguration and give children’s health services and those who work in them a stronger voice to influence the outcomes. It is the starting point of the process of reshaping children’s health services to better meet the needs of the next generation.

Who is this report for?

“No one will thank you for taking care of the present if you have neglected the future.”

Joel Barker

This first draft has been written by paediatricians, for paediatricians. This is not because other members of the multidisciplinary team are not important, nor that multi-agency working is not essential for the delivery of children’s services, merely that there are major implications of the European Working Time Directive (EWTG) on the ways that paediatricians work and the services they can offer.

It is the start of a process which aims to reach some consensus amongst paediatricians to form a vision on how children’s health services may be delivered in the future. It is aspirational so specific questions are included throughout in order to not only ground the process in reality but also engage and ascertain the views of readers.

What comes next?

“Vision without action is merely a dream. Action without vision just passes the time. Vision with action can change the world.”

Joel Barker

Large-scale change will not happen without the engagement and agreement between a wide range of stakeholders. Once feedback from paediatricians has been assimilated the process of external consultation with other professional bodies, commissioners and regulators and UK government departments will start.

At this stage we are not making firm recommendations - that will come later once a consensus is reached. More detailed work on the workforce and services implications will follow as part two of this project. In addition we plan to develop guidance on standards, criteria for decision-making, co-location of specialist services, examples of good practice and other relevant papers to support the process of change.

Background to this report

“Paediatrics is at a crossroads. The RCPCH can, and should, have a real influence on the pattern and delivery of care to children over the next 15 years or more. There is a great deal of work to be done to develop these, and other, ideas and to draw on the many examples of innovative practice which already exist.”

RCPCH, 2001

The NHS is a vast organisation and too complex for central solutions to local problems. While central Governmental politics and policies clearly have a role, meaningful solutions require a detailed level of knowledge of the local area and its community. There is now central acknowledgement seven years into the NHS Plan, that there needs to be a significant change in emphasis from centrally driven target orientated change, to a process of continuous local innovation and improvement led by clinicians delivering the service (DH, 2006).

The RCPCH Council discussed these issues and proposed this piece of work to develop and present models of future service delivery relevant to a range of populations, to enable members to develop and improve their services. The aim was to draw heavily on the talents and experience of College members to ensure that the document is useful and relevant in real-life settings.

The remit for this project was therefore:

To produce a document that proposes models of service delivery and examines their applicability in a range of settings, covering small, medium and large populations and urban, rural and remote areas.

To examine the reconfiguration and medical workforce implications of the various models (recognising the importance of teamwork and the competencies of other professional groups).

It was important to understand the current issues facing children's services, establish a set of fundamental principles to underpin all services and to set a clear direction for future service development to ensure safe, high quality, and sustainable services for children. The Report needed to be equally relevant for the four nations of the United Kingdom.

Excluded from the remit was the future of academic paediatric and child health departments, undergraduate and postgraduate training, NHS management structures, the provision of public health and paediatric intensive care.

Six working groups were formed loosely based on the English NSF standards. They examined emergency and acute care, neonatal care, services for vulnerable children, services for behaviour and neuro-developmental problems, long-term conditions and specialist services. Their findings were used as the basis of this report and were presented at the RCPCH Policy Conference in March 2006. Four broad themes, applicable to all services, emerged:

1. A safe and effective service depends on a partnership between knowledgeable and engaged patients and competent committed professionals working in a system that supports constant updating of their knowledge.
2. Strong teamwork and good networks are important to ensure a seamless patient-led service working across the traditional boundaries of primary, secondary and tertiary care and are necessary to deliver patient-centred excellence.
3. Innovation, evaluation and dissemination of learning are all integral parts of service delivery and need investment to reflect this importance.
4. The solutions proposed should be as simple as possible and should have intuitive appeal, so making sense to patients, clinicians, managers and commissioners working in any part of the health service.

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1. Where are we now?

The health and well-being of children

The 2007 UNICEF Report (see appendix 1.1) paints a challenging picture for all those involved with the health and welfare of children. The UK ranks lowest of the 25 richest countries for the health and well being of its children and young people. We have some of the highest rates of infant mortality, low birth weight and teenage pregnancy in Europe. Although the underlying causes of many of these problems lie outside the immediate control of the health service, they do make great demands on the health service, reinforcing the importance of including prevention in commissioning plans.

Inequalities

Inequalities in health and wealth continue to grow (Dorling et al, 2007) with 1% the population now owning 25% of the nation's assets. There is recognition that if inequalities in health could be reduced, there could be considerable reductions in demand on health services (RCPCH Equity Project, in prep).

Quality of health services

Children's hospital services in England have recently been reviewed by the Healthcare Commission (2007). They judged the quality of services on four criteria - quality and safety of medical and surgical care, safeguarding, communication, play and child friendly environments. They found only 4% of organisations were excellent, 21% good, with 70% being fair and 5% weak. They also identified 16-18% of hospitals with insufficient emergency cover for serious paediatric problems at night and 20 hospitals who admitted fewer than 1800 children per year within a 30 minute car drive of the next nearest hospital. RCPCH has identified 224 hospitals in the UK within 20 miles of each other. The Healthcare Commission report delivers strong recommendations - all children's hospital services need to be managed by one children's directorate and autonomous units and trusts need to cooperate to develop clinical networks across geographical areas.

Children's health outcomes

Outcomes of health services are often difficult to measure, so there are few robust studies. However, comparing the performance of UK health services with those in Europe suggests that the outcomes for diabetic control (DH, 2007), solid tumours and neonatal intensive care (Craft, 2007) are less than would be expected.

The four nations

The devolution of power and decision-making should improve local responsiveness and accountability but risks fragmentation and duplication of effort. It is essential that UK based organisations such as RCPCH learn from and spread good practice developed in one nation across all the UK nations. Examples would include the Welsh National Service Framework and specialist service frameworks from Wales and the work on pathways and networks from Scotland.

A voice for children

The Children's Commissioner for England has rightly highlighted the importance of giving children and young people a voice in society and that includes listening to their views about their experience of the health service and the health issues they feel are a priority. At an individual level children need to be appropriately involved in decision-making about their own health and the NHS needs to find ways of engaging with groups about their collective experience of the health service.

National spending on children's services

In real terms spending on children's services has never been greater. There have been very significant investments in health, education, social care and the criminal justice system over the last decade. However children's services have not been prioritised for investment within the health service which now spends a total of some £80 billion annually. The population up to 19 years of age is approximately 15 million (20% of the total population) but interestingly some 30% of all NHS spending is estimated to be in the last three years of life.

In England total healthcare spending for all children is £3,139 million, while spending on social care for 800,000 children is £4,000 million, which in turn is dwarfed by the education spend of £35,467 million. Most expensive of all is the total Criminal Justice System which spends £22.7 billion in total (all ages) and the estimated proportion of spend on the under 25 year olds is 30% (approximately £7 billion). 2.5% of GDP is spent on public order and safety - the highest proportion in the developed world. It could be questioned whether this is good value for money, and whether some elements of crime and disorder can be prevented through better services during childhood.

The boundaries of paediatrics

The remit of paediatrics is changing rapidly. Changes to general practitioner out-of-hours care have resulted in increasing attendances to emergency departments. A shortage of CAMHS

capacity is increasing referrals to paediatricians and rising expectations in schools are increasing referrals for assessment of learning problems. As the boundaries of paediatrics expand there is a need to critically examine the roles of paediatricians and to consider whether some of their work might be more appropriately undertaken by other professional groups.

Configuration of services

There is a clear message that the current district general hospital (DGH) model of care for acute conditions is increasingly unable to provide appropriate services for long-term conditions such as disability, behaviour problems or obesity (National Leadership Network, 2006; Farrington-Douglas and Brooks, 2007). As services have improved the survival of children, complex health care needs have increased. Services for adolescents and young adults, have not kept pace with the changing epidemiology and needs of this group. *Our Health, Our Care, Our Say* (2006) is an ongoing commitment by the government to provide healthcare in local settings. However the potential shift of patient funding from the acute settings to primary care generates many questions about what is appropriate and safe to deliver locally. It may undermine the viability of small hospitals, just as the move of elective work to treatment centres has called into question the sustainability of some hospital-based training programmes.

Policy drivers of change

In England, both the Kennedy (2001) and Laming (2003) reports identified multiple problems including disjointed services, lack of clear leadership, little patient involvement, and no quality improvement processes in place. These reports informed the development of two major policy documents: England's *National Service Framework for Children* (2004), and *Every Child Matters* (2003), which together with the *Children's NSF for Wales*, and a series of documents from Scotland, describe a set of standards for children's services. All these publications emphasise the importance of patient journeys, teams, pathways and networks as the fundamental building blocks of service delivery.

Unfortunately some other national policies do not support this approach and indeed may act in direct contradiction to them. In England, Payment by Results (PbR) has the potential to destabilise health care systems, increasing financial weakness, encouraging unhealthy competition between organisations, and rewarding cost-savings over quality. PbR could also create perverse incentives, encouraging Trusts to admit patients when not strictly necessary or to classify patients as having more complex interventions to gain additional income. PbR does little to support collaborative working or the development of networks of care.

The emphasis on patient choice fits closely with PbR and has the potential to work well for

elective surgery. However it does not work well for emergency care, or long-term conditions where patients expect a high quality local service. In many senses patient choice is a key lever for providing family-centred care and should encourage genuine consideration of how well a service meets the needs of its users. However there are significant questions about how to offer patients meaningful choice, particularly for emergency care, specialist tertiary services or in remote geographical areas.

Delivering High-quality Surgical Services for the Future (2006) is an eloquent a piece of policy analysis by the Royal College of Surgeons of England, on the numerous policy directives impacting upon the delivery of surgical services, the majority of which are applicable to children's services. The report stopped short of suggesting solutions, however the general finding was that there is no 'one size fits all' solution to issues of service design, configuration and provision, and that a flexible approach based on networks is required.

Workforce drivers

The new Consultant contract and EWTD 2009 pose very real challenges to service rotas, on-call commitments and overall service capacity.

Acute children's services

There are currently 246 units that admit children acutely and large paediatric inpatient units will need more than one rota of doctors. Cross-cover between adult and children's services at night is not a solution because of the differing skills and abilities required.

To achieve 2009 EWTD compliance, it is estimated that approximately 8 doctors per acute paediatric rota will be required. By 2009 it is estimated that there will be 1180 consultants in England available to support acute and neonatal rotas (excluding Tertiary Centres). There are 158 paediatric units in England (excluding tertiary centres), with 31 units having a separate neonatal rota, and 9 standalone neonatal units. Hence in 2009 we assume there will need to be sufficient consultants to staff 198 rotas. Using these simple assumptions, we predict that by 2009 only 75% of the current units could be covered by the current workforce. The relationship between people staffing rotas and units to be covered is illustrated in table 1.

		Number of paediatric units			
No. docs on rota		125	150	175	200
	6	720	900	1050	1200
	8	960	1200	1400	1600
	10	125	1500	1750	2000

Table 1 Number of paediatricians required to staff units according to number of units and number of paediatricians on acute rota.

Whether paediatricians working in remote rural areas with a small population can be exempted from the European Working Time Directive has yet to be explored.

Neonatal services

There are 25 Level 3 neonatal units that will need to be EWTD 2009 compliant. Again, this appears unsustainable with present staff numbers and unit configurations.

Specialist children's services

There are 36 tertiary centres and 14 specialties in paediatrics. If every specialty was represented in every tertiary centre, and all provided on-call services requiring eight people per rota, the consequences for the paediatricians would be enormous. However, not all specialties need to offer 24/7 hands-on care and not every specialty needs to be represented in every centre.

The impact of Modernising Medical Careers (MMC) is likely to be significant and place further strain on the system. As duration of training is shortened the proportion of time for service delivery becomes more limited and more consultant supervision for less experienced trainees will be needed. The long-term impact of MMC on the availability of staff-grade doctors is more difficult to predict at the present time.

Recent and on-going changes in the numbers and working hours of medical staff have not been matched by a sufficient expansion and development of other members of the clinical team. In particular the development of children's nurses and allied health professionals should be supported to enable doctors to focus on the more complex clinical problems. The proposals in modernising nursing careers (RCN, 2004) and the future of health visitors (DH, 2007) and school nurses are welcomed and will need to be matched with opportunities for further training.

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2. Where do we want to be?

Our vision, as paediatricians, is of a health service that places children and families at the heart of everything we do (RCPCH, 2006a). We believe this can best be achieved by working together in comprehensive and integrated systems that support the concept of a family-friendly journey, along a coherent pathway of services with care being delivered by competent teams working together as described in *Understanding Pathways and Networks* (RCPCH, 2006b).

This vision defines a truly integrated children’s service, one which can deliver both local accessibility for common problems and access to first class specialist services for rare or severe conditions. This mandates a careful balance between achieving safe services at all times, while ensuring a sustainable system in the longer term.

These concepts should be endorsed by all those who work together to achieve better children’s services. Politicians, commissioners, service providers, and regulators to ensure that this vision becomes a reality.

Core concepts for designing services

There are two important concepts that need to come together to inform the practice of service redesign. First is a clarity of purpose - *what* the service is to achieve, and secondly a set of values to determine *how* this is to be achieved, see figure 1.

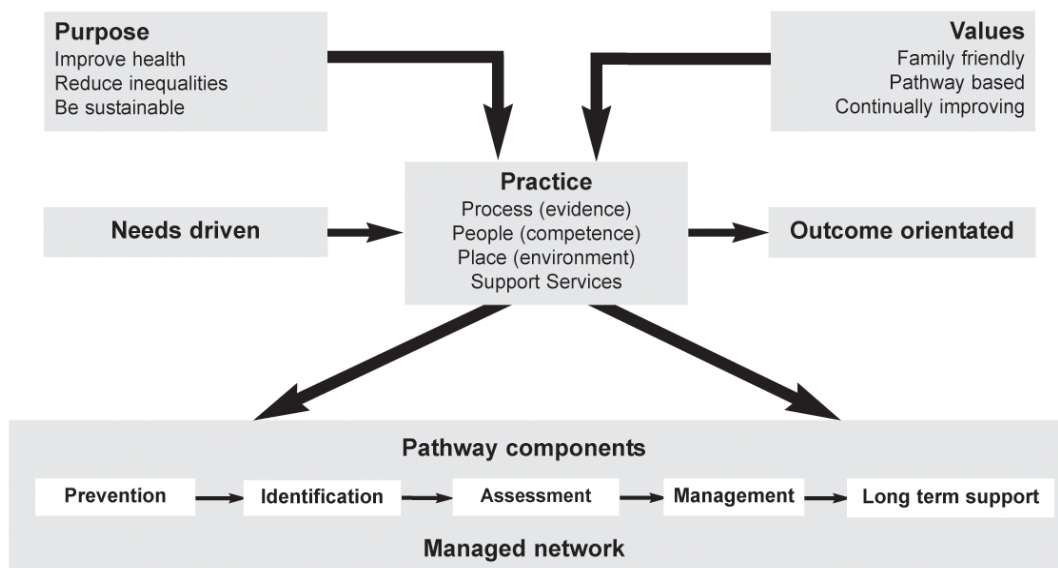


Figure 1. Schematic diagram of components of service design
 Assessment = diagnosis or formulation of the problem.
 Management = short-term intervention.

Purpose

Improving health - Every Child Matters (2003) has defined five health-related outcomes that should be achieved by all children and young people whether they have a long-term conditions, mental health problem or are unable to live with their biological parents:

- Staying safe.
- Being healthy.
- Enjoying and achieving.
- Economic well-being.
- Making a positive contribution.

Reducing inequalities - it is well recognised that health and wealth are not equitably distributed in society. One of the founding principles of the NHS is that it is available to all, regardless of wealth or status in society. The issue is generally framed in terms of access to health services but it is probably more important to consider equity of health outcomes. The Government has stressed the adoption of targets to reduce inequalities in life expectancy and infant mortality between social classes (DH, 2003) but these principles also hold true for the outcomes of injuries or long-term conditions, such as, cystic fibrosis.

Be sustainable - sustainability relates to resources consumed and the social and environmental impacts of human activity. Health services need to use resources wisely and this includes natural, financial, and human resources. The health service should not only ensure both value for money for taxpayers but also consider the social and environmental impacts that the delivery of services may create. Human induced global climate change is one of the major threats to the health of the human population and the NHS with an £81 billion annual budget must lead by example and positively contribute to this agenda.

Values

Three values should underpin the practical delivery of services;

Family friendly which means:

- Involvement of the child and family in the management of the child's condition.
- Assessment and management of the impact of the condition on the child.
- Appropriate support for the consequences on other family members.
- Consideration of wider community and public health issues for example, transport, leisure and housing that may exacerbate the burden of care.

Pathway based which means taking a whole-system approach to the delivery of services – being outcome orientated, but driven by needs and always using best evidence. To varying degrees there are five components to each pathway, which are:

- Prevention.
- Identification.
- Assessment.
- Interventions.
- Long-term support.

Continually improving means that there should be regular feedback and review of service performance to identify the weakest link in the pathway. To achieve constant learning four elements should be in place:

- Standards for the pathway components.
- Measures that reflect those standards and clinical outcomes.
- Relevant and timely feedback to those providing the service.
- A process to improve any identified deficiencies.

Improvement is not yet an integral part of service delivery in the UK. In contrast the USA is beginning to embrace continuous improvement with the Institute of Healthcare Improvement (IHI) and National Initiative Child Health Quality (NICHQ) leading the process.

Practice

Bringing purpose and values together should inform how children's services are planned, commissioned, delivered, assessed and improved. To ensure the success of this approach patient groups, commissioners, providers and regulators should be signed up to using pathways as the basic building blocks of service delivery. The component parts of pathways are delivered by teams working together within a managed network.

This approach is equally applicable across health, education, social care, and the voluntary sector. Generally *what* needs to be done for a child should be based on evidence and is less open to variation, but *how* it is done, by *whom* and *in what setting* varies depending on the staff and skills available, the local environment, family needs, and resources available. Figure 2 outlines a generic example.

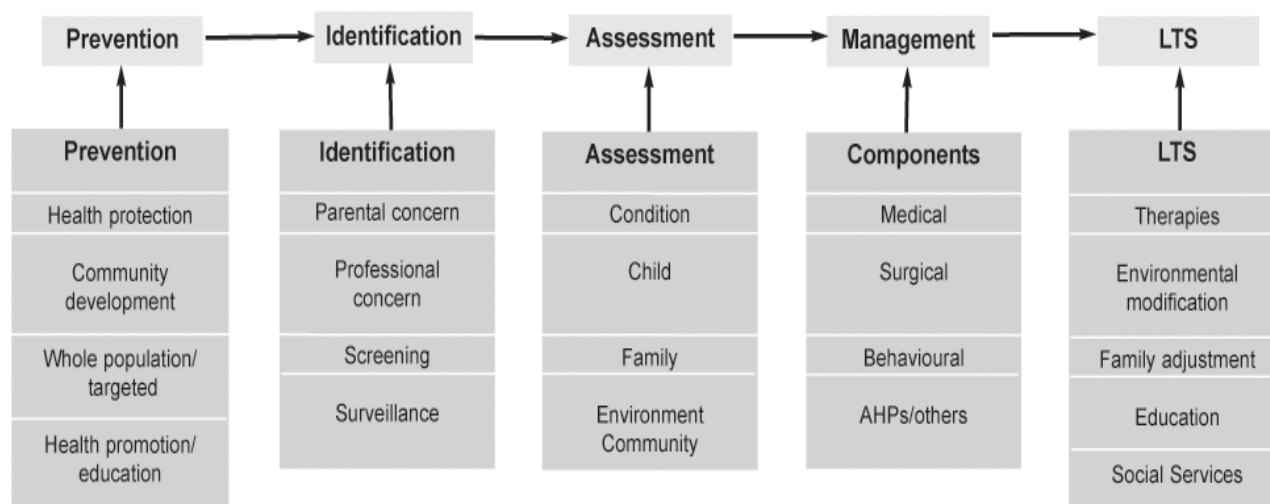


Figure 2. Example of interventions to support the components of the pathway

Designing networks to deliver services

A network can be described as “*linked groups of health professionals and organisations from primary, secondary and tertiary care working in a coordinated manner, unconstrained by existing professional and organisational boundaries to ensure equitable provision of high quality, clinically effective services*”.

Scottish Office, 1999

Networks also have a responsibility to balance the effectiveness, efficiency, and equity of service provision for individuals with the needs of the wider population. They should enable geographically dispersed units to work together to provide safe, high quality care by collectively defining the ideal pathway then identifying standards and measures at key points along the pathway that will support ongoing learning and continual improvement for those involved.

Networks allow formal links between various elements of the service and need to be carefully managed, but more importantly should allow resources to be moved within the network to where ever they are most effective.

There are many potential benefits to developing networks, including;

- Safe, effective, high quality care provided closer to home.
- Ensuring that all parts of a clinical pathway are provided, including prevention.
- Promoting the use of common protocols and clinical standards.
- Consistent quality assurance and improvement practices.
- Reduction in unnecessary referrals to secondary or tertiary care.
- Benefits for staff training and experience.
- Improved recruitment and retention.

Reconfiguration and innovation

Reconfiguration and innovation are both approaches to improving services, see table 2. Reconfiguration is usually a large-scale transformation involving multiple changes in organisational capacity, clinical activity or professional roles. It generally involves multiple stakeholders and often has significant financial implications for the organisations involved. It will need to incorporate public consultation and will need support of the Local Overview and Scrutiny Committees.

Examples	Reconfiguration	Innovation
Regional	Introduction of NHS Direct. Expansion of midwifery-led units. New screening test introduced. Changes in OOHs contracts.	Adding a new vaccine to programme. GP OOH cooperative development. Introduction of clinical governance. Creation of Map of Medicine.
Local	Closing an inpatient unit Opening an urgent care centre. Merging trust management structures. Specialist network development.	Substituting Nurse Practitioner for SHO Combined medical and nursing records Single point of entry for referrals. New IT system.

Table 2. Approaches to reconfiguration and innovation at a regional and local level

Innovation generally involves smaller-scale incremental changes in how services are delivered. This might be providing a service at a different venue, at a more convenient time, the substitution of clinical roles, or improvement in clinical practice. Patient consultation will have an important role but will occur in a less formal way.

Any proposed change will be viewed with a mixture of enthusiasm, concern and uncertainty by staff, patients, and the general public. It is important to plan the process carefully, to be prepared for the likely questions and concerns. Good preparation and understanding of the process, involving pre-consultation, consultation and implementation is crucial. Guidance is available on the RCPCH web site.

Questions

Q1. Is the message of combining purpose and values to inform practice simple and practical? Can this message be improved?

- Q2.** *Are there any additional important values that need to be included?*
- Q3.** *How can the pathway/network model be improved further?*
- Q4.** *Does the focus on improvement and the balance between reconfiguration and innovation feel right?*

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- Deming's improvement methodology (<http://www.deming.org>)
- Institute for Healthcare Improvement (IHI) (<http://www.ihl.org/ihl>)
- NHS Institute for Innovations and Improvement (<http://www.institute.nhs.uk>)
- National Initiative for Children's Healthcare Quality (NICHQ) (<http://www.nichq.org/nichq>)

3. How are we going to get there?

The forces at work on children's health services have been discussed and a set of service design principles that are universally applicable have been proposed. This section is in six parts and each briefly describes the service, examines the challenges facing the potential networks and their options for improving services.

What is interesting, although slightly repetitive, are the common problems facing each of the networks. Likewise the solutions are remarkably similar - improving commissioning capacity, workforce development including skill-mix within teams and having relevant information to aid decision-making, are the three commonest areas for improvement.

3.1 Acute and urgent care services

Definitions

The terms acute, urgent, and emergency can mistakenly be used interchangeably, resulting in confusion. In this paper acute implies a condition with rapid onset, usually within 24 hours; it could range from being life-threatening through to a self-limiting condition. Emergency and urgent care are *service responses* to an acute problem; by definition both are forms of unplanned, unscheduled care. **Emergency** implies that treatment or critical care is required within the hour. **Urgent** refers to a perceived need for health services within 24 hours. Children's emergency and urgent care applies to medical, surgical, mental health, and safeguarding conditions.

Key data (see appendices 1.6 and 1.7)

Primary care consultations (RCP, 2003)*

0-4 year olds see a GP 6-12 times per year*.

5-15 year olds see a GP 3-7 times per year*.

* *Not all are acute*

Admitted to hospital

1 in 9 children will be admitted in a year.

1 in 3 children under 1 year old will be admitted.

Emergency department consultations

3.5 million children attend emergency

departments annually in the UK.

25% of children attend ED per year.

Numbers of units nationally (RCPCH, 2001)

There are a total of 314 children's units in the UK. 246 admit children acutely and there are 36 dedicated children's emergency departments.

Where are we now?

Acute services are often perceived as the centre of children's health services. Historically each small town had its own hospital which included services for children. As time went on it became increasingly apparent that many of these hospitals were no longer fit for purpose, and so acute care was transferred to larger centres. However, there is a legacy of relatively small units, sometimes in close proximity to one another (often in large cities) where this rationalisation has not occurred.

There is an ongoing debate about what size of hospital is optimal for the efficient delivery of care. This is a complex question because of the changing epidemiology of disease and the rapid pace of technological development. The specific issue of the optimal size of a children's unit (emergency and inpatient services) to make optimal use of workforce time is currently being researched by RCPCH.

What is increasingly apparent is that the current configuration of acute services for children requires a fundamental review and needs a 'whole systems approach' to the totality of urgent care, whether this is delivered in either community or hospital settings.

Further centralisation of inpatient services always causes huge public concern mainly because there is little appreciation about the lack of safety within current configurations, for example lack of emergency cover at night. In countries where there are more centralised services there does not seem to be an increase in mortality or morbidity as a result of travel. It is important to learn why such systems are effective.

What are the major challenges?

Changes in primary care. A major cause for concern are the changes in out of hours provision, and in particular the introduction of urgent care provision by a wide range of practitioners, not all of whom have had appropriate training in the assessment of the acutely sick child. Many places are reporting increased numbers of children attending emergency departments and without an increase in paediatric capacity in EDs this may result in increased numbers of admissions.

Too many, too small hospitals. There are insufficient numbers of either paediatricians in training, staff grade paediatricians or consultant paediatricians to safely maintain the numbers of staff on rotas to be compliant with EWTD 2009. The option to substitute middle grade medical staff with senior children's nurses is significantly curtailed by the number of advanced nursing training places available to nursing staff.

Emergency departments. There are around 200 general emergency departments of which around 25% have dedicated children's facilities, and 36 children's emergency departments in the UK (RCPCH, 2001). The Intercollegiate group set standards for accident and emergency departments in 1999, (subsequently revised 2007) and an audit (Slater and Maconochie, 2005) demonstrated that significant numbers of standards were not being met.

Access to more specialist opinions. People working in primary care often complain of the difficulties accessing a consultant paediatrician to discuss a child that they are worried about, so as a result they refer the child into the local hospital for a second opinion.

Likewise those working in emergency departments complain about access to child psychiatrists on-call, radiological and surgical second opinions, while paediatricians would like better access to more specialist care.

What are the solutions?

Improved commissioning and regulation. Urgent care needs to be commissioned, delivered, inspected and regulated as a whole system. Because primary care, urgent care centres, emergency departments and inpatient units have developed as autonomous independent services, they rarely share protocols, pathways, training, audit or rotations to guarantee 24 hours a day quality and safety. SHA Unscheduled Care Boards (UCBs) must have appropriate representation to consider the urgent and emergency care needs of children.

Networks. The urgent care network will need a number of elements which work together to ensure that children receive the most appropriate care as quickly as possible within the system. This may range from emergency admission via ambulance through to self-care at home. Because of the unpredictability of the course of children's illnesses a period of observation is often integral to clinical management. Observation may be at home, in an assessment unit or on the children's ward. When it is clear that children are clinically deteriorating there should be clear protocols outlining when to intervene or to transfer to a place where more specialist care is available.

Competence of the first-line paediatric workforce. The competences of the 'new' emergency care workforce supplementing General Practitioners need to be rigorously assessed to ensure they are competent to look after children and families. GPs who are increasingly managing long-term conditions will eventually have far less exposure to the acutely sick child and will also need to maintain their competences if they work in urgent care centres.

Emergency care practitioners and emergency nurse practitioners will require a range of skills depending on their role within the acute practitioners team.

Essential urgent care competencies include:

- Recognition of the sick child.
- Basic life-support skills.
- The ability to initiate treatment using protocols for the management of common conditions.
- Recognition of rare but treatable conditions.
- Insight into when to access a more expert second opinion.
- Child protection recognition skills.
- Understanding the limits of their knowledge.

Co-location of urgent care centres, emergency departments and inpatient units.

Urgent care must be provided 24 hours a day with no distinction in quality or access between working hours and out of hours. It is essential that all frontline staff delivering urgent care for children are competent for safe practice in which ever setting they work. If these staff are not available it is proposed that only a proportion of urgent care centres are designated for the care of children.

Wherever possible urgent care centres treating children should be co-located or integrated with emergency departments with shared facilities for triage, observation, investigation and second opinions. The role of the GP who works across traditional primary and secondary care boundaries should be revisited. All urgent care venues should have systems to allow easy access to second opinions whether in person, by phone or via telemedicine. Alternative solutions need to be explored in remote areas without either emergency departments or inpatient facilities.

Where paediatric inpatient services are required, but not on-site, a prompt transport service will form an integral part of service delivery. Retrieval services (meaning transport and a skilled clinician) will be needed when children require access to either intensive care or specialist services but are too sick to travel by other means.

Improved emergency departments standards. The standards outlined in *Services for Children in Emergency Departments* (RCPCH, 2007) should be implemented. Standards for a children's urgent care network need to be developed and then translated into meaningful measures that have relevance to clinical care and fed back on a regular basis to drive improvement.

Models of service delivery

Within any region there will be a variety of small, medium and large district general hospitals, the majority of which will have an emergency department, but not all will necessarily have overnight inpatient accommodation. Additionally there will be a variety of urgent care provision including primary care, walk-in centres and urgent care centres. To ensure safe and effective care that represents value for money, these various elements need to work collaboratively together. Figure 3 illustrates the potential relationships of the component parts that might be present in one PCT area.

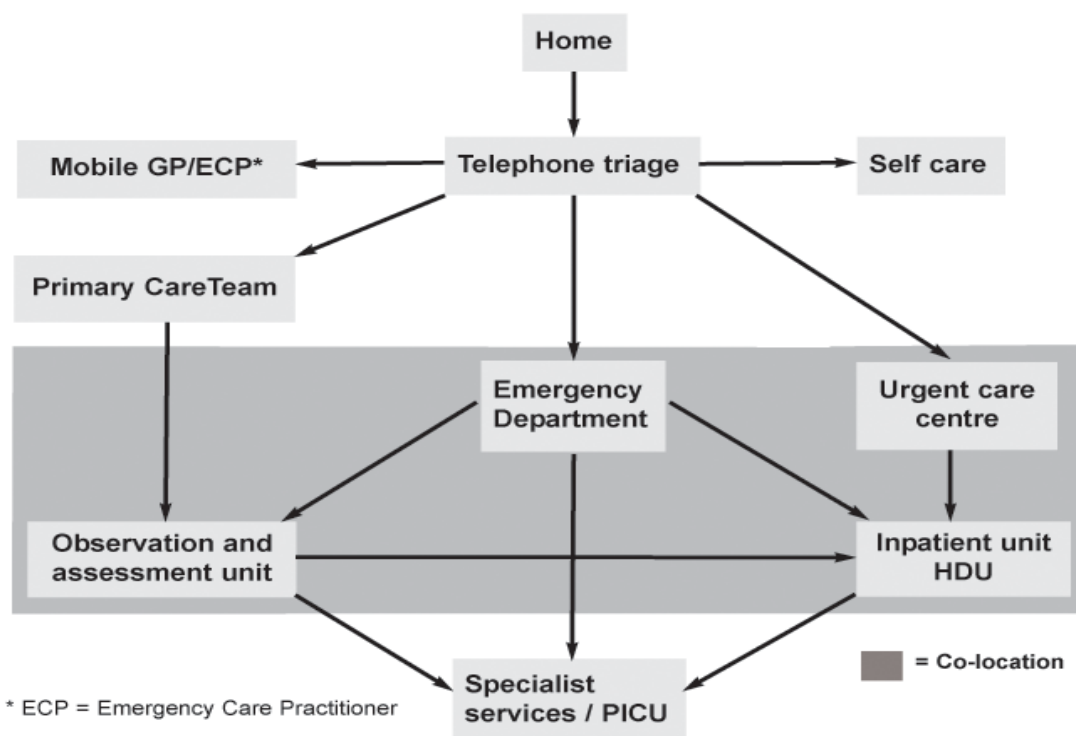


Figure 3. Diagram of possible acute care network

Exactly how urgent networks are configured will depend largely on the location and population. In units covering a small population, the challenge is to maintain the competence of practitioners when few children are to be seen and so uncommon conditions become a rare event. Networks that incorporate small or remote services must ensure that clinicians have access to support, guidelines and protocols, and education/training from larger centres. Rotation of staff between centres is recommended.

Consideration should be given to combining children’s urgent primary care, emergency department care and paediatrics services, especially out of hours and in remote places. When small units are located close to either medium or large centres, amalgamation or consolidation of services and management structures makes sense, providing the unit that has

increased in size can still function safely without a doubling of the workforce to accommodate the new throughput. The reduction in inpatient accommodation on one site may mean that the capacity of a local observation unit will need to be increased, combined with good transport or retrieval services.

Provision of acute services in remote and rural settings

- Emergency department with audio-visual separation for children.
- Urgent care centre co-located with the emergency department.
- Children's assessment and observation area either attached to emergency department or within children's ward.
- Children's ward.
- Retrieval or emergency transport service.
- Access to specialist second opinion, telemedicine support.

Provision of acute service for small settings near to larger centres

- Emergency department with audio-visual separation for children.
- Urgent care centre co-located with the emergency department.
- Children's observation area attached to emergency department.
- Retrieval or emergency transport service.
- Access to specialist second opinion either on site or via telemedicine support.

Provision of acute service for medium-sized settings

- Emergency department with dedicated children's area.
- Ideally, co-located urgent care centre.
- Some community-based urgent care centres appropriately staffed and designated for children.
- Children's assessment/observation area attached to emergency department or within children's ward.
- Children's ward.
- HDU.
- Access to transport and retrieval service.
- Access to specialist second opinion and telemedicine.

Provision of acute service for large settings

- Children's emergency department.
- Ideally, co-located children's urgent care centre.
- Some community-based urgent care centres designated for children.
- Children's observation area attached to emergency department.
- Children's ward(s).
- HDU.

- PICU.
- Provision of transport and retrieval service to other local centres.
- Co-located specialist services.
- Provision of telemedicine/second opinion to smaller places.

Workforce requirements numbers and competence. In emergency departments children require competent care from appropriately trained professionals whether from a paediatric or emergency medicine background or a combination of both. If an emergency department exists without a co-located inpatient service (i.e paediatricians on site), there needs to be a skills “uplift” throughout the emergency department in order to be able to manage the seriously ill or injured child. To provide 24/7 paediatric consultant cover for acute services (wards, assessment, ED, short-term follow-up) will require a minimum of 8 consultant paediatricians with exact job plans decided locally. In units where there is a small throughput of patients, there will be unused consultant capacity which can be used for non urgent (planned) care.

In small places, these consultants will also cover neonatal care, but in medium-sized places the designation of the neonatal unit will determine whether a separate neonatal rota is required. It is important that all those covering neonatal units, especially at night, maintain their neonatal skills.

In large tertiary centres there should be an acute/urgent general paediatric team for the local population, which can be identified separately from the provision of specialist care over a wider geographical area, so there is not a conflict of interest for paediatricians providing sub-specialist services, education and training, or research.

The issue of whether consultants need to be resident on-call depends on the capacity and competence of the urgent care team. When trainees are an integral part of service delivery consultant cover will depend on trainee experience, and may vary depending on where they are in their training.

The full potential of children’s nurses in acute settings has yet to be fully explored. Currently the safety of many units depends on the competence of the senior nurse on duty, especially out of hours. As the roles and responsibilities of ECPs expand so the skill mix of the acute team will evolve.

Local innovation. Examples of local innovation would include:

- Alternative forms of out of hours urgent care including MIMIS (Minor Illness, Minor Injury Service), urgent care centres, ECPs.

- The use of observation and assessment units.
- Combining functions of urgent care centres and emergency departments.
- “Consultant of the week” working.
- Combined medical, nursing, AHP clinical records.
- PICU based retrieval teams.
- Injury surveillance systems.
- Hospital at home teams.
- Primary care asthma nurses.
- Community children’s nursing teams.
- Proactive plans for acute deterioration for children with long term conditions.
- Electronic prescribing.
- Automated discharge letters.
- Ward-based decision support systems.
- Changed skill mixes within acute teams.
- Consultants resident on-call.
- Expert patient programmes.
- Pre-outpatient clerking questionnaires.
- Post hospital satisfaction assessment.
- Nurse practitioners in acute assessment units.
- Paediatricians in EDs.

Questions

- Q5.** *Are the proposals to move toward co-location of urgent care centres and EDs the correct solution to improve out-of-hours children’s care? What are the alternative solutions?*
- Q6.** *Is this also an appropriate model for in-hours acute care? If so, where would this be most appropriate?*
- Q7.** *Should paediatricians, working with emergency department and primary care colleagues, be planning to provide a networked service for urgent care for children (assuming appropriate financial flows)?*
- Q8.** *Should we be training more emergency department paediatricians?*
- Q9.** *How many children need to be seen for a dedicated children’s emergency and urgent care department (separate from adult services) to become viable?*
- Q10.** *Current modelling suggests that a minimum of eight consultant paediatricians are required in an acute rota for a balanced mix of activities. Is this the correct number direct clinical commitments and supporting professional activities. Is this the correct number for a) small units, b) medium units, c) large units?*

- Q11.** *What is the correct mix for an out-of-hours team in a unit of medium size size? For example, are three tiers of paediatrician (ST1-3, ST4-8 and consultant) necessary? What other team members might be appropriate for a paediatric hospital at night team? How would the team be structured?*
- Q12.** *When do consultant paediatricians need to be resident on-call?*
- Q13.** *In tertiary centres should the acute general paediatric service be provided by a separate group of general paediatricians who are not undertaking tertiary specialist services?*
- Q14.** *Do you have other examples of local innovations or service development you could share?*

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3.2 Neonatal services

Definitions

Neonatal services provide care for:

- Families with an antenatal diagnosis of a paediatric problem.
- The healthy mother and baby, including newborn screening programmes.
- The planned delivery and care of mature babies requiring specialist care.
- The emergency treatment of unexpectedly ill mature babies.
- The preterm baby.

Key facts

Service use

- Between 8-13% of all newborn babies are admitted to a neonatal unit, 2-3% will need intensive and/or high dependency care.
- 2:1000 deliveries are affected by hypoxic ischaemic encephalopathy (HIE).
- 3-4% of all births have a congenital anomaly.
- Around 5:10,000 births have Group B Beta-haemolytic streptococcal infection
- About 10% of NICU admissions are 28 weeks gestation or below.
- Babies 28 weeks gestation or below account for 40-50% of total NICU occupancy, and 70-80% of intensive care days.

Structure

England has 2000 intensive care cots and 1305 special care cots in 109 Neonatal units organised into 24 neonatal networks that serve the whole of England. The networks vary in size from 15,000 to 37,000 births covered by between 4-16 maternity departments. Most neonatal networks also include a perinatal care centre.

Where are we now?

A brief history and description of current provision Neonatal services first developed around a number of large obstetric units in the UK. Paediatricians trained in these units then took their skills out to DGHs, eventually developing neonatal intensive care capacity around the country. As neonatal intensive medicine progressed, DGH paediatricians faced a choice - they either needed to ensure sufficient numbers of local paediatricians developed their skills or transfer those babies requiring intensive care to a larger centre, sometimes requiring long journeys to find an available cot.

The 2003 Department of Health report on neonatal care and the NSF (2004) endorsed the British Association of Perinatal Medicine standards on workforce and configuration (2001). It recommended the development of managed networks for neonatal intensive care, together with the expansion of the larger regional centres for managing the most preterm or sick infants. Neonatal services are probably the best example of the introduction of pathway thinking and the use of protocols and managed networks at a national level.

The balance between maintaining local access to high quality services while sustaining specialist expertise in centres of excellence will always be challenging. The complexity of these issues is compounded by the fact that neonatal services must integrate seamlessly with antenatal services and co-exist alongside other hospital-based paediatric services.

What are the major challenges?

Prepared for the unexpected. All maternity units must be prepared for the birth of a baby with a life threatening complication whether it is a baby apnoeic at birth, one who becomes ill with Group B Streptococcal pneumonia or who has an unexpected major malformation.

Progress in neonatal medicine. A few years ago many babies at 30 to 32 weeks gestation required ventilation for Respiratory Distress Syndrome. This is no longer the case because of the rapid advancement of neonatal science. Many of these babies are now well cared for by a general paediatrician with a strong neonatal nursing team in a Level 2 unit.

The increased numbers of babies born at extremely low birth weights or surviving with congenital abnormalities is increasing so it is inevitable that the proportion of babies going on to develop disabilities is also rising. The highest quality newborn intensive care is essential to ensure good outcomes for the sickest and most premature babies otherwise the long-term cost to society is likely to be substantial.

The decision to transfer to a Level 3 unit needs to be taken on individual clinical grounds and while the smaller and more preterm infant is likely to need intensive care, mature infants with infection or Hypoxic Ischaemic Encephalopathy and those with serious congenital anomalies will also benefit.

Inequalities and antenatal care. The cycle of deprivation is well illustrated in many neonatal units. Teenage mothers and mothers who have significant mental or physical health problems are at higher risk for premature delivery, low birth weight, and infant mortality. The incidence of low birth weight could be reduced by 30% if the poorest people in our society enjoyed the same health as the most affluent. Developing effective support in pregnancy for these mothers is an important preventive health measure both for themselves and their babies.

Recruitment and competence of staff. Pressures on junior and consultant medical staffing pose significant challenges to the successful implementation of the networks. The investment required to achieve 24-hour consultant presence on Level 3 units is one factor that will drive the decision as to whether we should plan for greater centralisation of neonatal intensive care services than was envisaged in the DH review (2003).

At DGH Level 2 all consultants taking part in the on-call rota for intensive care must be competent to manage a neonatal emergency until a retrieval team arrives.

Level 3 neonatal intensive care capacity. The 2001 DH neonatal review rejected the option of major centralisation of neonatal intensive care services in favour of a more dispersed managed network system. However the investment that followed has not enabled sufficient Level 3 capacity to be developed in all networks. The result is either long distance transfers for high quality care, or the status quo whereby units designated as Level 1 and 2 continue to provide intensive care in cots that are not appropriately resourced.

Level 2 neonatal intensive care capacity. Insufficient special-care capacity in some referring units makes it difficult for Level 3 units to return babies. This leads to cot blocking in Level 3 units, and new referrals being refused. This is a grossly inefficient use of a specialist service, reducing access to Level 3 intensive care, and the services those units support such as neonatal cardiology and neonatal surgery.

Commissioning. Obstetric, neonatal, and paediatric services are often commissioned separately, obstructing the development of integrated networks of care. Since paediatricians often cross-cover newborn services and paediatric and emergency children's services, and because of the interdependence with obstetric care, changes in one service have knock-on effects on others. This makes for great difficulties in reconfiguration.

What are the solutions?

Reconfiguration. The reconfiguration and expansion in Level 3 capacity that started in 2003 should continue. This will help to ensure that the sickest infants within the network can benefit from the highest level of skill and expertise.

Level 2 capacity should enable infants to receive short term intensive care to the same standards as Level 3 with clear protocols, telephone support and retrieval/transport systems to guide transfers.

The move to provide greater choice of place for delivery needs to be accompanied by clear information for women about the level of neonatal care available in each option. In models involving birth at home and in stand-alone midwife led units, the midwives will need to assume an increased role in neonatal care.

Workforce. The skill-mix on a neonatal unit will depend on what clinical care needs to be provided. Once the competencies needed are determined, alternative models to the traditional three tier medical model should be considered. This may include expanding the role of neonatal nurses. Neonatal nurses could undertake many of the tasks traditionally performed by doctors in training. Only a small number of units have fully developed neonatal nurse capacity. In such units, specialist nurses can be the mainstay of hands-on care, running neonatal transport, leading neonatal resuscitation on labour ward, and taking part in practical training and supervision of trainees.

If expansion of neonatal nurses is the best option, then the arrangements for commissioning and providing all aspects of neonatal nurse training require urgent review as they are not keeping pace with demand.

All neonatal services, however small, must have at least one neonatal trained nurse per shift and should have at least one consultant with specialist training in neonatal care to ensure that all colleagues are competent to safely manage a neonatal emergency.

Traditional SHO duties on postnatal wards could be undertaken by midwives who would take on responsibility for postnatal examination and management of common newborn problems, with support from consultant paediatricians or neonatologists. This would of course require substantial expansion of the midwifery workforce.

Commissioning. Specialist commissioning capacity for neonatal intensive care requires investment to ensure that reconfiguration and workforce improvements become a reality. Commissioning neonatal services requires careful consideration of the impact on all the interdependent and linked services as described earlier.

Local innovation

- Neonatal nurse role expansion.
- Extended midwifery roles.
- Network management protocols with standards and audit.
- Earlier discharge and hospital-at-home for stable neonates requiring only oxygen or feeding support.
- Electronic records.
- Better nearby accommodation for parents.
- Improved retrieval and transport systems.

Questions

- Q15. Should GP trainees be working on a neonatal unit or should their roles be confined to problems encountered on postnatal wards?*
- Q16. At a DGH level, when should there be a separate consultant neonatal rota?*
- Q17. What is the optimal size of a Level 3 unit (both cots and staff)?*
- Q18. If neonatal consultants work in a shift system, how many are required during the day?*
- Q19. When should neonatologists handover the follow-up of infants with ongoing problems to other consultants?*
- Q20. How can access to neonatal retrieval teams be improved? Is a combined PICU and NICU retrieval team a viable option?*
- Q21. Do you have other examples of local innovations or service development you could share?*

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3.3 Services for behavioural disorders (neuro-developmental disorders and child mental health)

Definitions

The Children’s NSF (2004) in England states “*mental health problems may be reflected in difficulties and/or disabilities in the realms of personal relationships, psychological development, the capacity for play and learning, and in distress and maladapted behaviour. They are relatively common, and may or may not be persistent. When*

these problems are persistent, severe, and affect functioning on a day-to-day basis, they are defined as “mental health disorders”. Included would be:

- Conduct disorders for example, oppositional behaviours, defiant provocative behaviour.
- Emotional disorders.
- Anxieties, phobias and depression.
- Self harm and suicide.
- Eating disorders such as anorexia and bulimia.
- Psychotic disorders including schizophrenia and bipolar affective disorder.
- Substance misuse.

A neuro-developmental disorder exists when there are gaps, delays, or variations in the way a child’s brain develops. Included are:

- Difficulties with motor development, sensory integration disorders, speech and language delays and a range of cognitive difficulties including learning disabilities, poor organizational skills, self-regulation and behavioural disorders.
- Attention deficit hyperactivity disorder (ADHD).
- Autistic Spectrum Disorders (ASD).
- Other neurodevelopmental disorders such as Tourette’s syndrome.
- Learning difficulties.

Services for children with neuro-disabilities are covered with long-term conditions.

Key facts

Prevalence of mental health disorders in boys and girls (5-16 year olds) in 2004 (ONS, 2005)

Conduct disorder	5.8%
Hyperkinetic disorder	2.5%
Emotional disorder	3.7%
Less common disorders	1.3%
Any disorder	9.6%

Males are more commonly affected and children with multiple disorders account for one third of those using specialist mental health services.

Behaviour problems are not evenly distributed throughout society. Children with learning difficulties, those from a black or ethnic minority background, (especially if also they are refugees or asylum seekers), children in local authority care, and young offenders, will all have considerably higher levels of mental illness than the population average.

Where are we now?

Behaviour problems are extremely common. They are usually a manifestation of a complex interaction between genetic, social and environmental factors and this makes their management particularly complex. The long-term consequences for the child may be poor self-esteem, educational failure, and social isolation. The cost to society of delinquent behaviour both in terms of the criminal justice system, the impact of crime, and long-term costs to society through failure to achieve and adult mental health problems are enormous.

Services for children with neuro-developmental or mental health problems have evolved in a piecemeal way. Before the early 1970s the majority of child mental health services were provided by local authorities. Post 1972 most were integrated with adult mental health services rather than community child services. Services for children with learning difficulties were included in child mental health services in the past, but more latterly these children are considered to have a long-term condition and so their care is often provided by community-based paediatricians. The result is that the current provision is extremely variable from place to place. Generally paediatricians tend to see children with neuro-developmental problems and child and family therapy services those children with mental health disorders. With the increase in children with behaviour problems it is paediatricians, school nurses and health visitors who see and assess these children first, referring only a small proportion to CAMHS.

What are the major challenges?

Access to coordinated services. Behavioural problems have multifactorial causes and diverse manifestations. This leads to confusion among parents and professionals about how and where to access services. A child with a conduct disorder, initially recognised at school, may be referred to an education based behaviour support team, but that team would not normally deal with behaviour management at home. Conversely if referred to a CAMHS team they will address the home problems but are unlikely to address the classroom issues. For the most problematic children it is not uncommon for the CAMHS team, a community paediatrician, an educational psychologist, members of the behaviour support team and educational welfare officers all to be involved. In this situation the roles and responsibilities of each person are rarely clearly defined leading to either omission or duplication of activity.

The interface between the work of paediatricians and those working in the child mental health service particularly needs to be addressed. In some areas, particularly where CAMHS services are weak, paediatricians are managing the majority of children with attention deficit hyperactivity disorder and children with autistic spectrum disorders, whereas in other places these conditions are more commonly relayed to child psychologists.

Transition to adult services. Adult services for young people with autistic spectrum disorders and attention deficit hyperactivity disorder are generally poorly developed, and in many parts of the country general practitioners are unable to prescribe. Likewise adult services for drug misuse are rarely available to young people either under the age of 19 or 16, and child psychiatrists often do not have experience in this area.

Access to specialist services. In many places inpatient accommodation for the small numbers of children requiring admission is inadequate and remote. The result is that children with mental health disorders are looked after on paediatric wards without the necessary specialist skills being readily available. Likewise access to a child psychiatry second opinion for paediatricians on-call who have to undertake risk assessments on young people who have taken overdoses needs to be improved.

Commissioning. The integrated commissioning of children's mental health services is particularly challenging as it crosses primary, secondary and tertiary care as well as health, education, social care and sometimes the voluntary sector.

What are the solutions?

Prevention and early intervention. Webster Stratton, Triple P parenting course, and the FRIENDS programme have all been demonstrated to be effective when used either as preventative strategies or when problems have been identified. Access to these interventions is extremely limited.

Preventative programmes to promote emotional resilience, improve communication and family relationships have been positively evaluated and now need to be implemented universally. All first-line child mental health workers should have access to training and supervision in the use of one of the preventative programmes.

There is a role for health visitors and school nurses to become increasingly skilled in early identification and referral of suspected problems for further assessment using standardised tools (e.g. PEDS and SOGS). In turn, they can act as a skilled resource for Children's Centres and Extended Schools and support early years staff and teaching staff in prevention and early identification.

Workforce development. The Children's NSF in England recommends 20 WTE staff in a teaching CAMHS team, and 15 WTE in a non-teaching team both covering a population of 100,000 children (0-19 years) with an additional 5-6 specialists for learning difficulty. It is perhaps more important to examine total population need, consider what are effective

interventions, look at the competencies required to deliver them, and think creatively about where they need to be delivered. Then a local workforce recognising the work of paediatricians and community nurses can be developed that works across traditional boundaries.

Service commissioning and service management. The appointment of Directors of Children's Services, and Children's Trust arrangements should be used to further integrate Local Authority and health service components of child mental health services. The concept of whole system commissioning to deliver a network of behaviour support services has yet to be fully explored and used to full advantage in the commissioning process.

Greater outreach programmes. Several disparate professional groups are experts in the management of children's behaviour. Not all are accessible in home or classroom environments. Either there needs to be greater outreach of the professional groups, or alternative methods. For example, greater primary care team involvement to support parents and teachers in home and school environments.

Models of best practice.

There is no comparative evidence of the existing models, so no single model of service delivery can be recommended at the present time. However, integrated management structures within health, particularly between CAMHS services and community child health services, would facilitate equitable access to appropriate interventions and a more appropriate skill mix between the teams.

Local innovation

- Development or rollout of preventative interventions eg Webster Stratton or Triple P parenting course, FRIENDS child resilience programme.
- Development of tool kits for effective identification and appropriate referral of vulnerable families.
- Nurse Parent Partnership Programme or equivalent for families identified as most vulnerable.
- Care pathway development and management protocols for common conditions shared across agencies.
- A common (single) point of entry to services.
- A single set of notes or other systems for good information sharing.
- Development of key workers acceptable to all agencies to work in homes and schools.
- Development of more co-operative work between agencies and the community voluntary sector (CVS).

- Better use of the skills of GPs with special interests, nursing specialists, education staff and social workers to specialise and integrate into teams to care for children with conditions such as autism.

Questions

- Q22.** *Does it seem appropriate to group neurodevelopmental disorders and behaviour problems together?*
- Q23.** *Should the service for neuro-developmental disorders be split from the service for disabling conditions?*
- Q24.** *Should paediatricians or a CAMHS team assess and manage children with ADHD, ASD, and Tourette's Syndrome?*
- Q25.** *How can transition to adult services for young people with ADHD and ASD be improved?*
- Q26.** *Should paediatricians continue to provide medical input for children with learning difficulties or should there be a childhood equivalent to adult learning disability consultants?*
- Q27.** *Should CAMHS teams remain within adult mental health management structures, or should their management be transferred to children's service management structures?*
- Q28.** *In small and remote places could the local child psychiatry input be from appropriately trained paediatricians with specialist support from a larger centre?*
- Q29.** *Do you have other examples of local innovations or service development you could share?*

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3.4 Services for Disadvantaged and vulnerable children

Definitions

Children may be *vulnerable* because of poor health or disability and may be *disadvantaged* because of their family, social, physical, or economic background. Vulnerability and disadvantage together often lead to poor attainment, social exclusion and adult mental health problems.

Children-in-need are defined as requiring additional support or services to achieve their full potential.

Child abuse and neglect is defined as anything which those entrusted with the care of children do, or fail to do, which harms the child or damages their prospects of safe and healthy development into adulthood.

Safeguarding services are those which protect children and young people from harm, further abuse, or the consequences of abuse.

Key facts

Incidence and prevalence figures depend on the definitions used and therefore estimates vary widely. At least 150,000 children experience severe physical punishment, 100,000 have a potentially harmful sexual experience, and up to 400,000 live in environments consistently low in praise and warmth and high in criticism. (National Commission, 1996).

Category	%
Neglect	46
Physical abuse	29
Emotional abuse	18
Sexual abuse	18

(National Commission, 1996)

Studies report 33% children experience significant stress at home, 10% reported their families were not loving and relationships were not close, and 14% had assumed parental responsibilities because of parental illness, disability or personal problems.

The cost of services for children in need, experiencing abuse and who are looked after by the State is in the region of £4000m annually in England. The health service cost is more difficult to estimate because safeguarding and child protection is delivered throughout the NHS. (See appendices 1.6 and 1.4).

Where are we now?

Although there has been longstanding recognition of the impact of social and physical environments on the health of children, it has only been in the last 50 years that specific services have developed to care for children who have suffered physical abuse, neglect, sexual abuse and more recently services have arisen for children who have experienced emotional abuse. The focus now is to develop services to identify children at risk and intervene early to prevent injury or neglect.

There are significant numbers of children in the UK whose lives are profoundly marginalised and who are excluded from full access to the society in which they live. These children are often in poor health and have limited access to services, including health care. These children may include those from very poor families, refugee children, children from traveller families, children affected by drug and alcohol abuse, children in public care, homeless children and those living on the streets, and children affected by domestic violence and abuse.

While all areas of the UK are covered by safeguarding services, there is considerable variation in the way the services work and on occasions they fail children. The Laming Inquiry following Victoria Climbié's death highlighted a number of issues that led to *Every Child Matters*, a new edition of Working Together and strengthening of Local Safeguarding Children Boards. Although there have been significant improvements, creating a continuously improving system that is effective across all the agencies involved has yet to be achieved.

What are the challenges?

Balancing support and intervention. Providing family friendly services when family members may be perpetrators of abuse is often difficult and requires a carefully balanced response. Access to emotional and psychological support for abused and looked after children is often woefully inadequate, with consequent long-term costs on later mental health and social functioning.

Services for vulnerable children who need to be placed in care are less than ideal, certainly a long way short from a nurturing family environment. Outcomes for children who have been in care during their childhood remain poor. Educational achievement is low. They are 4-8 times more likely to be admitted with mental illness in adolescence or early adulthood.

Universal preventative services. The identification of the early signs of abuse by

practitioners across health, education, and social care remains a problem so throughout the health service all staff must have competent safeguarding skills. Health services are unique in that they provide a universal service in the antenatal and preschool periods and so have an important role to play in identifying vulnerable and disadvantaged families. It remains of great concern that any universal service may inadvertently increase inequalities, with the most vulnerable gaining least benefit from universal child health promotion programmes. Programmes such as nurse family partnerships attempt to mitigate such effects.

Coordination and continuity. The process of a child protection investigation can be very disjointed with police and social workers interviewing the child, doctors and nurses examining the child, and then a variety of people involved with providing ongoing emotional and psychological support.

Access to paediatric expertise. Recruiting and training paediatricians with specialist skills in child protection have become increasingly difficult over recent years. Moreover paediatricians who are already in-post are increasingly reluctant to take on these duties. This is at least in part because of the high media profile that some abuse cases attract and because of the rising numbers of complaints against paediatricians.

Ideally the person examining a child has both time and competence to do this, but this level of access and competence is often not available 24 hours a day. Moreover specialist forensic training and other areas of professional development are often not available or accessible to paediatricians or nurses.

Child death overview process. There is a proposal to introduce both rapid response teams after the death of a child and child death overview panels to inform Local Safeguarding Children Boards on how to prevent future deaths. This is generating considerable discussion about the role of the paediatrician in this process and how to release time to undertake these new duties, while maintaining current services.

Joined-up IT systems. Health, social care and police IT systems are a completely independent of one another which makes sharing information particular problematic, and does not encourage joined-up approaches to developing meaningful measures within pathways to drive improvement.

What are the solutions?

Commissioning. Commissioning capacity across agencies needs to be strengthened. Services for vulnerable and disadvantaged children are extremely complex and encompass

an unusually wide variety of types of care delivered by many different providers. They range from population-wide interventions to reduce poverty and deprivation, such as assisting with the take-up of benefits and tax-credits to targeted interventions for specific groups such drug abusing parents.

Safeguarding children is “everybody’s business” and so everyone must be aware of the issues and be able to take appropriate action if concerns are raised. The system then needs to ensure that a comprehensive assessment takes place, and that there is appropriate access to effective interventions. Child protection services are therefore nested within a larger system that is able to assess and manage children in need and cater for looked after children.

Centres of expertise. Children who may have been abused are currently assessed in a variety of settings. However with the increasing reliance on photo documentation, specialist investigation and sometimes the need for a second examiner, means that in future, services may only be offered in environments that can meet all these criteria. A dedicated unit, possibly within a children’s department in hospital, where video interviewing, photo-documentation of injuries, investigation and initial counselling and ongoing support can be offered would be a logical choice. The option of developing a team to provide these services with a designated member who can be involved with the child and family throughout the process of investigation and support should be considered. The use of sexual assault referral centres (SARCs) should be limited to young people who have been acutely assaulted and only when the competencies required to meet the paediatric and forensic components of the examination and ‘child friendly’ facilities are available.

Specialist paediatric opinion should be readily available, either at the time of examination through the use of telemedicine, or at a later time, when difficult decisions can be shared and discussed.

Workforce. Recognition of social paediatrics as an area of expertise, possibly as a subspecialty of paediatrics, supported by better training and ongoing professional development might improve recruitment and retention to this field. In the short-term, however, the highest priorities are to improve the evidence base and increase access to training and peer support.

The roles of nurses in child protection and in the care of looked after children have expanded in recent years. This needs to continue and be further developed so that all children in the system have a consistent point of contact to help manage their health problems and provide a crucial over-sight role, ensuring that all services for an individual child are in place and working for their benefit.

Models of service delivery

In small places. By definition the population is small and the number of paediatricians limited. In remote places one paediatrician will take the lead but all paediatricians will need to be able to undertake basic child protection examinations including CSA and will need easy access to a second opinion when they are uncertain about their findings. In small places in close proximity to, larger places consideration should be given to cross cover between PCTs to provide an on-call rota as an alternative model.

In medium or larger places. The numbers of children needing to be seen will be larger and all but the acute or serious injuries for the most part will be able to be seen as required during “office hours” in an appropriate clinical setting. Children with historical abuse can be seen in dedicated clinics that can be additionally used for training purposes. These larger centres need to be able to provide support to smaller places through the use of telephone or videoconferencing, peer review sessions or CPD opportunities. Furthermore the largest centres could be staffed by specialist child-protection paediatricians, who lead care across the region within clinical networks.

Local innovation

- Clinical centres of excellence.
- Use of colposcopy.
- Telemedicine for second opinions.
- Expert witness conferences prior to trial.
- Shared records.
- Covert video surveillance facilities for Factitious and Induced Illness (FII).
- Multidisciplinary audit of child protection practice.

Questions

- Q30. When should there be a separate child protection out of hours on-call rota?
How can this be organised practically?*
- Q31. Which paediatricians should form part of the rapid response teams proposed in chapter seven of ‘Working Together’ (2007)?*
- Q32. Should there be trained and accredited paediatric police surgeons or paediatric forensic medical examiners?*
- Q33. How can ongoing forensic training be provided for paediatricians involved with child protection examinations?*
- Q34. Is it a viable consultant post to work only with child protection, looked after children and adoption and fostering?*

Q35. Do you have other examples of local innovations or service development you could share?

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3.5 Long-term conditions services

Definitions

Long-term conditions (LTCs) are defined as lasting longer than 12 months and they may be intermittent or present all the time. LTCs result from disease, damage, disorder or injury to the body which then impacts on the individual and their family. Mental health conditions are considered as a separate category.

Examples would include predominantly single organ problems such as diabetes, epilepsy renal failure and asthma, and multi-system disorders such as cancer, cystic fibrosis or cerebral palsy.

Key facts

18% of children¹ have a long-standing illness or disability

- 42% of them have asthma
- 8% have skin conditions
- 6% of lung or respiratory disease
- 6% deafness or ear defects
- 5% have musculoskeletal conditions
- 4% digestive disorders
- 4% nervous system disorders
- 3% heart disease
- 3% urogenital disorders
- 19% other

¹Children 0-19 years old in GB (ONS 2000)

8 children² per 10,000 population have a severe disability

- 25% of them have autism and behavioural disorders
- 15% have severe learning difficulties
- 8% cerebral palsy
- 4% global developmental delay
- 3% epilepsy
- 2% asthma

²Children 0-16 years old in UK (ONS 2000)

There is a strong social class gradient for children with long term conditions. In Great Britain, 16% of children from the professional socio-economic group have a longstanding illness or disability compared with 25% from the unskilled manual group.

Where are we now?

Services for children with long-term conditions have often developed without a coherent service strategy. This is partly because of the wide variety and types of LTCs, some are relatively minor such as mild impairments of hearing or movement, whereas some are some profoundly disabling, such as life-threatening complex conditions requiring 24 hour ventilation. When the condition is rare and has a specific medical intervention specialist services are involved, for example cancer or renal failure. However, when the condition is more common, expertise can be maintained locally, for example diabetes and cystic fibrosis, with support from specialist services. While some conditions, such as cystic fibrosis, have medical interventions, others, such as Batten's disease may not, but both will have considerable day-to-day implications both for the child and family.

A small proportion of children with long-term conditions will die prematurely. Palliative care services have developed relatively independently from disabled children's services but in so doing have developed a model of service delivery based on pathways (ACT, 2004) which may be a more appropriate model for disabled children than current provision.

Services for children with neuro-disabling conditions. These services often revolve around a Child Development Centre (CDC) which may be based in hospital or in a community setting. In the community accommodation may be shared with a local nursery or childcare provision or Opportunity Group and more recently they are beginning to be co-located in children's centres or extended schools.

Child Development Centres are usually staffed by a multidisciplinary team, comprising at least a physiotherapist, occupational therapist, and speech and language therapist. Sometimes play therapists, nursery nurses, and other childcare specialists are involved. Some benefit from the involvement of social workers, the community voluntary sector (CVS) and staff from the education sector including education psychologists and specialist teachers. Paediatricians often work with Child Development Centre teams, particularly those with an interest in neuro-disability. Occasionally clinics for related medical specialties, for example orthopaedics, paediatric neurology, audiology, and ophthalmology are co-located. A minority of Child Development Centres continue to offer services through school age, ultimately transitioning into adult services. More frequently, services for school-age children are provided by individual clinicians or therapists working in a school setting.

Services for children with other (non-neurodisabling) conditions. These children are often under the care of a general or specialist paediatrician working from a local hospital or regional centre. Children usually travel to see a specialist, although some specialist services are developing outreach medical or nursing services to provide a service either at home, or closer to home. (See overlap with specialist services). The development of primary care asthma nurses has had a significant impact on improving the lives of children and reducing hospital admissions.

Generally the focus of these services is to manage the condition with less emphasis on managing the impact on the child or their family than for neuro-disabling conditions. Increasingly there is recognition of the importance of self-care, with the development of expert patient programmes being one example of increasing parental expertise in the day-to-day management of the child's condition. Transition to adult services works reasonably well where adult services have developed (for example, adult congenital heart disease), but this provision is far from universal.

Services for children with conditions requiring ongoing health technology support.

This group of children have a wide range of conditions, but they have a common dependence on technology to support life. Equipment ranges from syringe drivers through to full-time ventilation. Where there is more intensive life support there may be a requirement for round-the-clock carers trained and assessed in the use of the technology to support parents in their everyday lives. Often the team follows the child whether at home, school or respite care. The lead professional to this group is generally the community children's nurse, who may work within a multidisciplinary community-based team or as an outreach from hospital services.

What are the challenges?

Coordination and continuity of services. The challenges facing children and families with long-term conditions are well described in the NSFs. Families face difficulties with both duplication and omission of services, multiple assessments without access to interventions, lack of communication between individuals and services and poor multi-agency planning with arguments about financial boundaries. The coordination of care for children with multisystem disorders who are seeing multiple specialists can be particularly difficult.

Transitions between preschool and school, and between children's services and adult services are often problematic. While multidisciplinary and multiagency services have developed reasonably well for preschool children with neuro-disabling conditions that is

not universally the case for children outside that age group, or for many children with other long-term conditions.

Assessment and access to services. Despite a very wide range of diagnoses, the impact of long-term conditions on everyday living, such as feeding, toileting, mobility, behaviour, and sleeping, may be similar. While medical management of the condition may be good, nursing services to help manage the impact of the condition are often less accessible. Family support, either practical such as benefits and housing, or emotional and psychological, or short breaks are also all very variable.

Information. Traditional approaches to classification of disability using terms such as impairment, disability, disadvantage are not very practical in terms of describing additional help required and may indeed have hindered service development, as there is a paucity of reliable data on morbidity and service-needs on which to plan services. Information systems between health, education and social care remain separate so communication, audit and correlating service provision with outcomes remains limited.

Workforce. The current workforce for LTCs crosses health, education, and social care and roles and responsibilities are often poorly defined. There is considerable potential for skill mix within teams, but while the teams are managed by different organisations, this is often difficult to achieve.

What are the solutions?

Model of care. The management of children with long-term conditions is evolving from an acute care model to a chronic care model. Diabetes is a good example. In the past care was medically-centred, with doctors altering insulin regimes at hospital clinic appointments and patients being admitted when their diabetic control failed in between times. The new model (DH, 2007) promotes knowledgeable expert patients being supported by a multidisciplinary team of specialist nurses, dieticians, and psychologists, and they change their insulin regimes depending on their daily lifestyle and requirements. Management is proactive, aided by decision trees and algorithms for both patients and staff, with 24-hour access to telephone advice and shared health records. The diabetic network functions as a whole system with clear delineation of roles at a local and regional level; regular audit to drive learning and improvement at both the patient and wider-service level. The result is more satisfied families, better diabetic control, fewer hospital admissions and reduced long-term complications.

This approach when combined with local delivery in primary care centres, polyclinics,

community hospitals, children's centres and extended schools should enable community-based multidisciplinary teams to better manage children with long-term conditions in their environments and so improve their long-term health and well-being.

Commissioning pathways and networks. Services for children with long-term conditions could be greatly improved by being commissioned and organised according to pathways of care. An incremental move towards delivering care in networks is needed starting by working with specific condition groups, ensuring that all the components of the pathway are in place and are working well. A network for cystic fibrosis will be very different from a network for children with cerebral palsy, but the principles will be the same and some components may be shared.

Better information. A high quality information system to enable better decision-making, audit and improvement and communication is needed urgently. Such a system would have the immeasurable benefit of enabling rigorous needs assessments and resource allocation across primary, secondary, and tertiary health care, education and social services.

The recent development of the Common Assessment Framework is a welcome first step but it needs to be more detailed and nuanced to cater for the needs of children with complex and ongoing health care needs. Traditional information systems based on defects, disability, and disadvantage are too cumbersome in practice. A more pragmatic approach is needed, one which can describe the difficulty (disability), the diagnosis (medical cause of difficulty) and the impact on daily living (the interaction between the child and family and their physical and social environment). This would assist with determining a package of care tailor-made for a particular child. A seven-level system, known as WeeFIM, which describes level of need from independence to complete dependence, is available and a similar model could be adapted for the majority of long-term conditions.

Community nursing and multidisciplinary teams. The recent investment in services for children with life-threatening conditions by the New Opportunities Fund has enabled the development of a substantial number of multidisciplinary community children's teams. Initial evaluation suggests that having a comprehensive assessment, continuity of health provision, ideally with 24-hour a day access, and backed up with adequate therapy services and short-term breaks, can lead to a substantial improvement in quality of life for families.

The development of community children's nursing teams allows a re-evaluation of the role of paediatricians in the review and management of children and families with long-term conditions. Rather than paediatricians reviewing children on an annual basis, the review can be undertaken by a nurse, who discusses or refers specific problems to a paediatrician.

Multiagency multidisciplinary teams should be co-located to facilitate communication and joint working. Further work needs to be undertaken to determine the potential for more specialist knowledge and expertise to be devolved down to local teams. Clearly haemodialysis cannot always be available locally but expertise in the management of epilepsy can be.

Models of service delivery

In the longer term, a Community Children's Nursing Team appropriate to the population would be available in small, medium and large places. They would form the core of the larger multi-agency team supporting children with a range of long-term conditions.

The work of paediatricians generally maps onto the frequency and severity of conditions and their treatability. Treatable rare and multi-system conditions generally require the input of specialists (e.g. cancer, rheumatological disorders), care for more common treatable conditions should be with a paediatrician who has a special interest (e.g. diabetes, cystic fibrosis, epilepsy). Children who require largely symptomatic management because the underlying disorder is untreatable (e.g. cerebral palsy, learning difficulties) need a general paediatrician who can access specialists as required.

Small

Remote and rural. All paediatricians will need to provide clinical care with groups of individual paediatricians taking a management lead for the coordination of services for groups of children with long-term conditions.

Proximal to larger centres. Consideration needs to be given to working collaboratively with paediatricians from surrounding areas. Within this wider geography some paediatricians may then develop a management lead for the whole or part of the service.

Medium and large

Two models are emerging, one where a paediatrician sees all the children with a specific condition in a defined population. An example is the care of children with cystic fibrosis. These paediatricians with a special interest undertake joint clinics with visiting specialists from tertiary centres. The second model is where paediatricians are more community-based and see a range of children with long-term conditions. Large centres would provide a similar service to medium-size places plus an additional tier of specialist services.

Local innovation

- Multiagency Child Development Centres.
- Psychologists working as an integral part of the disabled children's team.

- Shared records and IT systems across agencies.
- Better assessment tools.
- Integrated Occupational Therapy teams.
- Peripatetic therapy teams.
- SENCO (Special Educational Needs Coordinator) training and development.
- Skill mix within teams.
- Parent involvement with service planning.

Questions

- Q36.** *Should services for children with neurological disorders be considered separately from children with long-term conditions?*
- Q37.** *Are the principles behind the management of children with neurological conditions the same as those with long-term conditions?*
- Q38.** *Should children's palliative care be seen as a separate service or should there be more integration with children with complex continuing health care needs whose lifespan is not significantly limited?*
- Q39.** *Children's community nursing teams for children with life-threatening illnesses are increasingly available throughout the UK. What group of children are the next priority for community children's nursing teams?*
- Q40.** *Which children with long-term conditions need to be seen regularly in a hospital setting? What prevents more community-based paediatric provision?*
- Q41.** *Do you have other examples of local innovations or service development you could share?*

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3.6 Specialist services

Service definition

Specialist services are defined both by the conditions they manage and the specialist interventions they offer. The conditions are generally rare (<1:1000), or they may be common conditions which are either severe, not responding to first-line treatments or exist in combination with other conditions that make their management more difficult. Specialist interventions include paediatric, surgical, anaesthetic, or investigative skills not available at local level.

Guidance from the Department of Health *Commissioning Arrangements for Specialised Services* (2006) identified the following specialised children's services:

- Anaesthesia.
- Cardiology and cardiothoracic surgery.
- Complex child and adolescent gynaecology.
- Dermatology.
- Endocrinology and diabetes.

- Gastroenterology, hepatology and nutrition.
- Immunological disorders/infectious diseases/allergy (*infectious disease, allergy, paediatric immunology, HIV*).
- Intensive care.
- Metabolic disorders.
- Neonatal intensive and high dependency care.
- Nephrology, including renal replacement therapy.
- Neurosciences (*neurodisability, neurology, neurosurgery*).
- Non-malignant haematology.
- Oncology and malignant haematology.
- Pathology.
- Respiratory medicine.
- Rheumatology.
- Specialised child and adolescent mental health services.
- Children's surgical services (*ophthalmology, oral and maxillofacial surgery, orthopaedics, otolaryngology, plastic surgery, urology*).

Key facts

Epidemiology and service use

Epidemiology and service use has been covered by the RCPCH publication *Commissioning Tertiary and Specialised Services for Children and Young People* (2004). Further detail is also available from the draft report of the Specialist Services Working Group from the RCPCH website (www.rcpch.ac.uk/modellingthefuture).

These definitions are currently under review, with the intention of defining which elements of the service are specialised and need to be commissioned for a population of >1 million people. The RCPCH currently recognises 14 medical paediatric specialties but accepts that some still need to be developed such as services for Chronic Fatigue Syndrome or palliative care.

Where are we now?

In the past specialty services have been developed by committed individuals using personal influence to develop informal regional networks. The development of more formal clinical networks varies widely and it is noteworthy that there are few examples of investment or resource allocation to help this development.

Generally specialised services are provided in a limited number of centres in order to achieve a critical mass, ensuring safe, high quality, sustainable services that use specialist skills most efficiently. Where services in one centre have been lacking, service provision is usually with

a neighbouring region to facilitate patient access. A number of specialist services are interdependent and need to be provided as a group. Examples of this are services for children with multi-organ failure requiring intensive care, or those needing surgical interventions or neonatal intensive care.

However some specialist services can be provided relatively independently, for example dermatology or clinical genetics, while others have natural partners for example non-malignant and malignant haematology, or gastroenterology, hepatology and nutrition. Some need to be provided in every tertiary centre while others can be provided from fewer sites. Some centres lack important sub-specialities or have some services that are much better resourced than others.

In recent years there have been significant improvements in multidisciplinary team working. The development of clinical networks with outreach clinics and shared protocols across geographical areas, together with the national training grid and definition of competences has resulted in better training programmes. There are some good examples of patient registers and audit projects and greater patient and public involvement which have led to significant improvements in some services.

NSCAG (National Specialist Commissioning Advisory Group) has been highly effective in supporting the development of a number of services. This systematic approach at a national level, has enabled much better equity to service development. National audits have demonstrated improvements in patient outcome, for example, in severe combined immune deficiency and the biliary atresia service.

What are the major challenges?

Commissioning specialist services. The single most critical issue identified by specialists is the inadequacy of specialist commissioning. As already acknowledged national specialist commissioning is relatively well developed, but it covers only the minority of children's specialist services, and does not always connect well with either local children's, or adult specialist service commissioning. What is required is a clear specification of the whole service, based on pathways, with clear responsibility and accountability for commissioning of the various elements.

An Audit Commission survey of specialised services commissioning arrangements found that only 50% of Local Specialist Commissioning Groups (LSCGs) and 60% of Specialist Commissioning Groups had the appropriate staffing levels to manage specialised services; and 50% of LSCGs had a pooled budget on behalf of their PCTs necessary to perform

their functions.

The model for commissioning PICU on a regional basis has led to significant improvements in this service. This success was based on clinicians at secondary and tertiary levels working together with respective managers and commissioners. Children's services have not benefited from the high priority and investment that adult services have often received in recent years. Indeed, not all children's specialist services are covered by SCGs, leading to further inequity.

In England, the introduction of Payment by Results has created further difficulties partly because the tariffs do not accurately reflect the high cost, low volume services for children with complex co-morbidities and they do not cover the time involved in supporting secondary care paediatricians in the delivery of services, such as protocol development and telephone consultation. The result may be that some Trusts may decide not to provide specialist services as they are not financially viable.

Academic responsibilities. Specialists often have roles and responsibilities relating to education and training, research and professional leadership which compete with their clinical time. Both clinical and academic time needs to be clearly delineated, costed, and then funded through the appropriate channels. Coherent pathway-based commissioning would help to ensure these important roles receive the attention they require.

Numbers of centres, co-location of departments and critical mass. Reduction in working time, the move to deliver more specialist care in local settings, and the national review of specialist commissioning all suggest the need to review the number of specialist centres, the specialist teams within those centres, and the out of hours arrangements for each specialty.

Spinal surgery is a good example of the need to co-locate services – in this case specialist orthopaedic surgery with paediatric intensive care - but it is also an example of a service where surgeons need to undertake a sufficient number of procedures per year to maintain their clinical competence. There are small numbers of children requiring such complex spinal surgery in the UK each year. Therefore, in order to ensure high quality services it makes sense to have only a few centres in the UK designated for spinal surgery.

Likewise, specialist metabolic paediatric services are not required in every tertiary centre but there does need to be access 24 hours a day to experts in this field to advise paediatricians on-call. On the other hand, Paediatric and Neonatal Intensive Care both require hands-on Consultant cover to be available 24 hours a day so in these specialties an EWTD compliant on-call rota will be required in every centre offering this service.

What are the solutions?

The local geography and population characteristics impact greatly on service provision. Large conurbations may require amalgamation of services to produce larger centres with the critical mass to maintain efficient use of staff to provide effective high quality services. By contrast in Northern Ireland, with its population of 1.5 million there may not be enough children to maintain specialist services locally (Darzi, 2007). Either specialists must rotate between centres to maintain skills or families must travel further to access the necessary services. Children and families will experience different patterns of care, but crucially not to different standards, depending on where they live.

The relationship between local and specialist paediatricians is important and needs to be fostered by the way services are commissioned, organised, and delivered. Local paediatricians need to develop their services with support and advice from specialists so that the referrals they make are appropriate and specialist advice can be implemented locally.

Success in the provision of specialist services requires specialists to support general paediatricians in a number of ways. Examples include:

- Better communication by telephone, electronic media, and telemedicine.
- Using algorithms and protocols for decision-making.
- Outreach services, and where appropriate joint clinics with local paediatricians.
- A commitment to quality assurance and improvement within a network.
- Leadership, innovation and team working.

Clarity about the roles of specialists. The need for an integrated approach between specialists and generalists has been described. Commissioning and finance systems need to be designed to reflect and encourage this approach.

Specialists and generalists need to build existing guidance (RCPCH, 2004) into practical guidelines for service delivery, setting standards, measures and clarifying the roles and responsibilities of both specialists and generalists. This can then be used for both commissioning and regulation of services. This process has been started by the Cystic Fibrosis Trust producing standards for the clinical care of children and adults with cystic fibrosis in the UK. In Wales, national standards for children's specialised services have been published for consultation (Welsh Assembly, 2006) and are a model of best practice which could be replicated in other parts of the UK.

Reconfiguration and networks. The consensus from the RCPCH Policy Conference 2006 was that collaborative networks are a more appropriate way forward to achieve high

quality, equitable services than reliance on choice and market principles. Where interventions are required they should be delivered as close to home as possible, accepting for reasons of safety, effectiveness or efficiency, that some interventions may only be available in a regional centre because they require specialist knowledge, environments or treatments.

Not all specialist services will need to be available in every tertiary centre. Very careful consideration should be given to the co-location of essential services. Specialist surgical centres, for example, paediatric cardiac surgery, neurosurgery, spinal surgery, transplant surgery, and neonatal surgery require access to anaesthetic services, neonatal and paediatric intensive care, as well as imaging and laboratory services, so they should ideally be located on the same site.

High-volume specialist services would need to be available in every specialist centre, with a proportion of these offering 24-hour access to specialist consultants. Low volume specialist services would be offered from a limited number of centres working together as a network to cover the whole country. Medium volume specialist services will need to create a network covering a number of specialist centres, in order to guarantee access to specialist opinion, and comply with working time directives.

Local innovation

- Specialist nurses.
- Telemedicine.
- Telephone consultations.
- Remote monitoring.
- Outreach specialist clinics.
- Rotations of staff into specialist centres.
- Pan-network algorithms and guidelines.
- Development of decision support software for example Map of Medicine.
- Expert patient programmes.

Questions

Q42. Would you support the proposal to release specialists from acute general paediatric on call rotas?

Q43. If specialists are released from acute general paediatric duties would this de-skill tertiary specialists of their general paediatric skills? Or would this enable the better delivery of outreach tertiary services?

- Q44.** Which specialists need to be available to provide 24/7 hands-on care? Or is providing telephone advice sufficient?
- Q45.** Which specialists need to be co-located on the same site with a paediatric intensive care unit?
- Q46.** Which specialists need to provide 24/7 telephone advice service? What potential is there for specialist paediatricians in tertiary centres to provide 24-hour telephone consultation, over a wider geographical area than the individual tertiary centres they currently cover?
- Q47.** When is a specialist children's nurse required, as opposed to a generic community children's nurse?
- Q48.** Do you have other examples of local innovations or service development you could share?

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4. Matching Services with Settings

Designing networks to deliver services

The population pyramid reflecting large numbers of people attending primary care, fewer entering secondary care and a minority receiving specialist care reflects how the system worked in the late 20th century and will be familiar to many people (figure 4). However the boundaries between primary, secondary and tertiary care begin to blur as individuals work across these traditional boundaries. The pyramid is still a helpful concept as it can represent the players in the network, but now components of the pathway are inserted around the patient journey with the areas within the pyramid approximately representing the work of teams. The terms of primary secondary and tertiary are replaced with venues of service delivery, with a multidisciplinary team working in a number of locations.

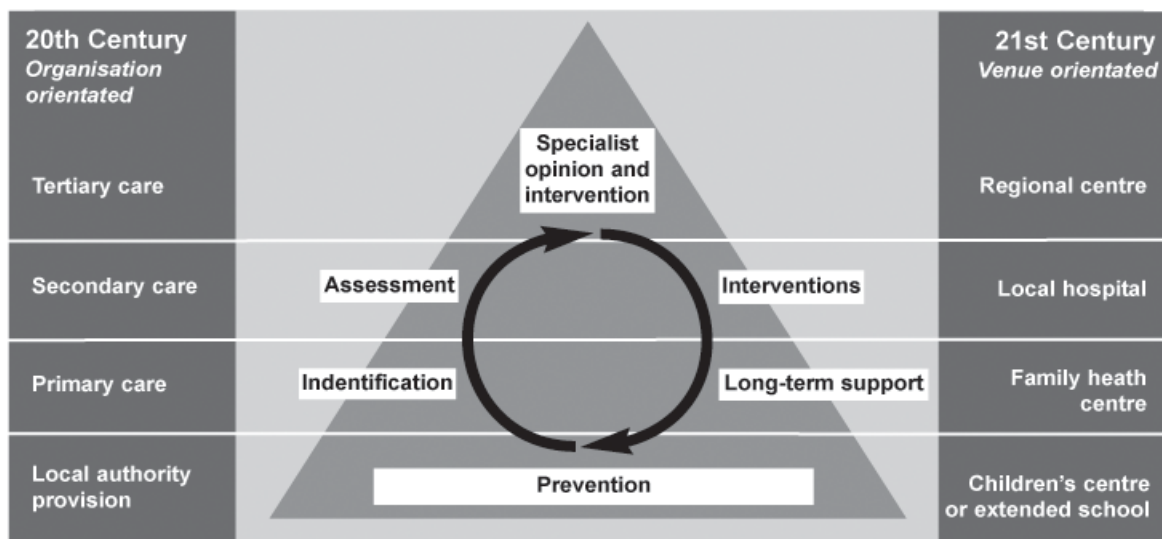


Figure 4. Schematic diagram of the pyramid of services surrounding a patient journey.

This report focuses on the health service networks within children's services but the importance of other agencies must be acknowledged especially those involved with health promotion, disease prevention and ongoing support for children with disabilities and long-term conditions.

Although this report is structured according to NSF standards, it should be acknowledged that an individual child does not always fit neatly into just one of the teams described. The clinical teams therefore need to be combined in a number of different ways, depending on the size of the population covered, the local demographics and health needs, the workforce available and prevailing political forces.

There is some merit to considering the delivery of urgent, reactive care separately from planned, proactive care.

1. Unplanned urgent care - available 24 hours a day
 - a. General acute paediatrics, urgent and emergency care.
 - b. Neonatal care.
 - c. Acute specialist services including PIC.
 - d. Child protection/forensic services.
2. Planned care - at times convenient to families
 - a. High prevalence conditions e.g. asthma, epilepsy, behavioural disorders.
 - b. Low prevalence specialist conditions e.g. renal impairment, metabolic disorders.
 - c. Services for vulnerable children and those in need.
 - d. Child health promotion and public health.



Figure 5. Illustration of the overlap between urgent care and planned care teams and the implications for paediatricians in small, medium and tertiary centres.

This proposal, as represented in Figure 5, essentially builds on the teams that already exist and clarifies their boundaries. The major additional change being that in the future they will work with other teams over a larger geographical area to achieve collective improvement and economies of scale. Exactly where the care is provided depends on whether it can be delivered safely locally and whether it can be afforded (recognising that specialist care is often more efficiently delivered in a central location).

In smaller places paediatricians will need to work in both urgent and non-urgent teams while in medium sized places there are two options - urgent and planned teams or a mixed economy of teams, while in the largest centres the development of multiple specialist teams is all part of the overall provision.

Service delivery and teams in small, medium and large settings

Across the UK there will be different solutions depending on size and geographical location, and the characteristics and needs of the population. Networks span a number of different sized units and the teams within each unit work cooperatively both with others locally and regionally within their network.

Figure 6 provides a representation of how services of different sizes might work together. Networks of care are represented by grey ellipses, showing the potential overlap within and between services at each size of setting.

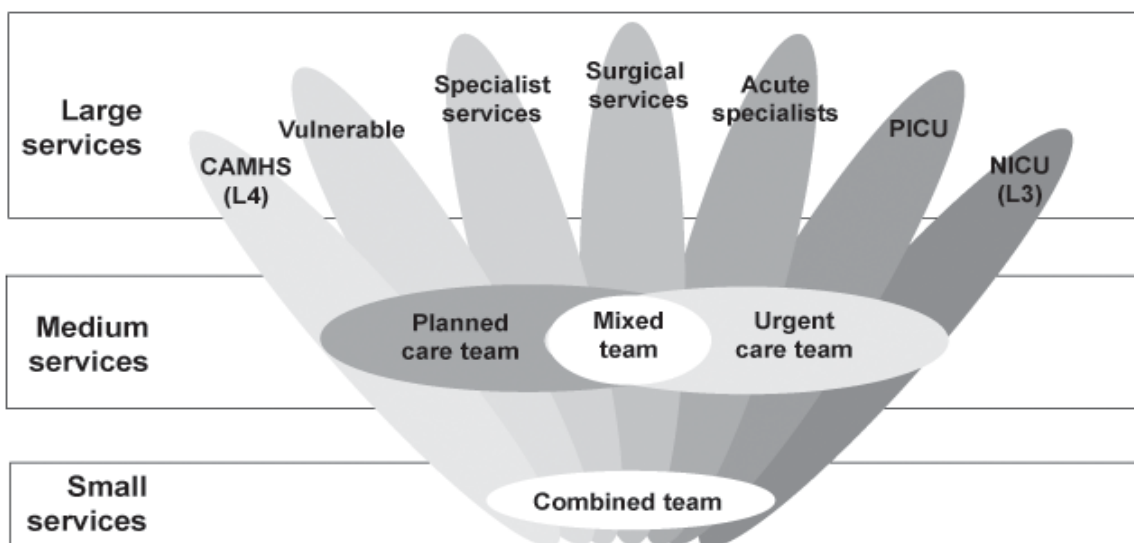


Figure 6. Schematic diagram of networks within a range of service sizes

Small, remote services

Minimum services

- Emergency department with children's area.
- 24-hour inpatient and assessment facilities, including child protection.
- Co-located urgent care centre.
- Level 1 or 2 neonatal unit.
- Merged child behaviour service, services for vulnerable children and those with long-term conditions.

Staffing

- A single general team of paediatricians, paediatricians with a special-interest, GPs with a special-interest, consultant child psychiatrist.
- Specialist services remotely located, with outreach. Staff rotations into specialist centres.

Small settings in close proximity to larger services

Minimum services

- 8-16 hour assessment and transfer/retrieval facilities.
- Emergency department with children's area.
- Co-located urgent care centre.
- Behaviour services.
- Long-term condition services.

Staffing

- A single general team comprising paediatricians, paediatricians with a special-interest, GPs with a special-interest, Consultant Child Psychiatrists.
- Specialist services remotely located, with partial in-reach from larger centres.

Medium sized services

Minimum Services

- 24-hour inpatient facilities, including HDU and assessment unit.
- Emergency department.
- Co-located urgent care centre .
- Level 2 neonatal unit, unless designated Level 3.
- CAMHS service .
- Long-term condition services.
- Vulnerable children's services.

Staffing

There are likely to be three or four teams:

- Urgent care team of hospital-based paediatricians, GPs with a special-interest, Emergency Medicine consultants.
- Non-urgent team comprising community-based paediatricians, paediatricians with a special interest, GPs with a special interest, possibly working in an integrated service.
- Behavioural team of Consultant Child Psychiatrist, Paediatricians, Community Psychiatric Nurse, family therapists, psychologists, possibly working together in an integrated team.
- Neonatal team, if Level 3 neonatal care is to be delivered.
- Specialist services remotely located, with out-reach, some paediatricians with special interests.

Large and Tertiary Centre Services

Minimum Services

- 24-hour inpatient facilities, 16-hour assessment unit.
- Children's emergency department.
- Co-located children's urgent care centre.
- Level 3 neonatal unit.
- Behaviour service with specialist inpatient psychiatric care.
- Long-term condition services.
- Specialist tertiary care-medical and surgical.
- Regional public health department.

Staffing

There are likely to be at least 6 co-located teams:

- Neonatal team with retrieval capacity.
- Urgent care team of hospital-based paediatricians, GPs with a special interest, emergency department paediatricians, paediatricians with a special interest. The team will link with PICU and specialist services teams.
- Non-urgent team of community-based paediatricians, paediatricians with a special interest, GPs with a special interest. There will be links with specialist services.
- Mental health team comprising Consultant Child Psychiatrist, Paediatricians, CPN, family therapists, psychologists.
- PICU team, if cardiac surgery or neurosurgery services are offered on site, with retrieval capacity.
- Specialist services, with academic component and with outreach to medium and some small centres. Some specialist services would network and provide on-call between large and tertiary centres.

Commissioning, health service management structures and regulation.

Although outside the remit of this paper a few recurrent themes need to be highlighted.

Commissioning structures

Duplication and fragmentation of commissioning, both within the health service and with other agencies, is a major impediment to both incremental improvements in services that require resources to move across management boundaries as well as to major reconfigurations.

There needs to be a major investment in commissioning capacity, with individual commissioners working together to produce collaborative networks. The formation of Children's Trusts combining Local Authority and PCT commissioning could be a major step forward especially if Children's Trusts over a wider clinical area could cooperate to achieve the right balance between commissioning local and specialist services.

Provider structures

Generally children's services should be under the least number of management structures all of which need to be committed to providing care in the right locations for children and their families. With pressure on finances there is a tendency to centralise in order to drive efficiency, but this will almost always increase inequity. Individual departments within a Trust providing children's services should have clear accountability to a children's directorate. The potential for trust structures to be based on networks has not yet been fully explored.

Inspection and regulation

The importance of networks has been stressed repeatedly, as has the importance of working with other agencies who contribute the component parts of the pathway. Increasingly regulation should be a balance between the inspection of organisations and inspection of networks.

Questions

- Q49. Do you find a separation of urgent care from planned care a useful concept?*
- Q50. Should we be training some paediatricians to predominantly work in urgent care services, and others to work in planned care services, particularly in medium and large places?*
- Q51. Is there anything you would add or subtract from the service description and teams in small, medium and large places?*

Overall workforce implications

The neonatal, urgent care and PICU teams all provide acute care 24 hours a day. In this era of EWTD this almost translates to a fixed number of people, depending on the exact skill mix between professionals. The efficiency of this structure depends on throughput, which in turn should reflect the numbers of children in the local population or in other words a certain throughput is needed for efficient use of resources. Any unused capacity could be used to

support long-term care or specialist interests to allow delivery of tertiary care locally within the overall managed network.

The numbers of paediatricians involved with long term or planned care depends on the size and needs of the population. There are a number of other factors such as how much of the behaviour service workload is shared with CAMHS, the unused capacity from the acute and urgent care team, how much tertiary care is delivered locally through managed networks and the capacity of Local Authority services. There is also the need to perform statutory duties such as special educational needs assessment, immunisation coordination, and duties of safeguarding and roles in adoption and fostering.

For each team there will be a fixed component - management, clinical governance, teaching, training and a variable clinical component depending on number of families served. Additionally there will be a workforce requirement for wider NHS duties, for example teaching and training, research, non-clinical management, external duties, commissioning and public health.

Each of these elements will need to be estimated separately and then combined to produce a local workforce configuration, depending on number of people, their competencies and the hours that they work.

Paediatricians' aspirations and career progression

Autonomy, innovation and learning, striving for perfection are all qualities that doctors and other professional groups use to achieve the best for their patients. They do not generally respond well to imposed decisions, targets or contradictory changes in management or policy directions.

Career development post consultant appointment is not well developed in medicine. Keeping doctors motivated and striving for improvement throughout their careers is a challenge - many diversify their interests into management, research, teaching or other national commitments. Acute and neonatal paediatrics is a demanding hands on specialty and with time eyesight and practical skills atrophy but hopefully wisdom matures. Further consideration needs to be given to clinical career progression options because while some people are dedicated specialists from the start, many more might welcome the option to gain new skills through formal training at consultant level, especially if the appeal of emergency care begins to wane.

The process of revalidation is likely to highlight the need for further training opportunities either to maintain current skills, or change career path. This presents opportunities to develop new career models, for example concentrating on urgent care at the onset and moving towards planned care later on.

Questions

- Q52.** *Should all paediatricians expect to take part in an acute on-call rota through the early and middle parts of their consultant career, regardless of daytime roles? Or should paediatricians train to work exclusively in urgent and non-urgent roles from an early stage?*
- Q53.** *Would recruitment and retention of paediatricians be improved by having the option to go directly into planned care (ie no acute on-call) after CCT?*
- Q54.** *Should consultants expect to have the opportunity to move to a less acute role at a later point in their consultant careers?*
- Q55.** *What do you think would be the impact on recruitment and retention if paediatricians adopted portfolio-style careers or moved from acute to non-acute work as their careers progressed?*
- Q56.** *How can we improve training for paediatricians after they become Consultants?*

Further Reading

Networks

- Banodlier Forum (2003) *Care pathways*. (<http://www.jr2.ox.ac.uk/banodlier/Extraforbando/Forum2.pdf>)
- DH (2006) *A guide to promote a shared understanding of the benefits of managed local networks*. (http://www.dh.gov.uk/prod_consum_dh/dcplg?IdcService=GET_FILE&dID=3790&Rendition=Web)
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- NHS Confederation (2001) *Clinical networks - a discussion paper*.
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- RCPCH (2006) *A guide to understanding pathways and implementing networks*. (http://www.rcpch.ac.uk/doc.aspx?id_Resource=1757)
- Scottish Executive (2002) *Promoting the development of managed clinical networks in NHS Scotland*. NHS circular:HDL (2002)69 (http://www.sehd.scot.nhs.uk/mels/HDL2002_69.pdf)

Commissioning

- DfES (2006) *Turning to curve toolkit. From talk to action-making a difference to children, young people and families lives*. (<http://www.everychildmatters.gov.uk/>)

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- DfES (2006) *Joint planning and commissioning framework for children, young people and maternity services*. (http://www.everychildmatters.gov.uk/_files/312A353A9CB391262BAF14CC7C1592F8.pdf)
- DH (2007) *Commissioning framework for health and well-being*. (http://www.dh.gov.uk/prod_consum_dh/idcplg?IdcService=GET_FILE&dID=134031&Rendition=Web)
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- DH (2006) *Care and resource utilisation. Ensuring appropriateness of care*. (http://www.dh.gov.uk/prod_consum_dh/idcplg?IdcService=GET_FILE&dID=115836&Rendition=Web)
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- Health Development Agency (2005). *Health needs assessment at a glance*. (<http://www.nice.org.uk/download.aspx?o=1846290090>)
- Monitor (2005) *Developing effective commissioning in the NHS*. (http://www.monitor-nhsft.gov.uk/docs/Commissioning_final_291105.pdf)
- Modernisation Agency (2004) *The commissioning friend for PCTs. Whole system commissioning of acute services. National primary and care trust development programme*. (<http://www.natpact.nhs.uk/uploads/CommissioningFriendMar04.pdf>)
- National Association of Connexions (2007) *Framework for involving children and young people in procurement and commissioning*. (<http://www.nacp.co.uk/pdf/improvingPractice/YPCcommissioningApril07.pdf>)
- Office for Public Management (2007) *Integrated commissioning for children's services. A practical guide to the development of simple commissioning frameworks and clear structures for children's services authorities*. (<http://www.opm.co.uk>)
- RCN (2004) *Commissioning health services for children and young people: increasing nurses influence*. (<http://www.rcn.org.uk/members/downloads/Commissioninghealthcareservicesforchildren.pdf>)
- Smith J. et al. (2004) *A review of the effectiveness of primary care lead commissioning and its place in the NHS. The Health Foundation*. (<http://www.hsmc.bham.ac.uk/news/HF-PCLC-RPT2%20text%20v-2.pdf>)

Improvement

- Bate, P. et al (2005) *Towards one million change agents. A review of the social movements literature: implications for large scale change in the NHS*. Modernisation Agency.
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- DH (2003) *Improvement, expansion and reform: the next three years. Priorities and planning framework to 2003-2006*. (http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4008430)
- Greenough, T. (2004) *How to spread good ideas. A systematic review of the literature on diffusion, dissemination and sustainability of innovations in health service delivery and organisation. Report for the National Coordinating Centre for NHS Service Delivery and Organisation Research and Development*. (<http://www.sdo.lshtm.ac.uk/files/project/38-final-report.pdf>)
- Institute of Medicine (2001) *Crossing the quality chasm: a new health system for the 21st century*. (<http://www.iom.edu/Object.File/Master/27/184/Chasm-8pager.pdf>)
- Langley, G. et al (1996) *The improvement guide: a practical approach to enhancing organisational performance*. Jossey Bass Publishers, San Francisco.
- Modernisation Agency (2004) *The PCT guide to applying the 10 high impact changes. A guide from NatPact*. (http://www.natpact.nhs.uk/uploads/2004_Oct/HIC_PCTguidefinal.pdf)
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- Wagner, E.H. (1998) Chronic disease management: What will it take to improve care for chronic illness? *Effective Clinical Practice*. 1(1):2-4. (<http://www.acponline.org/journals/ecp/augsep98/cdm.htm>)

5. Consultation process

The consultation period will run from September until mid December 2007. During this time, regional events will be organised to enable discussion and feedback.

Supporting resources will be available at the RCPCH website:

www.rcpch.ac.uk/modellingthefuture

Comments on the content of this paper, suggestions for future improvements, examples of good practice, and opinions on the questions posed should be posted on the RCPCH web site or sent to modellingthefuture@rcpch.ac.uk.

Appendix

Key Data and Information

1.1 Ranking by country of the UNICEF dimensions of child well-being

Dimensions of child well-being							
Country	Average ranking position (for all 6 dimensions)	Material well-being	Health and safety	Educational well-being	Family and peer relationships	Behaviours and risks	Subjective well-being
Netherlands	4.2	10	2	6	3	3	1
Sweden	5.0	1	1	5	15	1	7
Denmark	7.2	4	4	8	9	6	12
Finland	7.5	3	3	4	17	7	11
Spain	8.0	12	6	15	8	5	2
Switzerland	8.3	5	9	14	4	12	6
Norway	8.7	2	8	11	10	13	8
Italy	10.0	14	5	20	1	10	10
Ireland	10.2	19	19	7	7	4	5
Belgium	10.7	7	16	1	5	19	16
Germany	11.2	13	11	10	13	11	9
Canada	11.8	6	13	2	18	17	15
Greece	11.8	15	18	16	11	8	3
Poland	12.3	21	15	3	14	2	19
Czech Republic	12.5	11	10	9	19	9	17
France	13.0	9	7	18	12	14	18
Portugal	13.7	16	14	21	2	15	14
Austria	13.8	8	20	19	16	16	4
Hungary	14.5	20	13	17	6	18	13
United States	18.0	21	17	12	20	20	–
UK	18.2	18	12	17	21	21	20

1.2 UK Key child well-being trends (The Well-being of Children in the UK, 2005)

Improving	No change	Deteriorating
<p>Absolute child poverty</p> <p>Relative child poverty</p> <p>Children in workless families</p> <p>Infant mortality</p> <p>Child accidental deaths</p> <p>Breastfeeding</p> <p>Reporting good health</p> <p>Increased use of contraception</p> <p>Smoking</p> <p>15–24 suicide rate</p> <p>Domestic violence</p> <p>Time spent with parents</p> <p>Adoptions up</p> <p>Truancy</p> <p>Housing conditions</p> <p>Daycare nursery places</p> <p>Out of school places</p> <p>Educational qualifications</p> <p>Drop in young people leaving care at 16 and 17</p> <p>Proportion leaving care with one or more GCSE/Standard Grade</p> <p>Narrowing class differential in attainment</p> <p>Numbers not in education, employment or training falling</p> <p>Special Educational Needs in mainstream schools</p> <p>English, maths and science at Key Stages 2 and 3 (data not available for Scotland)</p>	<p>DPT immunisation</p> <p>Longstanding illness</p> <p>Risky sexual behaviour</p> <p>Teenage conception rate</p> <p>Numbers playing sport</p> <p>0–14 years suicide number</p> <p>Youth crime</p> <p>Illicit drug use</p> <p>Victimisation</p> <p>Persistent child poverty</p> <p>Child mortality</p> <p>Whooping cough immunisation</p> <p>English, maths and science at Key Stage 1 (data not available for Scotland)</p> <p>Pupils statemented with special needs (or issued with 'records of need' as in Scotland).</p>	<p>School exclusions</p> <p>Playing out/liberty to play</p> <p>Class gap in infant mortality</p> <p>Still-births</p> <p>Low birth-weight</p> <p>MMR vaccination</p> <p>Measles and mumps</p> <p>Asthma,</p> <p>Diabetes</p> <p>Childminder places</p> <p>Playgroup places</p> <p>Drug and violent crime</p> <p>Girls offending</p> <p>Child homelessness</p> <p>HIV/AIDS and sexually transmitted diseases</p> <p>Alcohol consumption</p> <p>Obesity</p> <p>Conduct, hyperactive and emotional problems</p> <p>Children born to drug using parents</p>

1.3. National spending on children's services

Total NHS expenditure (£ billion unless otherwise stated)						
	UK	England & Wales	England	Scotland	Northern Ireland	Wales
Total NHS spend	-	-	76.144 ¹	7.17 ⁵	-	-
Health spend per capita	£2,3892 ²	-	-	-	-	-
Health spend as % GDP	8 ²	-	-	-	-	-
Spend on children's and maternity services	-	-	3.139 ³	-	-	-
Maternity	-	-	942 ³	0.25 ⁵	-	-
Hospital ⁴	-	-	1.224 ³	-	-	-
Primary care	-	-	16.6 ⁴	2.97 ⁶	-	-

NHS children's spend (£ billion)						
Estimated spend on children in primary care (0-15 year olds) ⁴	-	-	1.26	-	-	-
Universal Community	-	-	-	-	-	-
Child health	-	-	0.471 ³	-	-	-
Targeted	-	-	0.44 ³	-	-	-
Spot purchasing	-	-	0.063 ³	-	-	-

Summary spend per child (£)						
Universal services	-	-	43	-	-	-
Targeted services	-	-	38	-	-	-
Hospital services ³	-	-	112	-	-	-

¹DH 2005-6, ²WHO 2003, ³A profile of Children's Health and Maternity Services in England 2006,

⁴RCGP 2004-05 ⁵Scottish Health Service Costbook 2006

Social care expenditure (£ billion unless otherwise stated)						
	UK	England & Wales	England	Scotland	Northern Ireland	Wales
Total Social care spend	-	-	4.00 ¹	-	-	-
Spend on Children's services	-	-	2.86 ²	-	-	-
Assessment and care	-	-	0.79 ²	-	-	-
Residential provision	-	-	0.78 ²	-	-	-
Non-residential provision	-	-	1.30 ²	-	-	-
Approx spend per child in the system	-	-	£5000	-	-	-

¹2003-4, ²DH 2000-1

Education expenditure (£ billion unless otherwise stated)						
	UK	England & Wales	England	Scotland	Northern Ireland	Wales
Total education spend	-	-	35.47 ¹	-	-	-
Under fives	-	-	-	0.26 ³	-	-
School age children	-	-	-	3.3 ³	-	-
Further education	-	-	-	-	-	-
Spend per child in state system	-	-	£3,980 ²	£4,553 ³	-	-

¹DfES 2004-5, ²DfES 2003-4 ³Scottish Executive 2006

Criminal justice system expenditure (£ million)						
	UK	England & Wales	England	Scotland	Northern Ireland	Wales
Total criminal justice system spend 2007-08¹	22,700	-	-	-	-	-
Youth Offending Teams total	-	245.99 ²	-	-	-	-
Contributing to YOT teams: Police	-	23.38	-	-	-	-
Contributing to YOT teams: Probation services	-	17.53	-	-	-	-
Contributing to YOT teams: social services	-	101.99	-	-	-	-
Contributing to YOT teams: education	-	12.60	-	-	-	-
Contributing to YOT teams: health	-	11.72	-	-	-	-
Contributing to YOT teams: local authority Chief Executive	-	27.90	-	-	-	-
Spend per child known to system.	-	£301,860	-	-	-	-
Spend per offence	-	£815	-	-	-	-

¹Independent Audit Centre for Crime and Justice Studies 2007, ²Youth Justice Board 2005-6

1.4 NHS children's workforce

Total NHS workforce	UK	England	Scotland	Northern Ireland	Wales
Obstetricians	-	2,673 ¹	-	-	-
Midwives	-	13,481 ¹	2,411 ³	-	-
Total number of paediatricians	8,905 ²	7,445 ²	711 ²	285 ²	464 ²
Career grade (WTE)	4,417 ² 3,330.9	3,652 ² 3,339.9	391 ² 121.8	145 ²	229 ² 204.5
Training grade	4,488 ²	3,793 ²	320 ²	140 ²	235 ²
Hospital workforce					
Paediatricians (Career grade)	2,793.5 ²	2,410.5 ²	189.5 ²	78.5 ²	115 ²
Nurses – listing paediatrics as work area	- -	19,178 15,413	2056 (WTE) -	- -	- -
Community workforce					
Paediatricians	1,573.5 ²	1,208.5 ²	198.5 ²	64.5 ²	102 ²
School nurses (WTE)	-	1,569	305 ³	-	-
Health visitors	-	7,753 ¹	1,479 ³	-	-
Therapists providing universal services	-	120 ¹	-	-	-
Therapists providing targeted services:					
Occupational therapists	-	860 ¹	-	-	-
Physiotherapists	-	1,222 ¹			
Speech and Language Therapists	-	2,544 ¹	-	-	-
Primary care workforce					
General practitioners ⁴	39,920	32,593	4,311	1,084	1,932
Practice nurses (E&W)	12,771 ⁴	-	2,006 ⁵	-	-

¹A profile of Children's health and maternity services in England 2006, ²RCPCH Workforce Census 2005, ³IISD Scotland 2005, Information Centre for Health and Social Care 2005 Non-medical workforce census, ⁴RCGP 2003. ⁵Information Service Division 2003

1.5 Population demographics

	UK	England & Wales	England	Scotland	Northern Ireland	Wales
Total population	60,209,500 ¹	-	50,431,700 ¹	5,116,900 ⁴	1,724,400 ¹	2,958,600 ¹
Birth rate (rate per 1000 population)	10.71 ²	12.1 ¹	12.1 ³	10.7 ⁴	13.0 ³	10.9 ³
Population 0-4	3,427,500 ¹	3,016,800 ³	2,855,358 ³	268,457 ⁵	110,148 ⁷	159,000 ¹
Population 5-9 yrs	3,560,500 ¹		3,019,292 ⁶	279,430 ⁵	118,878 ⁷	175,300 ¹
Population 5-15 yrs	8,256,700 ³	7,310,200 ³	6,896,700 ³	653,376 ⁵	271,086 ⁶	407,800 ¹
Population 10-14 yrs	3,821,300 ¹	-	3,227,823 ⁶	308,196 ⁵	126,048 ⁷	192,900 ¹
Population 15-19 yrs	3,964,700 ¹	-	2,606,040 (15-18 year olds) ⁵	328,706 ⁵	132,258 ⁷	199,700 ¹
Population 0-16 yrs	11,667,825 ³	-	-	921,833 ⁵	383,040 ³	566,800 ¹

¹ONS 2005, ²CIA 2006, ³ONS 2004, ⁴GRO 2005, ⁵GRO 2007, ⁶DH 2004, ⁷NISRA, 2005

1.6 NHS children's activity

	UK	England & Wales	England	Scotland	Northern Ireland	Wales
Maternity/neonatal (contacts per year)						
Antenatal	-	-	6,400,000 ¹	-	-	-
Births	-	645,835 ²	-	54,386 ³	-	-

¹ONS 2000, ²ONS 2005, ³GRO 2005

Hospital (contacts/admissions per year)						
	UK	England & Wales	England	Scotland	Northern Ireland	Wales
Emergency dept annual contacts	-	-	2,145,923 ²	169,966 ²	70,618 ²	77,962 ²
Emergency dept contacts per 1000 0-16 yr olds	250 ¹	-	201 ²	159 ²	161 ²	123 ²
Outpatient contacts	-	-	1,567,028 ³	136,208 ¹	58,464 ⁴	109,912 ¹

Hospital (contacts/admissions per year) cont..						
	UK	England & Wales	England	Scotland	Northern Ireland	Wales
Inpatient admissions	-	-	-	98,402 ¹	-	-
Admissions per 1000 children 0-4 years	99 ¹	-	-	-	-	-
Admissions per 1000 children 5-15 years	21 ¹	-	-	-	-	-
Admissions per 1000 children 0-16 years	-	-	112 ⁵	-	-	-
Total admissions ⁶ : elective emergency day case	-	-	-	14,683 56,596 26,763	-	-
Average no. of occupied beds	-	-	-	-	300.7	324.9
PICU Annual admissions ⁷	-	14,022 ⁷	12,877	891 ⁷	-	254 ⁷
Admissions per 1000 children 0-16 years	1.2 ¹	-	-	-	-	-

¹ONS 2004, data from 1996-2001, ²RCPCH 1999, ³DH 2006-07, ⁴DHSSPS 2005-06, ⁵Eastern Region Public Health Observatory 2007, ⁶Information Service division 2005-6, ⁷PICAnet 2005

Community (contacts per year)						
	UK	England & Wales	England	Scotland	Northern Ireland	Wales
Total Health visitor consultations.	-	-	-	969,650 ²	-	-
Proportion of children seen by a health visitor in one week ¹	1.5%	-	-	-	-	-
Therapist consultation Initial therapy contacts with 0-15 year olds ³						
Occupational therapy:	-	-	55,800 ³	-	-	-
Physio-therapy:	-	-	209,000 ³	-	-	-
Speech and Language therapy:	-	-	146,600 ³	-	-	-

¹GRHS 2002, ²GRO 2004-5, ³NHS Information Centre 2004-5

Child mental health						
	UK	England & Wales	England	Scotland	Northern Ireland	Wales
Total consultations	-	-	451,948 ²	-	-	-
Admissions tier 4 service ²	-	-	19,924	-	-	-

¹ONS 2004, ²CAMHS mapping 2005

Vulnerable children's services						
	UK	England & Wales	England	Scotland	Northern Ireland	Wales
Referrals to social services ¹	-	-	572,700	-	-	-
Initial assessments	-	-	290,800	-	-	-
Initial child protection conferences ²	-	-	38,500	-	-	-
On child protection register	-	-	26,300 ²	-	-	-
Number of children in care	-	-	69,100 ³	-	-	-
Children under 18 years in custody	-	2,841 ⁴	-	-	-	-

¹ONS 1-week survey in 2003, ²ONS 2003-4, ³ONS 2003, ⁴Youth Justice Board 2006

Primary care (consultations per year)						
	UK	England & Wales	England	Scotland	Northern Ireland	Wales
Total GP consultations	259 million ¹	-	-	15 million ²	-	-
Consultations children 0-4 years	19 million ¹	-	-	833,800 ²	-	-
GP consultation children 5-15 years	15 million ¹	-	-	827,600 ²	-	-
Practice nurse consultations with children	-	-	-	386,700 ²	-	-
Proportion of children seen by a practice nurse in one week ⁴	1%	-	-	-	-	-
GP consultations per child, per year, 0-4 year olds	5 ³	-	-	3.8 ²	-	-
Number of GP consultations per child, per year, 5-15 year olds	2 ³	-	-	1.4 ²	-	-

¹RCGP 2003, ² Information service division 2005-6, ³GHS 2002, ⁴ RCGP 2004

1.7 Acute services

Number of acute units ¹							
	Total number of units	Units with medical inpatients	Units with surgical inpatients	General emergency department	Children's emergency department	PICU	Total beds per 10k population 0-18y
England	253	203	231	153	30	32	8.2
Northern Ireland	14	9	11	9	1	1	9.6
Scotland	31	19	23	15	3	3	8.2
Wales	16	15	16	12	2	1	8.7
Total	314	246	281	189	36	37	

¹RCPCH 1999

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