

**Getting it right for children
and young people**

**Overcoming cultural
barriers in the NHS so as to
meet their needs**

A review by Professor Sir Ian Kennedy

September 2010

Contents

Foreword	2
Executive summary	4
Chapter 1: Introduction	15
Chapter 2: Services for children and young people – an overview	19
Chapter 3: Is the NHS meeting the needs of children and young people?	26
Chapter 4: Cultural barriers and how to address them	45
Chapter 5: Conclusion	105
Summary of recommendations	107
Annex A: Terms of reference	112
Annex B: Sites visited	114
Annex C: Review meetings	116
Annex D: Written submissions	120

Foreword



I began this review of children's services in the NHS in the autumn of 2009. The sense was that the NHS was not performing as well as it could: that children and young people (and the reference to young people is very important) were not getting the best deal. Pockets of excellent practice exist, but they are just that. The sense is that they are islands in a sea of mediocrity, or worse.

I was asked to see if I could get to the bottom of why this might be the case. There was, for me, a certain poignancy in the request. For as long as I can remember, services for children have been described both as an important priority for the

NHS and in the next breath as a 'Cinderella' service, save that this Cinderella has never got near to the ball. Nearly 30 years ago, I called one of my Reith Lectures¹ 'Suffer the children', in which I lamented the state of health and healthcare of children. Report after report over the decades have echoed the same message. In the Public Inquiry into paediatric cardiac surgery at Bristol Royal Infirmary,² my colleagues and I urged improvements in children's care. Now, 10 years later, I am returning again to the theme. Robert the Bruce and spiders come to mind.

In carrying out this review, I have travelled around England and spoken to a great many people. Wherever I've been, I've seen enthusiasm, commitment, and a real sense of caring and duty. I pay tribute here to the dedication of a wide range of professionals. They leave home in the morning wanting to do their best for the children and young people whom they look after. It is this knowledge which makes it that much more tragic, for children and for those caring for them, if, for whatever reason, the services provided don't on occasions pass muster. It is this knowledge that makes it all the more important for us to figure out why the system isn't working and set it on the road to recovery. This review is my contribution to the process.

I gratefully record my thanks to all those in the NHS and beyond who have helped me with their insights and their stories. In particular, I thank Sir David Nicholson, the Chief Executive of the NHS, who asked me to carry out the review, has provided me with necessary support and has let me get on with it. He genuinely cares about what the NHS is there for – to look after patients and the wider public. I was also assisted by Rebecca Lloyd in the early days, whom I thank warmly, and then by Michael West and Simone Abraham, both from the Department of Health.

1 Kennedy, I (1981) *The Unmasking of Medicine*. London: George Allen & Unwin, based on The Reith Lectures: *Unmasking Medicine The Listener* Nov–Dec 1980.

2 Kennedy, I (2001) *Learning from Bristol: The Report of the Public Inquiry into children's heart surgery at the Bristol Royal Infirmary 1984–1995*. London: The Stationery Office. Available at www.bristol-inquiry.org.uk/

Michael has tolerated me with equanimity and performed miracles in managing where I have to be and whom I should be seeing. He has also been closely involved in the thinking and drafting. He has been outstanding and I thank him. Finally, I thank those who read early drafts of the review and offered invaluable advice.

Postscript

I should add that just as I was completing the final draft of the review, a new government came into power. Much of what I had concluded about the mechanisms for change, not least the role of respective departments of state and of local organisations such as Children's Trusts, has had to be revisited. This is because the landscape of policy is changing. That being the case, any proposals for change that I make, if they are to have any prospect of being translated into policy, must take account of these changes and work with the warp of current government policy. The difficulty that I encounter, however, is that the Government's policy is not yet firmly set out. The result is that the section in which I propose the way in which policy can be got right and put into operation is more general than originally drafted. I have concentrated on setting out the principles, leaving the precise mechanisms for giving effect to them to be worked out as the Government's policy develops.



Professor Sir Ian Kennedy
September 2010

Executive summary

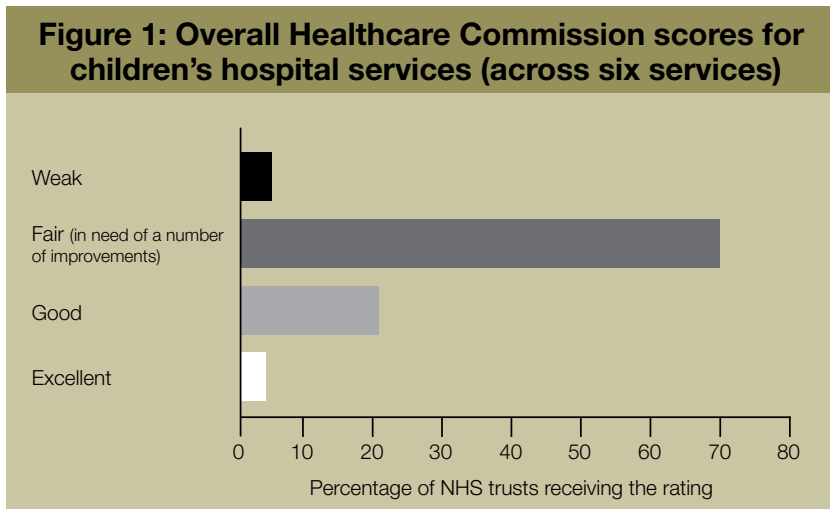
Setting the scene

- 1 This review was carried out amid widespread concern about the services provided by the NHS to children and young people. This concern relates in part to a number of tragic and high-profile cases, for example the death of Peter Connelly in Haringey in 2007 and the investigations and reports that followed.³ But concern goes much deeper and wider. Many people who work in and use the NHS would agree that the services provided do not measure up to the needs of children and young people. They are not good enough in a number of ways.
- 2 The review concentrates on understanding the role of culture in the NHS. It focuses on those areas where there are cultural barriers to change and improvement. The culture in and of the NHS deeply affects how it sees itself and others and how it is seen by others. It is essential to examine the NHS's position in a wider system of care and support so as to understand and improve the NHS's provision of services to children and young people. Thus, the NHS must be understood as operating in a much broader environment if change is to be achieved.
- 3 The review has uncovered many cultural barriers standing in the way of improving services for children and young people. They were created, and operate, at a number of levels, from Whitehall, through regional and local organisations, to contacts between individual professionals, and with children, young people and those looking after them.

The current state of services

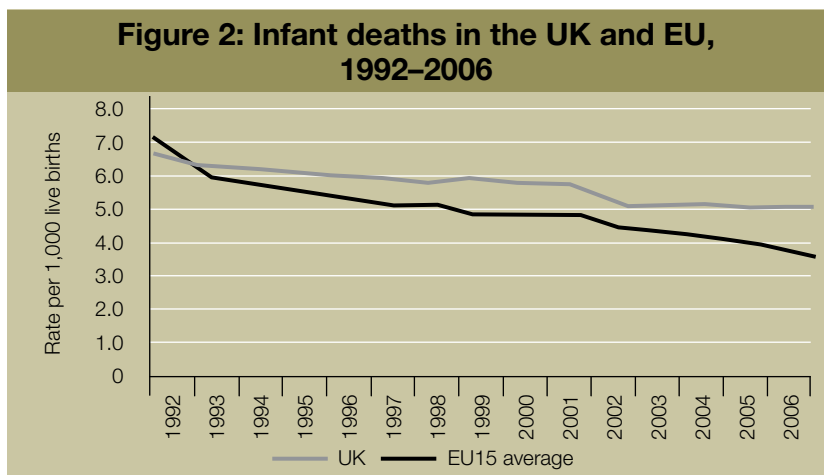
- 4 The quality of services for children and young people varies across the country. Assessments have shown not only that a large number of services are in need of significant improvement, but also, importantly, that there are some excellent services from which others might learn.

3 These include: Care Quality Commission (2009) *Review of the involvement and action taken by health bodies in relation to the case of Baby P*. London: Care Quality Commission; and Ofsted, Healthcare Commission and HM Inspectorate of Constabulary (2009) *Joint Area Review: Haringey Children's Services Authority Area*. London: Ofsted, HCC and HMIC.



Source: Healthcare Commission, 2007

- 5 Further evidence comes from international comparisons.⁴ Child mortality rates have fallen less quickly than in other EU countries and are now lagging behind. The UK also has some of the highest rates of teenage pregnancy and low-birth weight babies in Europe.⁵ These statistics are indicative of broader shortcomings in services.



Source: Organisation for Economic Co-operation and Development Health Data, 2008

4 For a brief discussion of international comparisons in health outcomes for children, see Kraft, A (2007) Are health services in England failing our children? *British Medical Journal* 335:268–9.
 5 Royal College of Paediatrics and Child Health (2007) *Modelling the Future: A consultation paper on the future of children's health services*. London: RCPCH. Available at www.rcpch.ac.uk/doc.aspx?id_Resource=2946

- 6 A recent study for UNICEF⁶ ranked the UK bottom out of 25 industrialised countries for well-being enjoyed by children, based on a range of measures, including subjective well-being.⁷ If nothing else, such international comparisons suggest that we can learn from other countries in providing a good environment for children to grow up in, taking account of the role of health and other public services in contributing to this.
- 7 Many GPs have little or no experience of paediatrics as part of their professional training.⁸ Given that the majority of their patients are adults, caring for children and young people is low on most GPs' priorities. Accident and emergency (A&E) has become the default option. While A&E departments dedicated to children and young people provide good care, the experience of children entering adult A&E departments can be quite different.
- 8 In successful networks of care built around specialist children's hospitals, children will receive the best possible quality of care as close to where they live as possible. Without successful networks, children might receive inappropriate or poorer-quality treatment locally, or else may be required to travel long distances, receiving treatment in specialist centres that could just as easily take place in their local hospital.
- 9 Despite the increased awareness in the NHS of the need to safeguard children and young people, on occasions the NHS fails to provide a safe and supportive environment.

Services working together

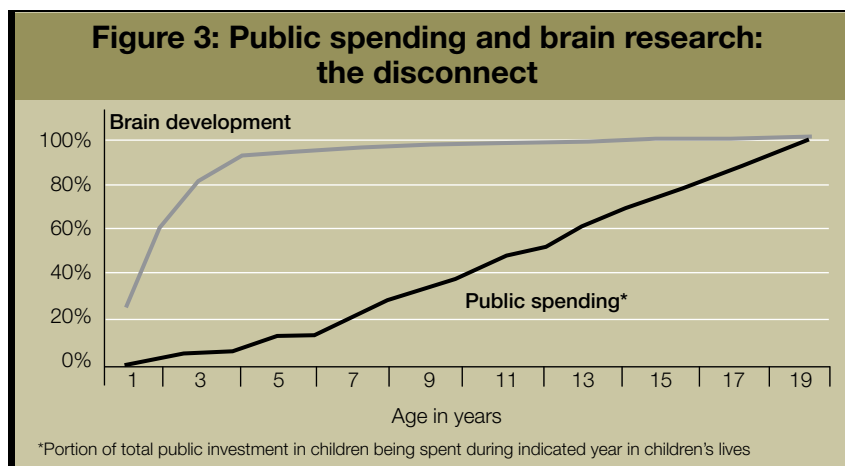
- 10 Parents and carers are often frustrated at the lack of co-ordination between services. Appointments are scheduled on consecutive days and at multiple locations, when arranging them in the same place on the same day would save a long journey and time off work.
- 11 Problems of co-ordination reflect the sheer complexity of the services that some children and young people need: a complex range of clinical services supported by complex organisational arrangements. Public perception of the NHS is that it is a single, universal system providing co-ordinated programmes of care. In fact, it is a complex array and interplay of organisations, units and teams.

6 UNICEF (2007) *An overview of child well-being in rich countries*. Innocenti Report Card 7.

7 Ibid., p. 34.

8 In many parts of the country, 40–50% of GPs will have had no formal paediatric/child health training. This is despite the fact that 25% of their patients are children, and up to 40% of consultations are with children and families. (RCPCH response to *Our NHS, Our Future*, available at www.rcpch.ac.uk/doc.aspx?id_Resource=3374)

- 12 This problem is particularly evident for young people whose care is passed from children’s to adult services. The ‘transition’ of a person’s care between clinical teams is a phenomenon created by the system. A young person’s needs, and the care that they require to meet them, evolve, yet the experience is that services change abruptly when they reach an arbitrary point (usually either their 16th or 18th birthday).
- 13 There is also frustration at the NHS’s lack of ‘join-up’ with other services. There is a clear need for close collaboration between professionals in health and education to ensure that children with long-term or serious health needs do not lose out. But some head teachers and schools are reluctant to make the necessary commitment. As regards the criminal justice system, strong links between the police and the NHS are often lacking, with NHS organisations described by one senior officer as some of the police’s “weakest” partners.
- 14 Children, young people and parents/carers are often frustrated that organisations fail to share relevant information appropriately. As for investment in services for children and young people, it is lowest in the very early years, which are the most crucial in the development of the brain, and increases only at the point when development slows.



Source: The Rand Corporation

Graph provided by Dr Sebastian Kraemer. The data refers to the USA, but the position is similar in the UK.

The relative priority given to children and young people

- 15 There is a real sense among professionals and organisations that services for children and young people in the NHS have a low priority. Children and young people receive a disproportionately lower priority than adults in the imperatives of management and delivery, in the relative funding allocated, and in the realisation that investment in the care of children and young people will reduce the cost of care later in life.

Getting policy right

- 16 The isolation of policy for children and young people's health and healthcare, separate from wider policy relating to children and young people, has two detrimental effects. It forces care for children and young people into an unwinnable battle with adult care for influence on policy, and, because policy on children emanates from more than one government department, it frustrates local co-operation as differences in departmental philosophy and priorities are played out in practice.
- 17 Responsibility for policy relating to children's healthcare and wider well-being must be brought together. The needs and interests of children and young people as regards health and healthcare are more likely to be advanced effectively if they are seen as part of a holistic approach to their overall welfare. The precise architecture of government is not for me to determine. What matters is not the precise location of responsibility for policy, but that this responsibility is brought together under one administrative and governmental roof, so that there is both the holistic view of the welfare of children and young people necessary to co-ordinate services and the clout within Whitehall to require them to be delivered.
- 18 The boundary between the responsibilities for the care of children and the care of adults must be very carefully mapped out. This must be an early task for government. This mapping of responsibilities has a virtue. It will mean that the problem of transition, long the cause of complaint and unhappiness, will now be exposed as a critical area.
- 19 Funding for the health and healthcare of children will have to be identified and separated out from the totality of funds currently allocated to the NHS. These funds would then be allocated to those bodies and organisations responsible for the delivery of services at local level.
- 20 All the relevant agencies and professionals in a given area that are involved in commissioning and providing services must, with the active participation of children and young people, agree a common vision for the healthcare, health and well-being of children and young people, and collaborate in achieving it.

- 21 Whatever the precise structural mechanism, there should be an organisation for every area (perhaps coterminous with that of the Local Authority) dedicated wholly to meeting the needs of children and young people, and which exists to bring local public services together in order to do this. This organisation should be the Local Partnership.
- 22 The Local Partnership must bring together agencies concerned with the welfare and care of children and young people in a particular locality so as to agree how the respective services that they provide should be delivered.
- 23 The Local Partnership must operate according to the following principles:
- there should be a holistic focus on children and young people;
 - there should be a duty to ensure that local organisations work together;
 - there should be appropriate ways of ensuring accountability to the public;
 - there should be an emphasis on efficiency in the provision of services; and
 - children and young people should be actively engaged and involved.
- 24 The commissioning of services from the NHS will sit alongside the commissioning of all the other services for children and young people. The connections and interactions of the various services can be choreographed so as to make them truly complementary. Savings in terms of greater efficiency, early intervention and the avoidance of duplication will be immediately realised.

Changing the NHS

How services are configured

- 25 The complexity of the NHS, as seen both from the inside and the outside, is a major barrier to offering the services that children and young people need and deserve. The premise for the future must be that the NHS is there for children and young people, rather than that the child or young person is there for the service. This means that the complexity must be addressed and managed. It means that current ways of working must change both from the inside and the outside.
- 26 The starting point must be a network of arrangements. The obvious candidate is the general practice. The practice must be the single point of access, open at all times, at which the child or young person, with a parent or carer or alone, is assessed and routed to the most appropriate professional (for example nurse, counsellor, doctor) for the most appropriate treatment, wherever it is best provided. The general practice will take on a

more positive role: not so much the ‘gatekeeper’ of the past, more the ‘navigator’ of the future. The general practice must be at the hub of the network of services that the Local Partnership has determined are necessary. The general practice has a particularly important role, as the hub of a network of services, to ensure that the services are sustainable over time.

- 27 A critical feature of being the hub is the control of information. Failure to share information among those coming into contact with the child or young person is one of the most serious shortcomings of current arrangements. To remedy this situation, there should be a dedicated information officer in every general practice or group of practices, or at the hub of a polysystem.
- 28 Those in the general practice must have the necessary training and skills to carry out their roles. This means that all GPs and practice nurses in particular, and all those other professionals attached to general practice, must be enabled to make up the gaps that exist in training. Both initial training and revalidation should include the comprehensive care of children and young people, as should the Quality and Outcomes Framework.
- 29 Of particular importance is the need to respond urgently to the mental health needs of children and young people. Mental health services must be available and accessible, including through self-referral, and be integrated with other services, particularly through schools.

Leadership

- 30 Children need champions – strong leaders who will advance their interests – at all levels in the NHS. It should be a duty of the Local Partnership, and one of its most important tasks, to create the environment in which leaders can flourish, realise their vision and be in progress for the benefit of those who will inherit the vision.

Promoting positive health

- 31 Obesity, teenage pregnancy and substance abuse are identified as areas for action by the NHS. But there are significant gaps where the cultural bias of the NHS towards identifying itself with the diagnosis and treatment of disease induces a kind of myopia. Against this background, the new Government’s intention to create an autonomous public health service provides both a significant opportunity and a challenge. The opportunity is to ensure that positive health has the focus and funding that I believe it requires. The challenge is that the creation of a public health service could see the NHS withdrawing further from the field of positive health and well-being. This must not be allowed to happen. One response should be to ensure that the Quality and Outcomes Framework is reviewed so that it includes a broad range of measures to do with the health, healthcare and welfare of children and young people.

- 32 Perhaps the single most important cultural shift that is needed from the NHS is to invest in the development of children in their early years (from minus nine months to two or three years old). These early years are absolutely central to the developmental fate of a child, yet until recently they have received virtually no attention. A huge cultural shift must take place. Resources must be invested in the early years of children, concentrating on those most at risk, whose parents/carers are least able to provide what the child needs.⁹ Of particular interest in this context is the development of the Family Nurse Partnership (FNP) programme.

Data, information, management and performance

- 33 Data in many areas of health and healthcare for children and young people is poor or non-existent. This must change. Data is necessary for effective management. It is also crucial for self-critical professional practice and for efficient commissioning. Data sets are currently being developed, that is, bodies of data that tell the story of performance and allow for setting benchmarks. They have been extremely slow in coming. It has to be recognised that no self-respecting health service should find itself in the position of being unable to discover whether its performance in a number of areas of its activity is good, bad or indifferent when judged against national or international norms of performance. Data relating to maternity, care of the newborn, and children and young people, including health promotion, safeguarding, acute care and of longer-term conditions, disability and child and adolescent mental health services (CAMHS) must be generated, used for analysis and published.
- 34 Data is only worth collecting and analysing if it is about what you want to know. What we need to know is whether the services provided for children and young people are of the appropriate quality. The indicators of successful performance are crucial. Historically, they have been expressed as targets or standards and there has been a large number. We need to depart radically from this past.
- 35 There should be only one indicator or criterion of successful performance: satisfaction with the service. Satisfaction needs to be deconstructed. It is crucial to be clear about what is being measured. Children and young people as patients and members of the public are expert in certain areas of care: their needs and desires, and the longer-term outcomes, such as whether they can walk without a stick, or do without medication.
- 36 But they are not experts on the technical aspects of their care. They cannot take a view on this because they do not know enough. As regards the technical features of care, the same criterion, satisfaction, should be used,

9 "Disadvantage starts before birth and accumulates throughout life", and disadvantage leads to significant inequalities in health. The Marmot Review (2010) *Fair Society, Healthy Lives: Strategic review of health inequalities in England post-2010*, Executive summary, p. 20. London: The Marmot Review. Available at www.marmotreview.org

but it should be differently defined. It should be satisfaction by reference to whether the outcomes achieved satisfy the benchmarks of performance developed by professionals (in conjunction with children and young people). This is the element of satisfaction that can be both subjective (was the professional satisfied with the outcome?) and objective (did the outcome meet current benchmarks of performance?). The subjective element captures the ambition and commitment of the professional.

- 37 This takes us into the world of data, analysis, norms of performance and benchmarks, and asks: *should* the professional be satisfied? So, standards will not have suddenly disappeared. The huge emphasis currently being placed on such benchmarking across the clinical professions must continue, not least the work of the National Institute for Health and Clinical Excellence (NICE) in developing a range of standards. It must, however, ultimately be focused on one single objective: the satisfaction of the children and young people and the satisfactory nature of the outcome. The system of performance management within the NHS must reflect this approach, as must external regulatory systems.

The NHS working with others

- 38 Merely agreeing to work in partnership, or making a commitment to do that which is in the best interests of the child, will not take us very far. While all can sign up to it, it will mean different things to different people and the seeds of disagreement and disharmony will be sown. What is needed is a common vision that is strong enough to bind all the agencies together while taking account of different perspectives and different points of departure. It will require significant leadership from the Local Partnership, supported by a realisation from the leaders of its constituent organisations that such a common vision is essential, and must take precedence over any particular organisation's concerns. The future must be one of a holistic approach to the child or young person.

The challenge of transition

- 39 One of the most important tasks for Local Partnerships will be to grasp the nettle of arbitrary boundaries around services, based on birthdays. Currently, there is a division of funding between services for adults and those for young people. While it may be bureaucratically convenient to draw a clear line between the two streams of funding, it makes no sense at all to the young person. Future arrangements must ensure that there is a greater flexibility, allowing for greater continuity of care even into early adulthood. This is a great prize to be won in terms of the future welfare of adults. It is essential that local organisations come together to ensure that the young person can enjoy a continuity of care that ignores birthdays and concentrates on needs.

Changing and challenging how people work

- 40 The most important agents for change to advance the interests of children and young people are the professional commitment and ethos of those who serve them. Many professionals feel beleaguered or beaten down, frustrated that they cannot achieve what they signed up to do and what they have spent their professional life trying to accomplish. Many have turned inwards, seeing the outside world of 'the system' as somehow hostile and designed to frustrate them. Many do as best they can and settle for that, in the knowledge that it is not what they would wish. The system must reconnect with its professionals.
- 41 If professionals are to be there for the child or young person as they develop and come into contact with services, sharing information is essential. Systems for storing and allowing access to information have to be aligned. This would mean that those entitled to enter data or have access to the data entered by others would be able to do so. Protocols can be agreed locally as to what is to be stored and who may have access.
- 42 Government, employers and professional groups must make the development of the workforce a very high priority. Training lies at the heart of making a better future for children and young people. A common curriculum needs to be developed to which all those who come into contact with children and young people, not just health professionals or those working in NHS organisations, should be exposed. It should address not only matters specific to the care and welfare of children and young people, but matters such as how to work in teams, how to see the child or young person holistically, an understanding of the development of children and young people, how to identify mental health problems, what other professionals dealing with children do, and how local services are commissioned, co-ordinated, provided and held to account. It must be a central feature that all those involved should learn to understand their fellow professionals as a first step to being able to trust and rely on them.
- 43 In particular, there are significant shortages of professionals trained to care for young people with mental health problems at a time when an epidemic of such problems lies beneath the surface of society. There is a pressing need to train GPs and others who work with them. The current level of training is poor and getting worse. If general practice is to be at the centre of arrangements for caring for children and young people, such training is required as a matter of urgency.
- 44 Professionals must train together. Working in a team is a central feature of modern healthcare. Training together breaks down cultural tendencies towards professional isolationism. It also fosters an understanding of one another's roles and contributions. And it sets the basis for a more holistic approach to the care of children and young people.
-

- 45 Indeed, the ultimate goal must be to shift the focus away from single professional units and identities, with their particular goals, to a single-minded concern only for the outcomes that are needed for children and young people: that is, work backwards and start with the child or young person (“I exist to provide for you”), rather than forwards from “This is what I, as a professional, do”.
- 46 To address the challenge of transition, there should be a cadre of professionals who are trained in both paediatrics and the care of young adults, putting the young person at the centre and addressing the needs of 16- to 25-year-olds.

Conclusion

- 47 We must invest. We must invest to save and we must invest because it is right to do so. There will be those who say that the times are not propitious for investment in anything, that disinvestment is the only way forward, given the state of public finances. My response is as follows. The new approach proposed in this review contemplates the integration of services, working collaboratively within the NHS and across the other agencies. Savings will be made through greater efficiency, through co-location and the benefits it brings, and through the joint planning and commissioning of services. They will also be made through the reduction of the current complexity that particularly surrounds the services provided by the NHS. A system that still relies on multiple appointments for different things in different places or, worse, by returning to the same place, is expensive. It does not meet the standards that children and young people are entitled to expect. As regards early intervention and a shift towards health promotion and the prevention of disease, the pay-off is obvious. What has been lacking at times has been the political will.
- 48 Finally, at the centre of any system for providing services are the professionals. The challenge for them is to re-engage with the system so as to change it for the better. It cannot change without them. The prize at stake is the chance to be the professionals they want to be. The greater prize is services for children and young people that they and the NHS can rightly be proud of.

1: Introduction

- 1.1 I was asked to carry out this review amid widespread concern about the services provided by the NHS to children and young people. This concern relates in part to a number of tragic and high-profile cases, for example the death of Peter Connelly in Haringey in 2007 and the investigations and reports that followed.¹⁰ But concern goes much deeper and wider. Many people who work in and use the NHS would agree that the services provided do not measure up to the needs of children and young people. They are not good enough in a number of ways.
- 1.2 Of course – and I need to emphasise this in case what follows is seen by some as too critical – there are examples of excellent care throughout the NHS and I shall refer to some of them. Equally, there is no doubting the commitment of all those working in the NHS to provide the best possible care and service. Yet the concern remains that there are things about how the NHS works which prevent it from achieving the sustained and significant improvements in care that children and young people have a right to expect.
- 1.3 My brief was to identify any shortcomings in the services provided by the NHS to children and young people, and seek to discover what lies behind them. I was asked to focus on the culture of the NHS: to identify the cultural barriers that lie in the way of change. I was asked to make recommendations to support sustained improvement (and sustainability is critical) over the medium and longer term in outcomes for children receiving services. Of course, there are also structural problems or barriers that contribute to the overall picture. I also examine these as they interact with the cultural forces.¹¹
- 1.4 Sadly, this is by no means the first review of services provided for children and young people. There have been many.¹² Much of what I say, therefore, is not new. What is new, however, is a renewed determination in the NHS and government to do something to make the services better.

10 These include: Care Quality Commission (2009) *Review of the involvement and action taken by health bodies in relation to the case of Baby P*. London: Care Quality Commission; and Ofsted, Healthcare Commission and HM Inspectorate of Constabulary (2009) *Joint Area Review: Haringey Children's Services Authority Area*. London: Ofsted, HCC and HMIC.

11 The terms of reference are set out at annex A.

12 As well as the Bristol Royal Infirmary Inquiry cited in note 2 above (which includes a summary of previous reports on pages 416–17), these include: Ministry of Health, Central Health Services Council (1959) *The welfare of children in hospital* (the Platt Report). London: HMSO; Committee on Child Health Services (1976) *Fit for the Future: The Report of the Committee on Child Health Services, Volume One* (the Court Report). London: HMSO; Audit Commission (1993) *Children First: A study of hospital services*. London: HMSO; House of Commons Health Select Committee (1997) *Hospital Services for Children and Young People, Session 1996–7, Fifth report*. London: HMSO; Laming, Lord (2003) *The Victoria Climbié Inquiry*. London: HMSO; Healthcare Commission (2006) *Investigation into 10 maternal deaths at, or following delivery at, Northwick Park Hospital, North West London Hospitals NHS Trust, between April 2002 and April 2005*. London: Commission for Healthcare Audit and Inspection; and Laming, Lord (2009) *The Protection of Children in England: A progress report*. London: The Stationery Office.

- 1.5 The review was carried out over eight months, from October 2009 to May 2010. During this time I met a wide range of individuals and groups, including NHS clinicians and managers, policy-makers, agencies working with the NHS, voluntary (third sector) organisations, and children and young people, their parents and carers. I visited a range of services, from children's centres to specialist acute and mental health services. I also received over 100 written submissions from individuals and organisations, including many from parents/carers and young people chronicling their own experiences and making suggestions for improvement. I am very grateful to them all.¹³
- 1.6 My review concentrates on understanding the role of culture in the NHS. It focuses necessarily on those areas where there are cultural barriers to change and improvement. It talks largely about how services in the NHS are planned, commissioned, organised and provided, and how they interact with one another and with other public services. The more that I sought to analyse what the NHS was doing, the more it became clear that I had to focus not just on the NHS but on the NHS's interactions with other organisations and services. The culture in and of the NHS deeply affects how it sees itself and others and is seen by others. It became clear that examining the NHS's position in a wider system of care and support is a crucial element in understanding and improving the NHS's provision of services to children and young people. Thus, while I focus on the NHS, I point out that the NHS must be understood as operating in a much broader environment if change is to be achieved.
- 1.7 My review covers the range of care provided by the NHS for children and young people.¹⁴ I do not go into detail about specific services, except when this allows me to illustrate a larger point. That said, submissions to the review did highlight a number of areas that are frequently overlooked and call for particular attention. They include: services for disabled children and young people; mental health; speech and language therapy; play therapy; and health visiting. I was greatly assisted by these submissions. I believe that the analysis that I offer, and the recommendations which flow from it, should provide a framework for change in these particular areas as well as many others.
- 1.8 In my approach to the health and welfare of children and young people, I adopt the perspective of the United Nations Convention of the Rights of the Child¹⁵ and of the World Health Organization.¹⁶ I am not concerned only

13 Full lists of engagements and written submissions are in annexes B, C and D.

14 I refer from time to time also to maternity services.

15 The Convention states that the state shall "ensure the child such protection and care as is necessary for his or her well-being [...] and, to this end, shall take all appropriate legislative and administrative measures" (article 3). In relation to involving children in their care, it states that "States Parties shall assure to the child who is capable of forming his or her own views the right to express those views freely in all matters affecting the child, the views of the child being given due weight in accordance with the age and maturity of the child" (article 12).

16 "Health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity." (Preamble to the Constitution of the World Health Organization).

with the presence or absence of disease; I am concerned to emphasise the role of the NHS, with others, in promoting the well-being of children and young people and in keeping them healthy and resilient for the future, as well as treating illness and injury from time to time.

- 1.9 I recognise the various initiatives taken by government and the NHS over the past decade. There has undoubtedly been a concerted effort, at least at the level of policy, to raise the profile of services for children and young people, and to give them a higher priority.¹⁷ Indeed, the range of policies that has been developed is recognised as among the best in the world. The *National Service Framework for Children, Young People and Maternity Services* (2004), published by the Department of Health (DH) and the Department for Education and Skills, was a significant watershed.¹⁸ It set out the standards that services for children and young people were to meet. *Every Child Matters: Change for Children* (2004), published by HM Government, set children's health and well-being in the context of the Government's commitment to their welfare. Last year saw the publication by DH of the three-part *Healthy Child Programme* (2009), which sets out an "early intervention, clinical and prevention public health programme", running from birth to the age of 19. The strategy for children and young people's health *Healthy Lives, Brighter Futures*, published jointly by DH and the Department for Children, Schools and Families (DCSF) in 2009, set out simultaneously a comprehensive vision for child health and well-being, child health services, and how these should interact with other agencies. These overarching policies are supported by a range of more specific guidance on such matters as mental health, maternity services and safeguarding. Guides to commissioning services for children and young people have also been produced, and guidelines on clinical services for them have been developed by the National Institute for Health and Clinical Excellence (NICE).
- 1.10 I also recognise the increasing extent of the collaboration between DH, DCSF (now the Department for Education, DfE) and others on a number of projects designed to improve the health and well-being of children and young people, such as the development of Children's Trusts. Specific initiatives, such as the joint funding by DH and DCSF of short breaks for those caring for disabled children, also need to be recognised.
- 1.11 Such policies and projects sit within a determination across the whole of government to give greater priority to children and young people, as illustrated by the previous Government's cross-departmental Public Service Agreements (PSAs). PSA 12 called for the improvement of "the health and well-being of children and young people".¹⁹ Another two PSAs addressed the

17 One senior official commented to me that there has been more done at the level of policy for children in the last 10 years than in the previous 50.

18 DCSF has, since the general election of May 2010, become the Department for Education (DfE). See later for the implications of this change for my analysis and recommendations.

19 HM Government (2007) *PSA Delivery Agreement 12: Improve the health and well-being of children and young people*. London: HM Treasury.

same aim, by calling for the need to keep children safe (PSA 13),²⁰ and a focus on young people's health (PSA 14).²¹

- 1.12 All of that said, the premise of the invitation to conduct this review is that the ambition represented by these developments has not always been matched by results. I will be asking in what follows whether, and if so why, this is so. The analysis and recommendations that I offer are based on the evidence provided to me. The scale of the review, both in terms of staff and its relatively short timescale, meant that I could not commission specific pieces of research or analysis. My recommendations are therefore largely at a strategic level. I do not set out detailed proposals to put into practice what I recommend. Should what I recommend be accepted, translating it into practice will be the next vital step in bringing about the much-needed changes that I recommend.
- 1.13 In the next section, I set out the current picture of the NHS's services for children and young people. It serves as the basis for a critical examination of the premise behind the review: that there exists a gap between the rhetoric of the NHS and its reality, between how the NHS talks about services for children and young people and the priority awarded them, and what in fact it delivers. I conclude that the premise is largely valid. I then analyse the cultural factors responsible. Finally, I make recommendations about the way forward.

20 HM Government (2009) *PSA Delivery Agreement 13: Improve children and young people's safety*. London: HM Treasury.

21 HM Government (2007) *PSA Delivery Agreement 14: Increase the number of children and young people on the path to success*. London: HM Treasury.

2: Services for children and young people – an overview

Services provided by the NHS

- 2.1 The NHS is traditionally divided into a number of sectors.²² The divisions reflect historical choices, such as the separation between primary and secondary care, which itself reflects a political compromise forged at the birth of the NHS. Such separations have, over the years, developed a life of their own and, far from being a convenient way of organising the service, have deeply affected the way in which the whole of the NHS has come to serve the population. Separations have become entrenched. Territories have been established. Careers have come to be mapped against them; bureaucracies have defended them; they were not designed with patients in mind; and patients have had to cope with them. In the case of children and young people, this has meant that pregnant women, parents/carers with their children, and the developing young person have had to negotiate the system. Moreover, it is a system which over the years has become increasingly complex, something that I will reflect on more fully in due course.
- 2.2 Reflecting the traditional divisions of the NHS, the services provided are broadly those in primary care, secondary care (mainly in the hospital) and in the community, and mental health care (child and adolescent mental health services – CAMHS). They also extend to schools through the school health team.
- 2.3 However, this description tells us very little. It is more instructive to look at the landscape of services from the perspective of the children and young people and their parents/carers.

Making contact with services

Services in the community – GPs, health visiting and children’s centres

- 2.4 Most children and young people will make contact with the NHS through their GP. Typically, a pre-school child will visit the GP around six times per year.²³ Much of this contact has to do with early development and public health measures, such as immunisation or self-limiting illnesses. A school-age child will see their GP on average between two and three times per year.²⁴ Even though children account for around 40% of the workload of a

22 For a general introduction to the NHS, see Klein, R (2006) *The New Politics of the NHS: From creation to reinvention*. Oxford: Radcliffe Publishing.

23 Department of Health (2007) *Making It Better: For children and young people*. London: DH, p. 2.

24 Ibid.

typical GP,²⁵ the majority of the population, and therefore also the majority of the average GP's patients, are adults. Most of the additional contractual (financial) incentives for GPs (as set out in the Quality and Outcomes Framework²⁶) relate to the care of adults.

- 2.5 Babies in the first months of life receive care and support from health visiting services, including referral to more specialist care if needed. This support is important at what is a time of significant change for families, and where the amount of information and advice about babies, families and parenting can be daunting. Many health visiting teams are now based in children's centres. For parents and carers, this means that their health visitor has ready links to a wide range of services provided at the centres, and can provide advice and information about them. Available services might include those provided by the NHS, such as speech and language therapy, as well as other relevant services such as playgroups, or classes in parenting skills or in healthy cooking.²⁷

Accident and emergency departments in hospital (A&E)

- 2.6 Children, young people and their parents or carers are often either unwilling or unable to gain access to the care of a GP or health visiting services. They choose to go instead to the A&E department of a hospital. Around half of infants (under 12 months) and a quarter of older children will attend A&E in a typical year. Around 26% of all those attending A&E are children.²⁸ Nearly one-third of calls to NHS Direct concern children.
- 2.7 Children and young people therefore attend A&E not only in emergencies, but also in cases that could be addressed outside hospital. Such use of A&E is unnecessary and inappropriate, given that A&E is designed and intended for accidents and emergencies. This recourse to A&E departments is because they are an accessible and high-profile service and provide guaranteed care around the clock. When combined with a parent's or carer's concern about a child, uncertainty about their condition and desire for problems to be addressed quickly, A&E is the default option. Direct access to A&E is particularly attractive to those who live on the margins of society, who are not registered with a GP, or who are unaware of the range of services that the NHS provides. Also, of course, A&E is used in evenings and at weekends when the great majority of GPs' practices are closed.

25 Children represent 19% of the population (Office for National Statistics), but account for up to 40% of a typical GP workload (RCPCH response to *Our NHS, Our Future*, available at www.rcpch.ac.uk/doc.aspx?id_Resource=3374).

26 Only four of 128 Quality and Outcomes Framework indicators relate specifically to children. These include one relating to maternity services.

27 I saw such services available on my visits to children's centres.

28 There were around 3.6 million attendances at A&E by children aged 0–18 in 2008/09. This does not include attendance at minor injury units and walk-in centres. (NHS Information Centre statistics)

Figure 2.1: Attendance by children at A&E by time of day, June 2009

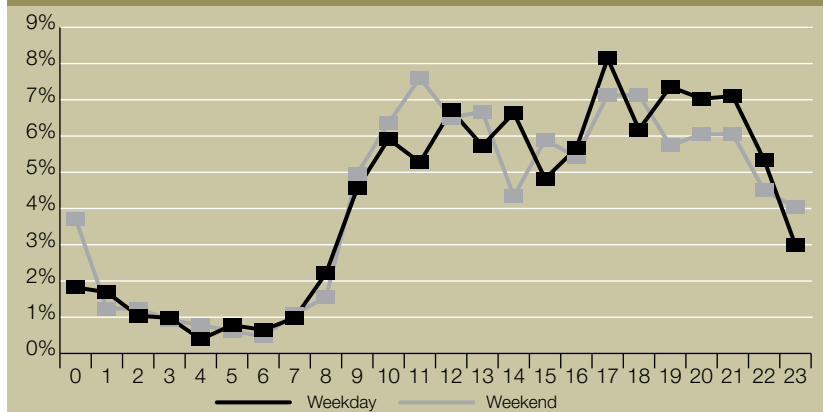
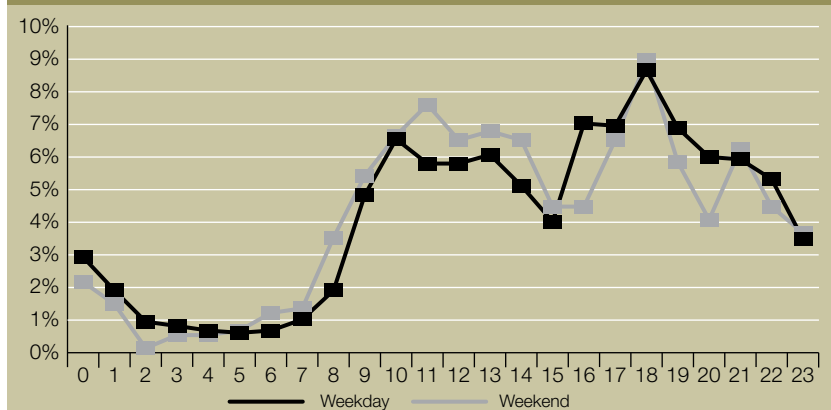


Figure 2.2: Attendance by children at A&E by time of day, November 2009



This analysis²⁹ shows that attendance differs slightly between winter and summer months, but an overall pattern of high usage in the evenings (up to around midnight) is clear.

Specialist care

- 2.8 GPs and A&E are the two most common routes through which children and young people are referred to specialist NHS services. Such services range from care in hospital to community children's nursing and paediatrics, CAMHS, and therapy services such as physiotherapy, speech and language therapy, and occupational therapy.

²⁹ This analysis has been helpfully provided to me by Ian Machonochie from Imperial College London.

Specialist care in hospitals

- 2.9 Every year around one in 11 children receives specialist outpatient care in hospital, and around one in 10 to 15 is admitted for inpatient care.³⁰ Specialist hospital care for children and young people often consists of complex, highly technical procedures carried out by highly trained specialist staff. In environments that are dedicated to the care of children and young people, staff are aware of what is required to provide the best possible experience for their sick patients. Specific efforts are made to make the environment welcoming to children, and staff are aware of their needs, desires, anxieties and frustrations. Additional specialist services, such as play therapy or distraction services to manage pain, improve children's experiences of treatment as well as helping to manage parents' and carers' anxieties. Increasingly, youth workers are available as part of young people's teams. They were described to me by the Young People's Health Special Interest Group as "important players" in designing services for young people, given the fact that they work closely with them and discuss, and sometimes address, health problems.

Mental health services

- 2.10 Children and young people with mental health problems may be referred to CAMHS. These services are mostly based in the community, but there is also a small number of inpatient and secure beds for those with serious conditions. For the most part, children and young people get access to these services through referral, but some services, mainly for young people, are also available through self-referral. On occasions, services are located away from dedicated health premises, for example in schools, youth centres or sports centres.

Specialist community services

- 2.11 Children with complex needs or long-term conditions, such as asthma, epilepsy, diabetes or palliative care, may receive specialist community nursing care. The focus is on helping children to lead a normal life to the greatest extent possible. Nurses co-ordinate clinical care, as well as supporting others, including professionals from outside the health services such as teachers, parents and carers, in providing care for the child. Children who would previously have been cared for either in hospital or full time at home are supported to stay in school and play a full part in school life. They are therefore given the opportunity to achieve their potential alongside their peers and are given the best chance of becoming independent as adults.

30 Department of Health (2007) *Making It Better: For children and young people*. London: DH. This publication also notes that the profile of specialist care is changing – "Over the past 30 years or so the number of children admitted to hospital has more than doubled, but the average length of stay has reduced from 8 to 2 days."

Therapy services

- 2.12 These services include speech and language therapy, physiotherapy and occupational therapy, dietetics and others. They are provided by a range of professionals, usually as part of a multi-disciplinary team. They may be offered or available in hospitals, general practices or settings in the community such as children's centres.

Keeping children safe

- 2.13 The NHS has an obligation to make various provisions to ensure that children are safe. Of particular importance are duties relating to 'safeguarding'.³¹ This duty has greatest significance in the context of abuse of children and young people. It extends not merely to taking action when there is suspicion that a child or young person is being abused, but also to providing care and support for the victims of abuse. Partly as a result of high-profile cases, professionals in the NHS are expected to be more aware than ever before of the importance of safeguarding and of taking appropriate action to ensure that children and young people are safe.³²

The NHS working in a co-ordinated manner

- 2.14 Children and young people, like any other patients, move through the NHS from one service to another, for example from the GP to the hospital to the community children's nurse. Networks have been developed formally for cancer and care of the newborn. They are increasingly being used for palliative care, children's surgery, child protection and other areas of children's medicine such as gastroenterology and respiratory, cardiac and renal services. The service is only as good as the efficiency of the organisation of these pathways of care.

31 These duties arise from various sections of the Children Act 1989 and the Children Act 2004, as amended. Duties vary by type of organisation, with primary care trusts (PCTs) and strategic health authorities (SHAs) being subject to more provisions than NHS providers or special health authorities. More information on the legislation most relevant to safeguarding is available in HM Government (2007) *Statutory guidance on making arrangements to safeguard and promote the welfare of children under section 11 of the Children Act 2004*. London: Department for Education and Skills and HM Government (2010) *Working Together to Safeguard Children: A guide to inter-agency working to safeguard and promote the welfare of children*. London: DCSF, p. 336f.

32 See, for a review of progress, Care Quality Commission (2009) *Safeguarding Children: A review of arrangements in the NHS for safeguarding children*. London: Care Quality Commission.

The NHS's interaction with other services

2.15 Just as there are divisions between elements of the health services provided by the NHS, so there are between the NHS and other public services. Again, the divisions are historical in origin and bureaucratic in nature.

Social services

2.16 Children and young people who need both health and social care include those with a disability or long-term condition, those who are looked after, and those who are potential or actual victims of physical, mental or sexual abuse or neglect. The links between the NHS and social services need to be suitably robust and aligned if the child or young person's health and well-being are to be maximised. A particular feature of these links is the importance of sharing information between professionals.

Education

2.17 Children and young people with health problems often require help to enable them to start or continue with their education, something that is vital if they are to fulfil their potential and live as independently as possible as adults.

2.18 Children and young people with long-term conditions or complex needs can be supported in school through specialist equipment and treatment, often supported by community children's nursing teams or school health teams. Teachers or other staff can be trained in the procedures necessary to support a child or young person, including how to operate special equipment. NHS staff can assist in raising awareness of ill-health and disability and in training staff in schools, supported by PCTs and Local Authorities. Acutely ill children can continue their schooling in hospital. Teachers in hospital work with a child's regular teacher to develop work programmes and monitor progress during the time in hospital.³³ This might include taking exams. All of this collaborative effort requires close co-operation between the NHS and schools, with professionals from health and education co-operating in understanding a child's overall needs and their role in meeting them, within a system organised to achieve this end.³⁴

2.19 Education also contributes to the health and well-being of children more widely. DfE's SEAL (Social and Emotional Aspects of Learning) programme encourages children in primary school to think about their emotions and their reactions to them, including seeking help and support

³³ I saw a very good example of this at University College Hospital.

³⁴ I was impressed by the work of Newcastle's Children's Acute Nursing Initiative team.

when needed.³⁵ A pilot programme, Targeted Mental Health in Schools (TaMHS), aims to support a variety of mental health services delivered in schools.³⁶ Both of these programmes provide children and young people with ways of addressing actual or potential problems related to mental health and emotional well-being at school, with the aim of preventing the development of more serious mental health problems and the distress and disruption they cause.

Police and criminal justice

2.20 The NHS works with the police in relation to safeguarding and caring for vulnerable children and young people, including those who offend against the criminal law as well as those who are victims of abuse. A large proportion of young people in the criminal justice system have a significant need for healthcare, especially in relation to mental health.³⁷

Working together and sharing information

2.21 Sharing information is a prime example of collaborative working between organisations. It requires them to have the technical capability to share information appropriately, for example compatible IT systems. It also requires organisations, and professionals within them, to trust one another and to be aware of the benefits that sharing information will have for the child or young person, and to have ways of working that enable this to happen.

2.22 Clearly, if organisations are to work together effectively, they must agree on what information to share and how to do so. The NHS is no exception. How this works in practice is a major theme throughout this review.³⁸

35 DCSF described SEAL as “a comprehensive approach to promoting the social and emotional skills that underpin effective learning, positive behaviour, regular attendance, staff effectiveness and the emotional health and well-being of all who learn and work in schools.” For more information, see <http://nationalstrategies.standards.dcsf.gov.uk/node/97662>

36 DCSF described TaMHS as “a three-year pathfinder programme aimed at supporting the development of innovative models of therapeutic and holistic mental health support in schools for children and young people aged five to 13 at risk of, and/or experiencing, mental health problems; and their families.” For more information, see www.dcsf.gov.uk/everychildmatters/healthandwellbeing/mentalhealthissues/tmhsproject/tmhs/

37 See paragraphs 3.51–3.52 for more information on mental health and the youth justice system.

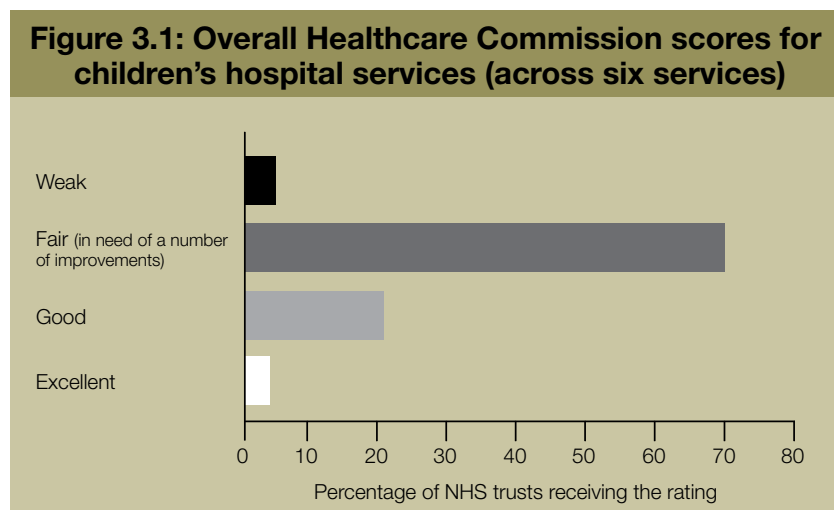
38 For a recent evaluation of how well healthcare organisations manage information, see Care Quality Commission (2009) *The Right Information, in the Right Place, at the Right Time: A study of how healthcare organisations manage personal data*. London: Care Quality Commission. This report also touches briefly on information-sharing between the NHS and social care organisations.

3: Is the NHS meeting the needs of children and young people?

3.1 My terms of reference³⁹ proceed from the premise that, while some NHS services for children and young people are very good, others are poor. The assertion is that although these services have been represented as a priority in the NHS for decades, the reality has fallen short of the rhetoric. The premise is also that the services have the potential to be better were it not for ‘cultural factors’ inhibiting their improvement. I now need to determine how valid the premise is.

General

3.2 The quality of services for children and young people varies across the country. A recent assessment by the Healthcare Commission showed not only that a large number of services are in need of significant improvement, but also, importantly, that there are some excellent services from which others might learn.



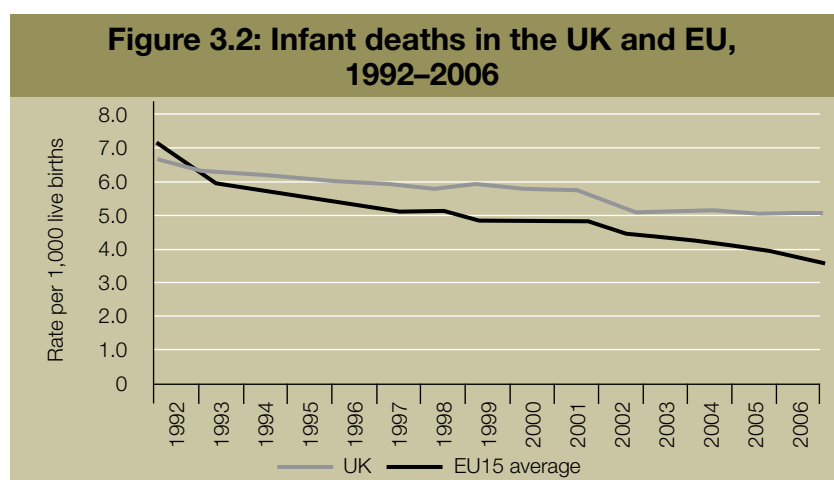
Source: Healthcare Commission, 2007

3.3 Further evidence comes from international comparisons of outcomes.⁴⁰ Child mortality rates continue to fall and are now at a historic low. However, rates have fallen less quickly than in other EU countries and are now lagging behind. Infant mortality is influenced by a wide range of health and social circumstances, and is therefore an important proxy indicator of health and the performance and contribution of both the NHS and other public

39 The terms of reference state that “successive HCC and CQC reports and other evidence indicate that good practice is not always embedded effectively. While the NHS responds positively to specific initiatives and reports, short-term improvements tend not to be sustained.” The full terms of reference are included at annex A.

40 For a brief discussion of international comparisons in health outcomes for children, see Kraft, A (2007) Are health services in England failing our children? *British Medical Journal* 335:268–9.

services. The UK also has some of the highest rates of teenage pregnancy⁴¹ and low-birth weight babies in Europe.⁴² Again, these are indicative of broader shortcomings in services.



Source: Organisation for Economic Co-operation and Development Health Data, 2008

- 3.4 A recent study for UNICEF⁴³ ranked the UK bottom out of 25 industrialised countries for well-being enjoyed by children, based on a range of measures. Importantly, this study also ranked the UK lowest as regards children and young people's subjective sense of well-being, showing a lack of optimism from children themselves about their own health and well-being.⁴⁴ If nothing else, such international comparisons suggest that we can learn from other countries in providing a good environment for children to grow up in, taking account of the role of health and other public services in contributing to this.

The relative priority given to children and young people

- 3.5 There is a real sense among professionals and organisations that services for children and young people in the NHS have a low priority. It is important, however, to understand what this might mean. Certainly, on one level, it is entirely proper that these services attract less attention than those for adults, for the quite simple reasons that adults make up 80% of the population and that, as adults grow older, their needs for care get greater. So, if the assertion is to mean anything, it must be rephrased to state that children and young people receive a disproportionately lower priority. Measures of this would include the extent to which the care of children and young people figures in the imperatives of management and delivery, in the

41 A teenage mother under the age of 18 presents a particular challenge to the NHS, in that she is both technically a child or young person and also a mother. The lines of demarcation between various services make it hard for the NHS to see her as both.

42 Royal College of Paediatrics and Child Health (2007) *Modelling the Future: A consultation paper on the future of children's health services*. London: RCPCH. Available at www.rcpch.ac.uk/doc.aspx?id_Resource=2946

43 UNICEF (2007) *An overview of child well-being in rich countries*, Innocenti Report Card 7.

44 *Ibid.*, p. 34.

relative funding allocated, and in the realisation that investment in the care of children and young people will reduce the cost of care later in life. On each of these criteria, children and young people do clearly attract a lower than appropriate level of support within the NHS.

- 3.6 I will refer later to the NHS's Operating Framework, the basis for action by managers up and down the land. The care of children and young people gets no mention, apart from warm words, when it comes to the hard choices about what has to be delivered.⁴⁵
- 3.7 The President of the Royal College of Paediatrics and Child Health (RCPCH) told me that children's health is "a 'Cinderella' subject within medicine" and that "The NHS is designed by older people for older people." The Royal College of Nursing told me that "Children are not a priority for NHS trusts. Specialists are enthusiastic about working together around the child, but senior managers are not interested."
- 3.8 The Healthcare Commission, in its report on the state of healthcare in 2008, wrote:
- "While many NHS trusts and PCTs have worked hard to raise the profile of children's services, concerns remain about the priority given to children's issues by some NHS trust and PCT boards and by independent healthcare providers."
- 3.9 I heard the same message from many who wrote to me about their children. One area of particular concern is the care of children and young people with disabilities. As I will point out several times, many parents and carers were frustrated by the difficulties in negotiating their way through an often hostile environment to secure help for a disabled child. Moreover, there appears to be only limited recognition that one of the consequences of extraordinary advances in care is the growing number of disabled children and young people who have very complex needs. There are, for example, over 6,000 technology-dependent children and young people. Their needs must be factored into the calculation of priorities, as must the fact that they will now progress to adulthood.
- 3.10 Perhaps the most obvious, although somewhat crude, measure of the priority given to children and young people by the NHS is the amount of funding allocated to their care as a proportion of the total funds of the NHS. The total allocation to the NHS is around £110 billion. The overall amount spent on children and young people is not clear (which may itself say something), but DH estimates that the figure is around £6.7 billion. The RCPCH offers the estimate of £3.1 billion (2007). The Healthcare Commission put the figure at £3.2 billion (2008). The differences may lie

⁴⁵ See paragraphs 4.112–4.124.

in the extent that a service can be disaggregated and that the element wholly dedicated to children and young people can be identified. The spending on CAMHS is said by DH to be £523 million. Another way of assessing the balance of spending is to compare what is spent on the NHS for the care of children and young people with that spent by other services. The social care budget is £4 billion. The budget for education is £35.4 billion. The spending on children and young people (including those up to age 25) by the criminal justice system is said to be £7 billion. How much of this last amount could be saved through a strategic shift of policy and resource by the NHS to preventative measures, and early intervention to support children and families at risk, is a theme that I shall pursue.

Particular services

3.11 I set out above the general landscape of services. I now ask how the various areas of service that I have previously identified measure up: whether the premise that reality falls short of the rhetoric is true here as it is in general terms. My aim is to describe what I perceive to be the current state of affairs. Once I have done so, I will be able to analyse why this has come about (the ‘cultural barriers’). Then I can offer proposals for change.

Services in the community – GPs and children’s centres

3.12 Despite the high number of children coming into their surgeries, many GPs have little or no experience of paediatrics as part of their professional training.⁴⁶ This means that, technical competence notwithstanding, many GPs lack the confidence to assess and treat children effectively, something that comes from specialist training and experience. The practical consequence of this is that they will often refer children to specialist care when better trained and more experienced practitioners would regard this as unnecessary. Examples include children with a fever, or asthma, or common ailments such as constipation and straightforward problems of behaviour. For children and parents/carers, this causes not only the disruption of additional appointments and consultations, but also worry and frustration, as problems may remain undiagnosed or untreated. And, of course, from the point of view of the NHS, it is extremely inefficient and wasteful of resources. Furthermore, the fact that GPs’ surgeries are closed at those times when parents/carers and young people often need access to a GP produces dissatisfaction with the service and resort to the local hospital’s A&E department.⁴⁷

46 In many parts of the country, 40–50% of GPs will have had no formal paediatric/child health training. This is despite the fact that 25% of their patients are children, and up to 40% of consultations are with children and families. (RCPCH response to *Our NHS, Our Future*, available at www.rcpch.ac.uk/doc.aspx?id_Resource=3374)

47 “Changes to general practitioner out-of-hours care have resulted in increasing attendances to emergency departments.” (*Modelling the Future*, RCPCH 2007 – see note 42). Also, see the graphs on p. 21 on attendance at A&E. Changes to out-of-hours arrangements also mean that GPs have fewer opportunities to develop experience in seeing and treating children.

- 3.13 Given that the majority of their patients are adults, caring for children and young people is low on most GPs' priorities. One senior manager commented to me that the biggest single problem is getting GPs to be interested. One illustration of this is that they frequently fail to attend meetings called about safeguarding.⁴⁸ This, in turn, is a problem that reflects poor working relationships between GPs and other services, as in part it results from meetings often being arranged or rescheduled at short notice, which means that GPs are unable to attend due to clinical commitments.
- 3.14 As regards the services provided by children's centres, it is obvious that parents and carers clearly value them, including the ease of accessibility that comes from providing them on a single site close to where they live. Many parents/carers would like them to provide yet more services, including primary medical care (which is now beginning to be available in some areas). However, many parents/carers do not associate children's centres with health services, possibly due to poor communication and consequent lack of awareness of what is on offer.⁴⁹ Take-up of health services is, therefore, comparatively low, especially compared with childcare and nursery education.⁵⁰

A&E

- 3.15 The NHS has consistently attempted to educate people about the range of services available from the NHS for parents and carers with sick children, so that the services of A&E departments will only be used when appropriate – and, it must be stressed, sometimes it is appropriate. Equally, there are occasions when it is not. But A&E is always there and always open, when other services are not; and it is far from obvious to a parent/carer which services are available, and to which people, at which times. Navigating through the complexity of NHS services, finding the system's preferred point of access for each child, can be difficult for even the most articulate and well informed. A&E becomes the default option. The NHS and those who use its services suffer as a consequence.
- 3.16 Children and young people's experience of A&E will vary by age, location and time of day. Children's hospitals and larger general acute hospitals often have either a dedicated paediatric A&E department or a separate section of A&E for children. Staffed by clinicians with specialist training, these departments are aware of and able to address the different clinical

48 A senior police officer commented that "if any of five people from the NHS might turn up at a meeting, then you just have to hope you get someone good."

49 "Our focus group participants used children's centres largely for childcare services, and for involvement in social groups but did not associate them with health services." (Audit Commission (2010) *Giving Children a Healthy Start*. London: Audit Commission)

50 Audit Commission (2010) *Giving Children a Healthy Start*.

needs of children and young people, as well as their anxieties and those of their parents or carers. For children entering adult A&E departments the experience can be quite different. An intimidating setting is often exacerbated by the presence of injured, drunken or violent adults. This is a problem encountered especially at night, when dedicated paediatric A&E services are more likely to be closed.⁵¹

- 3.17 Lack of training in treating children and young people may lead staff to treat them inappropriately, however unintentionally. This includes not recognising children's different clinical needs, or not engaging with them in an age-appropriate way or, for younger children, not engaging with their parent or carer appropriately.⁵²

Specialist care

In hospital

- 3.18 Children and families may have to travel some distance to receive specialist care. In successful networks of care built around specialist children's hospitals, or large teaching hospitals with specialist children's facilities that also involve larger district general hospitals, children will receive the best possible quality of care as close to where they live as possible.⁵³ Without successful networks, children may receive inappropriate or poorer-quality treatment locally, or else may be required to travel long distances unnecessarily, receiving treatment in specialist centres that could just as easily take place in their local hospital. Such experiences cause unnecessary inconvenience and frustration. They also mean that care may be of poor quality or even dangerous.
- 3.19 Smaller centres that lack dedicated specialist facilities also lack the range of supplementary services which can make such a difference to a child's experience of hospital, often due to lack of funding rather than lack of recognition of their value. For example, the management of pain is often

51 16–18% of hospitals provide insufficient cover for paediatric emergencies at night. (Healthcare Commission (2007) *Improving Services for Children in Hospital*. London: Healthcare Commission)

52 The benefits of specific training, including formal training in communication with children and young people, as well as evidence of young people's desire for greater involvement in decision-making about their care, are explored in more detail in *Improving Services for Children in Hospital*. These are vital issues, to which I will return.

53 For example, in the case of paediatric surgery, the percentage of operations carried out in district general hospitals has been falling over the last 10 years, reflecting a trend to increased specialisation that has improved outcomes (Department of Health, 2007). However, the Chair of the Children's Surgical Forum of the Royal College of Surgeons of England was of the view that "while there are some examples of a network operating effectively, the key barrier to transforming the delivery of surgical services for children is the current inability of the NHS to develop and support clinical networks in practice." (Royal College of Surgeons of England's submission to the review)

poor,⁵⁴ and I was told of at least two hospitals where play therapy services, so important as regards the experience children have of treatment, have recently been withdrawn for financial reasons.⁵⁵

- 3.20 The smaller number of children using these smaller centres may also mean that staff lack sufficient experience in caring for them, sufficient specialist training, or both, especially if the child or young person has rare, specialist or complex needs. Indeed, a number of hospitals and their specialists see too few cases for the facilities and skills to be kept up to date.⁵⁶
- 3.21 For parents/carers and children, the variation in the level of service is confusing and frustrating and seen as unfair.

“We’ve never really had any bad experiences at [Great Ormond Street Hospital]; however, smaller, more local hospitals are more daunting, where staff have little specialist knowledge and do not embrace disability or difference.”

Parent of disabled child

Mental health services

- 3.22 Young people using CAMHS have, in most cases, already overcome significant anxiety and risk of stigma to gain access to services. Often the need to be referred for such services is a potent factor in their not being used.⁵⁷ But self-referral, although attractive to some young people, is relatively uncommon.⁵⁸
- 3.23 Young people are often further distressed by inappropriate environments, including being treated on adult wards.⁵⁹ I also heard from young people how, on occasions, the attitudes and behaviour of staff can be insensitive to their specific needs and concerns.

54 Healthcare Commission (2008) *State of Healthcare 2008*. London: The Stationery Office. This was also mentioned during review meetings.

55 The services were mentioned independently in two communications to the review.

56 In 2007 the Healthcare Commission found that, in 8% of trusts, surgeons carrying out elective surgery did not carry out a sufficient number of operations to maintain their skills to work with very young children, and that 16% of paediatric inpatient units were carrying out less than the professionally recommended minimum level of interventions. (Healthcare Commission (2007) *Improving Services for Children in Hospital*. London: HCC) I recognise that special arrangements may be needed for remote areas.

57 The Mental Health Foundation noted that both children and young people and their parents/carers are more comfortable with mental health services provided in generic, non-stigmatising settings, including non-health settings such as schools or youth centres. (Summary of evidence for the Good Childhood Inquiry, available at www.childrenssociety.org.uk)

58 One outstanding example of a service based on self-referral that I visited is the Brandon Centre in Camden, north west London.

59 Healthcare Commission (2008) *State of Healthcare 2008*. London: The Stationery Office.

- 3.24 CAMHS also care for victims of assault and abuse, and are increasingly involved in safeguarding. Using these services in this context can cause anger and frustration for the children and young people being cared for.⁶⁰ They feel that they are being labelled by the service as suffering from a mental health problem which they do not have.

Specialist community services

- 3.25 Despite major successes in some areas,⁶¹ availability of these services is still a problem. Specialists are confined to a small number of conditions and there are fewer of them than are needed. This means that many children are unable to benefit from these services.

Therapy services

- 3.26 Many parents and carers are frustrated at the lack of availability of specialist therapy services, including speech and language therapy, physiotherapy and occupational therapy, which are often dwarfed by services for adults. Finding that their child is entitled to services does not mean that such services are available in their local area. Parents/carers report that services are overloaded, or that they have to travel long distances to receive them.
- 3.27 Parents/carers of disabled children in particular often feel that getting access to suitable health services is dependent on a “constant battle of resources”, as investment in high-tech interventions to keep severely disabled children alive has not been matched by investment in services to support them in leading their lives (including in the transition to adulthood):⁶²

“The paed[iatrician] will refer us for other services if I push and push but they are not offered. I’m tired of fighting – it’s exhausting!”

Parent of child with Down’s syndrome

60 View submitted at a meeting with independent experts.

61 For example, hospital admissions for childhood asthma fell 40% during the 1990s, despite an increase in diagnoses. (Department of Health (2007) *Making It Better: For children and young people*. London: DH)

62 This was mentioned in meetings with both senior officials and third sector organisations. One senior manager commented that people get “operations five times faster than wheelchairs”.

- 3.28 The impression is gained that such services, and therefore both the people who need them and those who provide them, are a low priority for the NHS. Even where services are available there is often a recurring problem about sharing information. Failure to share information between therapists and others looking after the child or young person, such as medical or nursing teams, is a common frustration.

“We see so many different specialists at so many different times and there is no working together and little contact and information-sharing.”

Parent of disabled child

This is something that I will return to later.

Keeping children safe

- 3.29 Despite the increased awareness in the NHS of the need to safeguard children and young people, it is acknowledged that, on occasions, the NHS fails to provide a safe and supportive environment. For example, young people are reluctant to tell health professionals about abuse, for fear that they will not be believed or that no action will be taken.⁶³
- 3.30 Evidence from the Care Quality Commission shows that many NHS trusts need to do more in relation to their duties regarding safeguarding children. They need to ensure that clinical staff are trained to the necessary level and that they keep this training up to date, that strategies for safeguarding are in place and that their effectiveness is audited, and that trust boards and senior management ensure that they keep safeguarding under regular review, rather than merely respond to serious incidents.⁶⁴ Worryingly, the Commission noted that the need for action in some of these areas had been given priority in previous reviews, but that action had still not been taken.
- 3.31 There is also other evidence that lessons have not been learned from previous tragedies. Lord Laming’s recent report on safeguarding children⁶⁵ indicates that recommended guidance and other actions are not being implemented. This shows clearly that services which need to make improvements are, for whatever reason, not making them.

63 Palmer, T and Raby, C (2010) *Taskforce on the Health Aspects of Sexual Violence Against Women and Children: Consultation with Children*.

64 Care Quality Commission (2009) *Safeguarding Children: A review of arrangements in the NHS for safeguarding children*. London: Care Quality Commission.

65 Laming, Lord (2009) *The Protection of Children in England: A progress report*. London: The Stationery Office. The report also highlights other problems, including training and support from practitioners and the sharing of information between organisations.

3.32 The Government's definition of safeguarding includes "ensuring that children [grow] up in circumstances consistent with the provision of safe and effective care" and "enabl[ing] children to have optimum life chances and enter adulthood successfully."⁶⁶ I have heard how recent tragedies have led social services and others, including the NHS, to focus attention and resources overwhelmingly on protecting children from abuse, to the exclusion of the broader obligation to safeguard their well-being and resilience. This means that outside the formal child protection system a wider, often unrecognised group of children continue to lead constrained and unfulfilling lives, at risk from a wide range of problems and poor outcomes and prevented from achieving their full potential.⁶⁷

"There has been a negative change [in safeguarding in the past year] – more work and more pressure on staff plus more difficulty engaging other agencies because of the stress they are experiencing."

Designated doctor for safeguarding

Access to NHS services

3.33 Access is a key dimension of the provision of services. The services offered by the NHS fail those for whom they are intended if, as is too often the case, children and young people are unable to gain access to them, or if difficulties in doing so are put in their way. This is particularly important for children and young people with complex needs, who require many services to work together around them.

The NHS working in a co-ordinated manner

3.34 A number of parents and carers wrote to me expressing their frustration at the lack of co-ordination between the many services that their children required. Appointments are scheduled on consecutive days and at multiple locations, when arranging them in the same place on the same day would save a long journey and time off work. Support groups for parents/carers routinely meet during office hours, meaning that working parents/carers are unable to receive the vital support that they provide.

"Over the last 18 years I have never been able to see two consultants on the same visit. This has cost me a fortune in transport costs and time. My child is profoundly disabled, and has been under orthopaedic, neurological, spinal, and general paediatrics... all at the same time. Yet we have never had a combined appointment."

Parent

66 HM Government (2010) *Working Together to Safeguard Children: A guide to inter-agency working to safeguard and promote the welfare of children*. London: DCSF, p. 34.

67 Royal College of Paediatrics and Child Health (2009) *Modelling the Future III*. London: RCPCH, p. 8. Available at www.rcpch.ac.uk/doc.aspx?id_Resource=5855

- 3.35 Parents and carers expressed their frustration that diagnoses, advice and other information from one episode of care are not passed to the team conducting the next. In some cases, parents/carers felt forced to take on the role of co-ordinating their child's care themselves.

Question: In your experience, how well do the different services contributing to your child's care work together to meet your child's needs?

"They don't! I'm the hub of everything! I have to tell the paediatrician for example what services my son is using so that he can mark it down on a bit of paper."

Parent

"The biggest problem is lack of communication between health professionals... It should not be up to parents to copy clinic letters and relate details to other professionals."

Parent

- 3.36 Both young people and the parents/carers of younger children are frustrated at having to re-explain their or their child's condition to a number of different services because of a lack of effective information-sharing. In some cases, this frustration is compounded by a high turnover of staff, meaning that patients must explain their story not only many times to different services, but many times to the same service, as staff change.
- 3.37 When information is communicated to children and young people or parents/carers, it is often in a form that is barely understandable to the people it relates to. Professionals in the NHS lapse all too frequently into jargon, which is baffling and intimidating to parents/carers and children. This includes organisational as well as clinical jargon.

"It's a whole new world and new language for parents to learn if they have never had any experience of special needs before. A better explanation of what each service is, why your child might need it, less jargon and how to access it should be made available."

Parent

- 3.38 Such problems are not inevitable, even in cases where complex care is required. I have seen examples of services that are careful to use accessible language and have developed devices for doing so, for example writing care plans in the first person and ensuring that they are then understandable to the person for whom they have been written.

- 3.39 Problems of co-ordination reflect the sheer complexity of the services that some children and young people need: a complex range of clinical services supported by complex organisational arrangements. As more services come to interact and work around the needs of a particular child or family, this complexity multiplies. The danger is real that services lose focus on whom they are there to serve, as each service or clinical team provides the best it can without sufficient regard to how children and families view the ‘whole picture’ of the care that they are receiving. Public perception of the NHS is that it is a single, universal system providing co-ordinated programmes of care. There is little recognition or understanding of the complex array and interplay of organisations, units and teams of which it actually consists.⁶⁸
- 3.40 Lack of co-ordination of services is particularly evident for young people whose care is passed from children’s to adult services. The transition of a person’s care between clinical teams is a phenomenon created by the system. It views care from the perspective of organisations providing services, rather than the children and young people being cared for. The ‘problem of transition’ arises from the administrative divisions between different NHS services. A young person’s needs, and the care that they require to meet them, evolve, yet the experience is that services change abruptly when they reach an arbitrary point (usually either their 16th or 18th birthday). ‘Transition’, in reality, often amounts to no more than ‘transfer’. For many young people, transition is experienced as a disruptive discontinuity in their care, as they move suddenly from child services, with a specific child focus and (often) trained staff, to adult services with different staff, different settings, different attitudes to patients and no training in the care of children and young people or in dealing with parents/carers.⁶⁹

“Upon turning 18 a person’s needs do not change, but the range of services available to them becomes radically different!”

Young person

“We have started asking all consultants that we see regularly at children’s hospitals where we will be referred to next year when she reaches 16, but nobody has yet been able to answer my questions as they do not know.”

Parent of disabled child

⁶⁸ In a recent publication, the RCPCH draws attention to the official government position that “The NHS is not a collection of separate and autonomous units of varying degrees of independence, responding to the invisible hand of the market and incentives and reforms. It is, in fact, a healthcare system. The different parts, whether GPs or consultant nurses working in primary care or acute care, are all working for the benefit of patients, whose pathway of care often crosses the boundaries of professions and organisations. This system requires active management by both PCTs and SHAs as local system managers”, noting that this is the stated intention for the future rather than a description of the present. (RCPCH (2009) *The Comprehensive Spending Review, Public Service Agreements and the NHS Operating Framework*. RCPCH Policy Briefing)

⁶⁹ More information on transition, including young people’s views about their care and good practice examples, is included in Department of Health (2006) *Transition: Getting it right for young people – Improving the transition of young people with long term conditions from children’s to adult health services*. London: DH.

- 3.41 In some cases, the thresholds for receiving care are different. Children and young people with mental health problems may stop receiving CAMHS at the age of 16, but the threshold for receiving mental health services as an adult is different. The consequence may be that, at 16, a young person's problems may abruptly be considered to be below the threshold that will qualify them to receive adult mental health services. The absurd consequence is that their condition may well deteriorate before they can get help.
- 3.42 The shortcomings in care arising from transition add weight to a wider feeling that young people, or adolescents, are a 'forgotten group', caught between child and adult and therefore also between bureaucratic barriers and professional spheres of influence.

"One of the main cultural obstacles... for young people is the lack of recognition of them as distinctly different to children as well as adults... Many young people are at risk of falling out of view of children's services and either get lost as a minority group in adult services or are lost in the transition between them."

Young People's Health Special Interest Group

"Usually professionals are competitive and try to take one another's work, but not the 16–19 age groups, probably reflecting a lack of knowledge, skills and facilities."

Consultant paediatrician

- 3.43 Two other factors worth mentioning in any consideration of the NHS working in a co-ordinated manner are the extent of the involvement of parents or carers in the care of children and young people, and the involvement of children and young people themselves. As regards parents/carers, I was told on a number of occasions how they felt that they were not properly involved in what was going on.

"I found out later that an assessment had been carried out... I had no prior knowledge [and was not] invited to attend. A 'report' was sent directly to the school and I did not receive this until last day of term... Again due to the timing, this left me no opportunity to discuss this with anyone... These services send letters without being clearly titled and without clear explanations of clinical terms... no proper examples of how conclusions are being made and no input or consideration of parents and their expertise and knowledge of their child."

Parent

- 3.44 As regards children and young people, not only was I told of occasions when they felt that they were not really involved in their care, but there is also another deeper cultural point. DH and the NHS are anxious to suggest that the NHS's services respond to the needs expressed by the public. The only catch is that the only members of the public who are routinely surveyed are in fact adults. There is no regular survey of children and young people. Not asking means not knowing.

NHS interaction with other services

Social services

- 3.45 Children, young people and their parents/carers are often frustrated that the health and social care services do not have a 'joined-up' approach to the services that they provide. Simple needs for care may go unmet as NHS and social care organisations dispute which is responsible for funding a particular need. Such disputes can be very disruptive for the child. They may, on occasions, result in a child's condition deteriorating, resulting in pain and distress as well as additional costs. For example, I heard of one case in which a child discharged from hospital required a plastic feeding tube, which cost around £2.50. The responsibility for funding this tube was disputed by health and social care organisations. By the time the case was finally settled out of court, it had cost around £20,000.
- 3.46 Of particular importance and concern are failures of health and social care to work together in the context of safeguarding. In 2008, the Healthcare Commission stated that "Our recent work in Haringey looking at arrangements for the protection of children found that systems were not adequate to enable agencies to work together effectively on behalf of children."⁷⁰

Education

- 3.47 Despite the obvious need for close collaboration between professionals in health and education to ensure that children with long-term or serious health needs do not lose out in education, and the enthusiasm of most head teachers for school health services and recognition of the benefits they provide,⁷¹ some head teachers and schools are reluctant to make the necessary commitment. They are concerned about the implications for the safety of the child and the risk to which they might be exposed to by assisting with healthcare for which they believe they are insufficiently qualified.⁷² That said, with sufficient support, most are happy to contribute to care that clearly is in the best interests of the child.

⁷⁰ Healthcare Commission (2008) *State of Healthcare 2008*. London: The Stationery Office.

⁷¹ View submitted at a meeting with a professional body.

⁷² View submitted at a meeting with third sector organisations.

- 3.48 If children do not receive appropriate support from the school, at worst those with severe health problems receive a ‘double whammy’ as their ill-health damages their education by disrupting their schooling, either through being forced to stay at home or by long stays in hospital. Children with severe or long-term conditions receive enormous benefit from continuing their education during their treatment. And there are social as well as educational benefits. Continuing in education is a signal, to the child themselves, the parents/carers and the peer group, that a child with a severe or complex health condition continues to belong to the ‘community of children’ and does not become defined by their condition.
- 3.49 A particular area of concern is mental health. Young people with mental health problems told me that, although support from school was good once their diagnosis was made and treatment begun, they were frustrated that schools did not provide them with more help during the early stages of their illness prior to formal diagnosis.
- 3.50 These young people considered that schools could do a lot more to identify and help pupils who were showing signs of mental illness. This view is supported by the Mental Health Foundation, in their submission to the Good Childhood Inquiry, which argues that “Schools need to be able to identify emotional problems in children early on and seek timely help and support to deal with them.”⁷³

Police and the criminal justice system

- 3.51 Strong links between the police and the NHS are often lacking, with NHS organisations described by one senior officer as some of the police’s “weakest” partners. This means that investigation and intervention in cases of suspected abuse are not as co-ordinated as they should be. Police forces often find it difficult to engage with health services, as the complexity of the NHS’s internal organisation, matched with a high turnover of staff and frequent structural reorganisations, means that they do not know which organisation or whom within the organisation they should talk to.⁷⁴
- 3.52 Over 200,000 children and young people come into contact with the criminal justice system each year. Over 2,000 find themselves in some form of institutional setting. They are acknowledged to have multiple health problems, including problems with mental health (as high as 90%), learning disabilities, speech and communication, and sexual health. Many have not been immunised. Over half have been ‘looked after’ in homes. At least 60% have problems with substance abuse. They frequently come from a chaotic

73 Summary of evidence for the Good Childhood Inquiry, available at www.childrenssociety.org.uk

74 This was mentioned by senior police officers on more than one occasion.

family environment. Early intervention to break the cycle of deprivation and decline into anti-social behaviour is crucial.⁷⁵ But, although the criminal justice system seeks to do its part, once the children and young people leave the system, there is no effective continuity of care. The criminal justice system operates in a silo. There is no effective partnership with the other services for children and young people. The child or young person just gets back onto the conveyor belt of social exclusion.

Working together and sharing information

3.53 Children, young people and parents/carers are often frustrated that organisations fail to share relevant information appropriately.⁷⁶ This mirrors the frustrations and problems already referred to in the case of poor sharing of information between NHS organisations.

3.54 Failure to share information, for whatever reason, can mean that organisations do not know of relevant information about children and young people's problems or their care. Social workers may be unaware that NHS services have a suspicion that a child is being abused. This is damaging in two ways. Not only will social services be unable to take action that the information would have prompted had it been shared with them, but they might also hold information which, when combined with that held elsewhere, gives a more complete picture which can better inform the actions of all agencies.

Missed opportunities

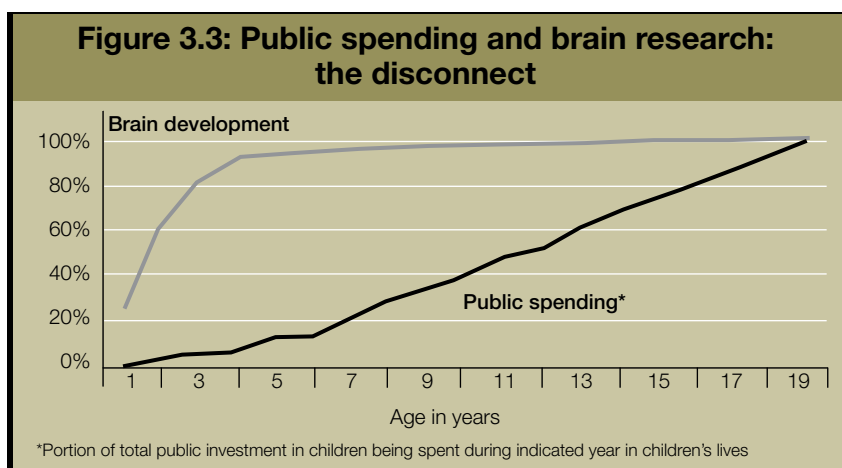
3.55 In addition to the NHS's failing to meet its potential in providing for children and young people, decisions about how to configure services and where to place more or less emphasis have led to its delivering less than optimal outcomes. And, of course, missed opportunities during childhood and adolescence mean increased problems for the NHS later in life.

⁷⁵ See paragraphs 3.59–3.61.

⁷⁶ This point was emphasised in a number of submissions to the review. For example, parents' and carers' frustrations about the lack of information-sharing between the clinical teams caring for their child are explored above.

The early years

- 3.56 The importance of investing in, and concentrating services on, the first years of life cannot be overstated. As highlighted in Professor Michael Marmot's review of health inequalities,⁷⁷ and elsewhere,⁷⁸ the determinants of health and well-being, whether good or bad, start before birth and accumulate over a lifetime, with a particular importance attached to the very early years. As a result, giving every child the best start in life is widely recognised as crucial in improving the health and well-being of the population as a whole, as well as being the most important step required to tackle health inequalities⁷⁹ and to contain long-term demand on the NHS.⁸⁰
- 3.57 In the light of this somewhat self-evident proposition, I was unpleasantly surprised to discover that evidence submitted to the review shows that investment in services for children and young people is lowest in the very early years, which are the most crucial in the development of the brain, and increases only at the point when development slows.



Source: The Rand Corporation

Graph provided by Dr Sebastian Kraemer. The data refers to the USA, but the position is similar in the UK.

- 3.58 If services are to influence how children grow up and prosper, much more investment and effort are essential in this crucial early period.

77 The Marmot Review (2010) *Fair Society, Healthy Lives: Strategic review of health inequalities in England post-2010*. London: The Marmot Review. Available at www.marmotreview.org

78 "The single most effective method to improve the long-term health of the whole population is to invest in the health of children and families." (RCPCH (2009) *Modelling the Future III*. London: RCPCH, p. 15. Available at www.rcpch.ac.uk/doc.aspx?id_Resource=5855)

79 The Marmot Review (2010) *Fair Society, Healthy Lives: Strategic review of health inequalities in England post-2010*. Executive summary. Available at www.marmotreview.org

80 Royal College of Paediatrics and Child Health (2007) *Modelling the Future: A consultation paper on the future of children's health services*. London: RCPCH. Available at www.rcpch.ac.uk/doc.aspx?id_Resource=2946

Promoting positive health and well-being

- 3.59 In addition to other measures, a more general focus on promoting health and preventing ill-health, together with early intervention services for mental health problems, is of critical importance.⁸¹ Failure to provide such services for children and young people before they reach adulthood, bearing in mind that mental health problems in adulthood begin in childhood, leads to the situation in which, as the previous Government noted, “Mental illness accounted for more disability adjusted life years lost per year than any other health condition in the UK”, including cardiovascular disease and cancer.⁸² The total cost of mental illness, including treatment, formal and informal care, lost employment, premature mortality and reduced quality of life, was calculated at more than £77 billion for 2002/03.⁸³
- 3.60 These costs, including opportunity costs and their effects on family, employers and the individual as well as on the state and its agencies, can be no more than speculative. They do, however, serve to demonstrate not just the importance of mental health and health services, particularly for children and young people, but also the interdependence and overlap of different public services’ priorities and objectives. Investment in early intervention, and particularly early intervention for young people with mental health problems, can potentially save millions of pounds for the NHS and for the education system. Further savings will be made in reducing the costs of unemployment, social care and benefits, and costs to the criminal justice system.⁸⁴
- 3.61 While I emphasise the financial cost, what is also at stake in calls to improve the services provided by the NHS for children and young people is a fundamental issue of social justice. Providing care for those who need it, especially those who are vulnerable or unable to care for themselves, is a matter of fairness. It is not just about economics, but also the kind of society in which we want to live. Preventing a mental health problem becoming a crisis, or providing support and intervention to give a baby the best possible start in life (rather than waiting for problems to develop in childhood or adolescence) serve both a moral and an economic purpose.

81 About 75% of adults with mental health problems first experienced mental health problems in childhood. (Kim-Cohen, J, Caspi, A, Moffitt, T E et al (2003) Prior juvenile diagnoses in adults with mental disorder. *Archives of General Psychiatry* 60:709–17)

82 HM Government (2009) *New Horizons: A shared vision for mental health*. London: DH.

83 Sainsbury Centre for Mental Health (2003) *The economic and social costs of mental illness*. Policy Paper 3.

84 For example, I was advised that in year one of the Family Nurse Partnership (FNP) programme in Tower Hamlets, an assessment was made of how many children had not been placed in care as a result of the FNP programme. The estimate was six children. Given that it costs £2,500 per week to keep a child in residential care, and assuming an average of three years in care for each of the six children, the saving just in this particular area would be £3 million per year, less the cost of the programme of £250,000 per year.

Conclusion

- 3.62 This brief overview clearly shows that the premise of the review, that services are not as good as they could be, is broadly valid. International evidence shows that better outcomes are possible, and recent developments and examples of excellent practice show that positive change is possible in the NHS.⁸⁵
- 3.63 However, there is also considerable evidence that changes to improve services are not being made; that planners, professionals, parents/carers and children and young people themselves remain unhappy with aspects of current services; and that opportunities to invest in services that will bring significant long-term benefits are being missed. In the next chapter, I analyse in more detail the reasons for these problems, including the factors currently preventing services from changing for the better. I do so from the perspective of the culture of the NHS.

85 I was very impressed with the services I saw at St Stephen's Children's Centre in Newham, east London, where a range of services, including NHS services, were offered in an integrated manner. I shall refer to other examples in the next chapter.

4: Cultural barriers and how to address them

- 4.1 The preceding chapter leaves no doubt that change is needed. The child and the young person must be at the centre of the services provided by the NHS and other agencies. They must be involved in the shaping and delivery of those services. The services must be organised around the children and young people: they should not have to work out which door to go through to get what they need. The services must be responsive to their needs, not organised around buildings or the preferences of staff.⁸⁶ The services must meet the expectations of good practice that we are entitled to call for. Those providing the services must regularly monitor and review their performance by reference to whether they are meeting the needs of those they exist to serve. The services must be delivered efficiently on behalf of the taxpayer. And, above all else, it is as they start out in life that children must be given the greatest possible assistance in making a start which will equip them with the well-being and resilience to become the successful citizens of the future.
- 4.2 Very little that I propose here is new. It has been said countless times.⁸⁷ What perhaps is new is the concentration on the cultural roadblocks and the role that they have in causing the NHS to sell children short. What is also new, and welcome, is the growing awareness in many parts of the NHS and government of the need for the sort of changes that I am proposing. I will, therefore, be working with the warp of policy as it currently stands, not against it.
- 4.3 In this section, I set out a way forward for services for children and young people. I do so by identifying cultural barriers or roadblocks in the way of change⁸⁸ and proposing ways whereby they can be removed or avoided. My proposals for change are couched in general terms: there will be many details to fill in. And, of course, change will be slow, as is always the case when habits and assumptions of long standing have to be modified or abandoned.
- 4.4 It can and probably will be objected that the changes that I propose will cost too much, given that we are entering a period of constraint in terms of the money available for our public services. My response is that the shortage of money can always be used, and often has been in the case of children's services, as the reason to justify the status quo or to do nothing. Moreover, to the person who says "Do you know how much it will cost the nation to do what you recommend?", my answer is a simple one: "Do you know how much it will cost the nation if you don't take action, and take

86 One young person explained the current system by saying that "they expect your illness to adjust around what they can offer".

87 Chapter 1 gives some examples.

88 See the helpful analysis offered in the report by Barnardo's policy research unit (February 2010).

action now?" Secondly, the fact is that the best services are usually the cheapest, since they are, by definition, more efficiently organised and more effectively delivered. Thirdly, my proposals, for example, for integrating services would, simply through the process of integration alone, save money by eliminating duplication and delay. Fourthly, investment in early intervention and the prevention of ill-health saves money 'downstream'. It is so blindingly obvious that it needs to be said again and again: today's children and young people are tomorrow's adults. Unless the NHS wants to go on responding to the never-ending and growing numbers of adults presenting themselves for care, it needs to direct an increasing element of its energies to cutting down those numbers by intervening earlier. Fifthly, while the economic case is strong, fundamentally caring properly for and about children and young people is a question of social justice. They deserve better of us.

The approach

- 4.5 My review has uncovered many cultural barriers standing in the way of improving the services of the NHS for children and young people. These barriers were created, and operate, at a number of levels, from Whitehall, through regional and local organisations, to contacts between individual professionals, and with children, young people and those looking after them.
- 4.6 The most important barriers can be grouped under five headings, as I set out below. In practice, of course, they cannot be so discretely categorised. They run together and overlap, and reinforce each other. They appear in a number of forms. For example, breaking down services into an ever-increasing number of sub-specialisms (atomising them), and defining children by their condition, as opposed to taking a more holistic view, cause problems not only between the NHS and other organisations, but also between different parts of the NHS, between different professional groups, and between the professional and the child or young person.
- 4.7 Before embarking on my analysis, I must make one point very clear. Concentrating on barriers to improvement does not present the whole picture of the state of children's services. We must not forget that very many children are well looked after and receive a range of services not dreamed of only a few decades ago. Moreover, I do not suggest that the problems that I identify are to be found throughout all parts of services for children and young people, or that all members of a professional group will think and act in the way in which the behaviour of some is described. I have visited and heard about a large number of excellent services where many, if not all, of the barriers to change and improvement have been met and overcome.

4.8 The approach that I adopt is as follows:

- getting policy right;
- the vehicle for change;
- changing the NHS;
- the NHS working with others; and
- changing/challenging how people work.

4.9 Why have I chosen this approach, beginning with policy rather than practice? It might be objected that it is looking at the problem through the wrong end of the telescope. If I am concerned with culture, surely, it is said, the real focus should be on what is happening 'at the frontline', not in the corridors of power where policy is made. Moreover, the objection continues, action and change take place locally. So, that is where my review should begin. Failure to change is because of local inaction. It is easy to point the finger at government and policy-makers, but it misses the target. The argument reaches its peak by asserting that, in fact, those actually in 'the frontline' pay little attention to policy and government. They merely work in their time-honoured and unchanging way, and it is their failure to change that is at the root of any problems that I may identify. The role of government is at best limited.

4.10 I reject this view. I do not reject the central importance of what has come to be called localism, of focusing on what is happening at the point where services are delivered. It informs much of what I will say. But I insist that, in the case of the health and well-being of children and young people, policy and government is the right place to start. The reason is that services are delivered according to certain centrally ordained imperatives and funds follow these. The Operating Framework and performance frameworks set the context. They shape the culture in which the NHS delivers its services. And children and young people do not get much of a look-in, as has been seen, when it comes to these twin drivers of action. So, it does matter what government does, what policy it sets. It matters because those 'at the frontline' are either at the front of the queue or at the back, when decisions are made about what to concentrate on and what to do. Those caring for children and young people are at the back, because that is where policy puts them. They may try their hardest to push their way forward, but the imperatives cascading down from government keep them in their place. That is the culture of the NHS.

4.11 And there is a further reason to begin at the top. It is born of the need to change the culture and behaviour of over a million people who work in the NHS. Such a change is not achieved by telling them to change, or by

blaming them for the state we are in. It is achieved by leadership: leadership at all levels of the NHS and beyond. Government and the NHS must set the pace through the development of a national vision and through policies to realise it. Professionals also must show leadership through rediscovering themselves, what they stand for and their sense of purpose. But the professionals are the orchestra. Government is the conductor and calls the tune.

Getting policy right

- 4.12 Cultural tensions begin in Whitehall. Until this review was in its final draft form, there were two principal departments of state responsible for children's health and well-being: the Department of Health (DH), and the Department for Children, Schools and Families (DCSF). They had very different approaches (almost philosophies) in relation to children and young people's well-being.⁸⁹ Following the change of government, DCSF has been renamed the Department for Education (DfE). The implications of this change of name, including what it might mean for departmental structures and responsibilities, are not yet clear. However, it is obvious that a change of name alone means very little in terms of culture. The continuation of staff and responsibility for policy at DfE, for the moment at least, will mean that its underlying philosophy remains.
- 4.13 DfE is dedicated entirely to, and therefore entirely focused on, children and young people. It is responsible not only for their health and well-being, but also their welfare more broadly (including, of course, their education). It takes a 'holistic' view of children, setting their health and well-being in a broad social context. By contrast, for DH, children are one group of the population among many, and a relatively small group at that, who do not make a major claim on the resources of the NHS. Within DH, children and young people must compete for priority and attention against powerful other interests and needs, not least of older people, who have significant political clout. DfE does not have to consider the relative merits of attending to children rather than any other group. Children and young people are their exclusive concern.
- 4.14 The two departments also have contrasting perspectives on the relationship between services and those who use them. DH and the NHS take an 'intervention-based' view of their role. By and large, they organise and deliver interventions to make sick people better. By contrast, DfE focuses on the broader notion of well-being.

89 In their submission to me, the NHS Confederation advised that, when members were asked to name the top barrier they were experiencing in the development of services for children and their families, they highlighted the lack of national strategic clarity, as between DCSF and DH.

- 4.15 Fundamental differences in departmental philosophy manifest themselves as tensions, as policy is translated into practice, from national, to regional, to local level. As one senior official, speaking before the change of government, put it to me:
- “You might think that DCSF and [DH] don’t work for the same Government.”
- 4.16 The evidence presented to me was that DH and DCSF took very different approaches to effecting change within the services for which they were responsible. DCSF relied heavily on prescribed action from the centre. By contrast, in recent years DH has, at least on the surface, become less prescriptive, with local autonomy and decision-making being given greater prominence in the NHS’s operating model. Whatever the reasons for this difference at national level, locally it means that NHS bodies may have a degree of freedom of action which the children’s services departments of Local Authorities have lacked.⁹⁰
- 4.17 This may all be about to change. The new Government has a clearly articulated aim of ensuring greater local accountability and freedom, and reduced prescription, control and performance management from the centre of government, across all public services. Recently announced plans to remove the NHS from day-to-day political control by the creation of an autonomous NHS Board charged with commissioning services are a clear example of this. Similar structural changes are anticipated in relation to other public services. Such changes, if suitably co-ordinated and successfully implemented, may have the effect of more closely aligning the ‘philosophies’ of government departments and thereby alleviating the frustrations of the public services which, at local level, must collaborate and work together to ensure that government policy is effectively joined up. For the moment, however, it is clear that the various differences in philosophy between government departments which I have alluded to will continue to cause confusion and frustration at local level.
- 4.18 Apart from tensions in Whitehall, it is important here to notice one other factor that is crucial in getting policy right: the place of children in DH and the NHS. Within the NHS as a whole, children have a low profile. The inevitable consequence is that their needs also are given a low priority. In some ways this is unsurprising. They form only a small proportion of the population (around 19% of the population is under 16) and are thought to

90 One example of this was the preparedness of DCSF to ring-fence funding for a particular purpose, while allocations by DH to primary care trusts are not ring-fenced. This can cause significant tension and, ultimately, frustrate the objectives of the policy, where organisations are required to work together. A well-known example was the announcement of funding for palliative care and short breaks for the carers of disabled children in 2008, together with equipment such as wheelchairs. DCSF’s contribution was ring-fenced. By contrast, DH’s contribution was provided as part of a general allocation and, as a result, only some of it was used for the purpose intended.

be broadly healthy. Moreover, and this is a point stressed by many of the professionals whom I met, children and young people do not have a vote. It is well recognised that the votes particularly of older people (the so-called 'grey' vote) are important in ensuring that their needs are addressed by the NHS. Having disparate needs, children also lack an organised lobby of the type which has developed on behalf of older people in recent years.

- 4.19 The challenge for the NHS as a whole is seen almost exclusively as being how to deal with demographic changes and the ageing population. The scenario is one in which demand for services will rise and changes in services will be needed. Against this background, the profile and priority which the NHS assigns to children are likely to get even less, unless something is done.
- 4.20 The low profile enjoyed (if that is the word) by children also affects, as I have pointed out,⁹¹ many individual NHS services. Outside specialist paediatric services and settings, NHS professionals often have little training in caring for children, and little awareness of how their needs differ from those of adults. As children are only one small section of their patients, staff such as GPs or clinicians in A&E departments have little time to devote to children and young people's needs outside the clinic or the surgery. This leads, for example, to poor engagement by healthcare professionals with colleagues from other services and with meetings of Local Safeguarding Children Boards, and a failure to ensure that their practices are 'young people friendly'.
- 4.21 It is therefore clear that the isolation of policy for children and young people's health and healthcare within DH, separate from wider policy relating to children and young people, which is currently the responsibility of DfE, has two detrimental effects. It forces care for children and young people into an unwinnable battle with adult care for influence on policy, and, because policy on children emanates from more than one government department, it frustrates local co-operation as differences in departmental philosophy and priorities are played out in practice.
- 4.22 The radical yet necessary conclusion must be that responsibility for policy relating to children's healthcare and wider well-being must be brought together. My reason for adopting this approach is that the needs and interests of children and young people as regards health and healthcare are more likely to be advanced effectively if they are seen as part of a holistic approach to their overall welfare.

⁹¹ See paragraphs 3.11–3.32 for more information on this.

- 4.23 The aim of this shift in responsibility is to achieve three principal objectives. The holistic approach to the provision of public services to children will inform the way in which the NHS delivers health services for children, irrespective of the particular department of government which sets the policy. Secondly, providing a single departmental home for policy relating to children's well-being will mean the end of interdepartmental tensions and contradictions which have previously caused so much frustration for those planning and delivering services for children and young people at local level. Thirdly, children and young people will have the undivided attention of one single, powerful policy grouping within a single department of state, a necessary if not sufficient condition for ensuring that their interests receive appropriate attention, or, at the very least, a more joined-up form of attention across health and social care and wider well-being than previously.
- 4.24 The precise architecture of government is not for me to determine. Moreover, it changes over time. What is important for me is that policy aimed at improving the lives of children and young people is properly co-ordinated by government, such that their needs, including their needs for health and healthcare, are addressed holistically. This is far more important than precisely where in Whitehall this policy is to be made. There are a number of options. It could be made in DfE, DH or elsewhere. Although DfE currently retains responsibility for policy relating to education and children's services, proposed changes to DH may provide an opportunity for responsibility for these policies to lie within a newly conceived Department of Public Health (DPH).⁹² As I shall argue below, the importance of positive health, including mental health and well-being for children and young people, would fit in well with such a change. The well-being of children and young people could be at the heart of DPH's role. It would be able to take on responsibility for a large element of the holistic approach to well-being that I advocate, including mental health (child and adolescent mental health services – CAMHS), disability and the care of those with long-term conditions as well as more typical 'public health' services.
- 4.25 What matters is not the precise location of responsibility for policy, but that this responsibility is brought together under one administrative and governmental roof, so that there is both the holistic view of the welfare of children and young people necessary to co-ordinate services and the clout within Whitehall to require them to be delivered.

92 The argument for this will be all the stronger if DfE reverts to a narrower focus on education, as its change of name seems to suggest.

Recommendation 1: Responsibility for policy relating to the health and well-being of children and young people should be brought together in a single government department. In addition to health and healthcare, this responsibility should extend to include as many other aspects of public services used by children and young people as possible.

- 4.26 Before going further, I also need to recognise and respond to those who might ask why children and young people, and not those with dementia, or some other large sub-group of the population, should receive such very special attention. The answers are both socio-moral and economic. Children and young people have, as the premise of this review assumes, been comparatively neglected as a group by the NHS for a very long time. This is not fair to them and reflects badly on us. We are charged with their welfare until they may take responsibility for themselves. We fail in that charge if we do not do our best to provide them with the best possible opportunity by way of health and healthcare and other services to grow into adulthood able to flourish and fulfil themselves. They are, therefore, special. And, of course, to neglect their needs is merely to guarantee that the burden on the NHS will continue to grow as they take the problems of childhood and adolescence into adulthood. It makes good economic sense to invest in the welfare of children and young people.
- 4.27 And, I stress, what is needed is action. There is no shortage of policies, frameworks, guidance and other similar documents which have appeared regularly from DH and other departments. Taken together, I have no doubt that England has some of the best and most detailed policy and guidance in relation to children and young people in the developed world. The only difficulty has been translating it into action! Indeed, it is clear that having so many players in the formation and dissemination of policy, from departments of state to a complex web of local organisations, works against the aim of delivering effective services to children and young people. In fact, it virtually ensures that the services will not be efficient or effective.
- 4.28 It would be my fervent hope, therefore, that the new Government could curb the temptation to continue this never-ending treadmill of policies. Time and effort would be better spent over the next five years in establishing a clear direction for change, preferably reflecting the approach that I am taking here, and then ensuring that it is actually implemented, i.e. that rhetoric becomes reality.
- 4.29 There are two major challenges that flow from the approach that I am proposing. Firstly, the boundary between the responsibilities for the care of children and young people, and the care of adults, must be very carefully mapped out. This must be an early task for government. This mapping of responsibilities has a virtue. It will mean that the problem of transition, from

young person to adult, long the cause of complaint and unhappiness, will now be exposed as a critical area.⁹³ It will receive the attention it needs, across the spectrum of public services as, for example, adult health and social care align themselves with children's health and social care as regards the respective responsibilities that they have and how they will work together.

Recommendation 2: Relevant elements of government and national organisations must clearly establish, and agree on, their respective responsibilities in relation to the care of children, young people and adults, how these responsibilities interact, and how services for them can be appropriately aligned.

4.30 Secondly, funding for the health and healthcare of children will have to be identified and separated out from the totality of funds currently allocated to the NHS. These funds would then be allocated, by the responsible department of state, to those bodies and organisations responsible for the delivery of services for children and young people at local level. Just as in the discussions above relating to responsibility for making policy, there is more than one possible model for how services could be delivered locally. What is important is that they perform certain functions and take on certain duties, not that they have any particular form or structure. This is a vital issue to which I return below.

Recommendation 3: Funding for the health and healthcare of children and young people and for 'transition' to adulthood must be identified, separated from the funding dedicated to the care of adults, and transferred to the responsible government department for further distribution to organisations at local level.

4.31 I take this view on separating out funding because I believe that a radical change from the past is the only way in which the culture of the NHS will shift away from its unbalanced focus on services for adults and on the acute sector. And, in the light of what I have said about transition to adulthood, a further sum should be identified specifically to manage that transition.

4.32 What is important here is, firstly, that the sum to be spent on children and young people is *separated out* from that spent on adults. Only then will it be possible to achieve the necessary *transparency* in relation to how much is spent on children and young people's care. Secondly, this money must then be *separately allocated* to the organisations responsible for managing

⁹³ See paragraphs 3.40–3.42 for a discussion of 'transition'.

care at local level (which, depending on the model chosen, may or may not also have other responsibilities – and other budgets). Only then will the system achieve the necessary *accountability* for how this money is spent. Being clear about what we are spending on children and young people's care, and on how we are spending it, is vital in ensuring that they get the deal to which they are entitled.

- 4.33 To those who say that such calculations will be difficult, the answer must be that if a coherent policy is to be adopted regarding services for children and young people, the sums must be done. Furthermore, DH is already committed to identifying and separating out budgets for the NHS (which will be allocated to the NHS Board) from those for public health (which will be allocated by the Department of Public Health to local organisations which, at the time of writing, are yet to be finalised). Separate allocations in other areas may follow. If it can be done in these areas, it can be done for children and young people and for transition.
- 4.34 If a major cultural barrier to serving the interests of children and young people, as reflected in the tensions and inefficiencies within government, involves a transfer of responsibility within government, what flows from this in terms of the NHS and its services? The first step lies in identifying how the necessary changes are to be achieved.

The vehicle for change – local partnership

- 4.35 It is clear from what has gone before that services for children and young people must have certain features if they are properly to meet their needs. In essence, they must be organised in a way whereby all the relevant agencies and professionals in a given area, with the active participation of children and young people, agree a common vision for the healthcare, health and well-being of children and young people, and collaborate in achieving it.
- 4.36 There are a number of ways in which this could be achieved. Under the previous Government, local organisations providing services to children and young people were brought together under the overall co-ordination of Children's Trusts. It is not currently clear whether the new Government will seek to use and develop Children's Trusts in the way set out by the previous Government. If it does, they will be ideal vehicles for the type of change I propose. If it does not, in essence, this does not matter. What matters is not what the organisation is called, or its specific structure, but that there is, *for every area (perhaps coterminous with that of the Local Authority), an organisation dedicated wholly to meeting the needs of children and young people, and which exists to bring local public services together in order to do this.*

4.37 Given the many options for the exact configuration of such an organisation, for the moment, and given the current uncertainty as to the precise direction to be taken by the new Government, I shall call it simply the Local Partnership.

Recommendation 4: There should be a dedicated Local Partnership in every Local Authority or similar area which is responsible for the planning and delivery of children and young people's health and healthcare at the local level and for integrating these services into all of the services provided.

4.38 From the analysis so far it will be clear that one fundamental question that I am seeking to address is: what is for the state or the centre and what should be left to local delivery? The history has been one of centrism, of tinkering with structures, and of tight financial and managerial control through the Operating Framework and performance frameworks. What I am proposing here is clear responsibility for all aspects of policy relating to children and young people at the centre, and local, really local, delivery through the Local Partnership.

The role of the Local Partnership

4.39 The Local Partnership must bring together agencies concerned with the welfare and care of children and young people in a particular locality so as to agree how the respective services that they provide should be delivered. The aim here is to ensure that the activities of local organisations providing public services, including the NHS, are co-ordinated in the best interests of children and young people.

4.40 Once an agenda (currently in the form of the Children and Young People's Plan) has been agreed, the Local Partnership must have the tools at its disposal to ensure that it is delivered. This is not the place to attempt to establish organisational arrangements for the Local Partnerships, except to remark that the challenge is to avoid unnecessary bureaucracy while creating an entity that can function independently of the various agencies of which it is constituted. A lean organisation is called for which does not duplicate what already exists in the constituent agencies. At the same time, the Local Partnership as an organisation must have the responsibility for agreeing the agenda or plan between its constituent bodies and have the power to require it to be delivered. As it was put to me (referring to Children's Trusts), "There is a need to turn a good, soft partnership-working model into a decision-making body, driving the integration agenda and setting priorities for spending to meet local needs".⁹⁴ Equally, this is not the place to speculate in detail about how Local Partnerships should be managed and held to account. However, it is obvious that the Local

94 View submitted at a meeting with senior officials in Hammersmith and Fulham Council.

Partnership must have clear arrangements for governance and accountability, and that these must be worked out to fit in with national structures and approaches to accountability as they develop (for example, those relating to the NHS Commissioning Board, the public health service, and the relationship between national and local government), including proper financial accountability for funds provided to Local Partnerships by national government.

- 4.41 Importantly, Local Partnerships must also incorporate suitable arrangements to ensure that there is local accountability to the public. This may be through links to the democratic accountability of Local Authorities, the proposed introduction of democratic accountability in the NHS, or another mechanism. The key point is that the Partnership must ensure that there is some way in which it is accountable to the people it is there to serve.

Recommendation 5: The Local Partnership must establish mechanisms to ensure that there is local accountability to the public.

Recommendation 6: The Local Partnership must have the power to require that a Children and Young People's Plan is drawn up and implemented.

- 4.42 As regards health and healthcare, the Local Partnership should undertake a systematic examination of the needs of the population falling within its responsibility. This must be done using appropriate analytical tools, not least by segmenting or profiling the population in terms of their respective needs, particularly identifying those most in need. Then there must be an analysis of how resources should be allocated to reflect the picture identified. This will inevitably involve examining how resources are currently spent, so as to make necessary adjustments. Such adjustments will make the health service itself and its interaction with other services more efficient. Throughout these processes, the views of local healthcare professionals are of the greatest importance and must be heard. Not only are they experts in what may be needed and how it can best be delivered, but they must see the Local Partnership as an arrangement that they can buy into, in that it shares their concerns for the welfare of children and young people. The local healthcare professionals must be engaged in all matters, policy, governance and the commissioning of services, and at all levels. Only if they are will the integration of the NHS's services into a wider set of services be possible. And this integration is essential if all services are to be aligned to meet the common goal of securing the welfare of children and young people.

Recommendation 7: The Local Partnership's plan must set out the agenda for children and young people's health and healthcare.

Recommendation 8: The Local Partnership's plan must integrate the agenda for children and young people's health and healthcare into the overall plan for all the services that the Local Partnership is responsible for providing, so as to ensure that a holistic approach to the care and welfare of children and young people is adopted.

4.43 Given the intrinsic limits on resources and the constrained fiscal times ahead, local organisations will have to take a number of tough decisions with regard to priorities in investment and spending. A Local Partnership bringing together all local public services is an ideal vehicle for making these decisions for at least two reasons. By being wholly focused on the concerns of children and young people, the Partnership can ensure that their voices are heard as priorities are determined. Indeed, it would be an advantage to take a further step by seeking to ensure that there is some mechanism to enable the Local Partnership, in its structure, to be broadly representative of the community served, so that there will be a degree of local democratic legitimacy in decisions, something which may be said to be lacking currently, as regards primary care trusts (PCTs). In particular, the Local Partnership should be required to devise and operate mechanisms through which children and young people's voices can be heard and appropriately acted upon.

Recommendation 9: The Local Partnership must create structures whereby the views of children and young people can be sought and taken account of in the planning and delivery of health and healthcare services.

4.44 Secondly, by being an organisation bringing together all relevant public services, the holistic approach to the welfare and well-being of children and young people, seen as so important by so many, will be the prevailing cultural approach. Then, once the needs of the children and young people for whom it is responsible are identified, the Local Partnership must ensure that they are provided for in an efficient and effective manner. To do so, the Partnership must have the requisite information. I shall explore these and other points in what follows.

4.45 I recognise that the localism represented by this approach invites the danger of structural atomisation: too many small organisations literally cluttering up the landscape. For reasons of size and because of the fact that networks and pathways of care will often transcend boundaries of a Local Partnership, it will be imperative that the Partnerships develop ways of co-operating in groups, whether on a permanent or an ad hoc basis. Such groupings, and the need for and nature of collaborative action, must

be reflected in Local Partnerships' thinking about the services they themselves are organising, including the commissioning of services across a number of Partnerships where this is appropriate. Localism will, on this basis, be achieved, but not at the expense of atomising services. Moreover, localism in this form will provide the necessary space for local action and initiative which Government historically has been reluctant to grant.⁹⁵

How Local Partnerships can take the agenda forward

- 4.46 The fundamental benefit of using Local Partnerships as the vehicle for change lies in the fact that Partnerships would exist to put the interests of children and young people first. The Partnership would be the one organisation to bring together and co-ordinate all the public services that exist in the locality to provide for children and young people. These include the NHS, social services, education, police and, often overlooked but crucial, housing. Given that the problems that children and young people encounter are more often than not the product of the interaction of a variety of social forces, the response has to be equally multi-faceted.⁹⁶ For example, the family living in crowded, unsafe accommodation, in which no one has had gainful employment for several generations, and where a parent or carer is an alcoholic and the children are the victims of violence and neglect, is a family whose needs have to be addressed. They are the ones who appear in A&E departments, who become teenage parents, who suffer from a variety of mental health problems, who are excluded from schools, who are most frequently mugged or stabbed. If their needs are not addressed, another generation will emerge to repeat the cycle, at huge cost to them and to society.
- 4.47 Responsibility and accountability for implementing the Local Partnership's plan should lie with the Partnership itself, rather than with its constituent organisations. The Partnership will then assign to the various services their objectives. These will be managed by the particular service but in a collaborative way. The services will report to and be held responsible by the Partnership. Not only will this ensure that each service knows and understands what the others are doing, but it will also require services to co-operate with each other in the achievement of the overall aims as established by the Partnership. Indeed, this is one aspect of the overall leadership provided by the Partnership that is particularly worth mentioning here: that the cultural barriers which have been described as existing

95 It was put to me by one senior official that the further one gets from central control, the fewer the levers available to government, so the ones available become very critical – enter the Operating Framework.

96 The young women who were the clients of the Family Nurse Partnership (FNP) programme in Tower Hamlets encountered significant problems with housing, education and employment and in claiming benefits. The FNP programme works with a range of hostels for the homeless, bed and breakfast accommodation, hotels and agencies such as Street Matters, an agency that safeguards young women at risk of sexual exploitation.

between those providing various services will have to break down. The leaders of the various services will regularly come together around the same table. They will have to do business with each other.⁹⁷ Moreover, and critically important in terms of the culture of the services provided, the complexity of the services and their interaction will have to be addressed. The particular complexity of the NHS must be an early focus of attention. Its habitual organisation around buildings and the working practices of professionals, particularly doctors, will have to be replaced by a real commitment to designing and delivering services around the needs of children and young people. No longer will their care, health and welfare depend on their choosing the right door to gain access to an otherwise impenetrable service.

- 4.48 An extension of this comprehensive overall leadership is the benefit of co-location. This was cited on numerous occasions as a critical step in breaking down the cultural barriers that get in the way of services working together. The benefits include allowing discussions to be organised more easily, and hence decisions to be taken more quickly. Co-location also helps organisations to build trust through increased contact with each other.⁹⁸ Thus, both managerially and in terms of the design and delivery of services, to the extent that it can be achieved, services, or elements of them, should be co-located. It should be one of the Local Partnership's most important goals that wherever co-location would deliver better services it should become a reality, given the benefits that flow from it.⁹⁹
- 4.49 Given the fact that the new Government has yet to publish its White Paper on health and healthcare, it is not yet clear what form Local Partnerships could take at local level, nor how the local NHS which they will have to interact with will be organised. Whatever final organisational landscape emerges, it is vital that Local Partnerships play the role that I have outlined, and that they operate under the principles that I have set out here: a holistic focus on children and young people and their needs; a duty to ensure that local organisations work together; accountability to the public; an emphasis on efficiency; and the active involvement of children and young people. These must be the basic principles by reference to which services for children and young people are organised. They are a necessary, if not sufficient, condition of making services better for children and young people.

97 One model worth considering is as follows. The leaders of the relevant services should serve as members of the Local Partnership, and thus be involved in the determination of the plan. They should then meet regularly themselves as leaders to co-ordinate the actions required to implement the plan. These actions will then be taken by the various organisations.

98 I saw evidence of this in action in Hammersmith and Fulham and in Croydon, and was told of plans in a number of other places to adopt it as a policy.

99 Co-location is identified as "a major factor" in promoting integrated working in the report of Barnardo's policy research unit (February 2010). The unit also identifies as "factors that promote integrated working", "understanding the role of other professionals... regular contact/communication... compatible information-sharing systems..." and "strong commitment to change". I gratefully draw on these in what follows.

Recommendation 10: The Local Partnership must operate according to the following principles:

- **There should be a holistic focus on children and young people.**
- **There should be a duty to ensure that local organisations work together.**
- **There should be appropriate ways of ensuring accountability to the public.**
- **There should be an emphasis on efficiency in the provision of services.**
- **Children and young people should be actively engaged and involved.**

Local Partnerships and funding

4.50 I have proposed earlier that the funds for the health and healthcare of children and young people should be separated from those funds spent on adults (with proper attention to the period of transition). I now propose that these funds should be made available to Local Partnerships to be spent in accordance with their local agenda and plans.

Recommendation 11: The funding of health and healthcare services, and all other services for children and young people, must reflect and give effect to the Local Partnership's agenda and plan.

4.51 Two important consequences flow from this. Firstly, it means that each service must manage its funds to achieve the goals set for it. And since some of those goals will be specifically designated as goals shared with other particular services or with all of them, the funds must to that extent be shared with or incorporated into the funds of these other services. One device for achieving this is to pool budgets. This may not be necessary (or even desirable sometimes).¹⁰⁰ What is necessary is the need to embrace a cultural approach to funding which says that the purpose of the service's funding is to achieve the best possible result for the children and young people served. It is not any service's private cash, to protect and guard against what are seen as the predations of others. It must serve the holistic goal which is the basis of the new culture being put forward.

¹⁰⁰ Audit Commission (2009) *Means to an End: Joint financing across health and social care*. London: Audit Commission.

- 4.52 This objective will be that much easier to achieve if the policies that guide decisions emanate from only one department of state rather than, until recently, two which do not always see eye to eye. I recognise that, currently, decisions of particular organisations reflect, to an extent, the regime of performance management and regulation that they exist under. If they are required by a regulator to do something, they will tend to do that something. In the future, therefore, performance management and regulation must also be aligned towards facilitating collaboration.
- 4.53 The second important consequence is that this approach will produce savings. Indeed, as I have indicated, the pursuit of efficiencies must be a major objective of every Local Partnership.
- 4.54 The savings will take a number of forms. Duplication of action, whereby different services involve themselves with children and young people in different ways at different times in an unco-ordinated and unsystematic way to address aspects of the same issue, will be eliminated. Priorities will be agreed across services so that funds spent by one will not be wasted because of the lack of support by another. Efficiency will be improved through greater clarity over what is to be done and who is to do it. And, as I will set out in more detail later, the Local Partnership's focus on well-being will enable concerted action by all services in the promotion of well-being, the prevention of ill-health and social harm, and the early intervention of services to build the capacity of children to be healthy and resilient. This focus will pay dividends, among them financial dividends, in future years. The financial burden borne by the state in addressing the demands placed on the NHS, the benefits system and the criminal justice system because of the failure to take early action will be reduced.¹⁰¹ And, make no mistake, this financial burden dwarfs, and has dwarfed for decades, the cost of investing in the health and well-being of children and young people. A further benefit arising from using a Local Partnership as the agency to orchestrate the delivery of services lies in its role in commissioning (purchasing) and providing services. I will set out the details later, but it is important to make some general points here.
- 4.55 One of the most important advantages of the Local Partnership, as detailed above, is that it has the ability to bring together staff from different public service organisations, to co-ordinate their actions and focus them around the needs of children and young people. Once these organisations have come together to plan what is needed, they should continue to work together in commissioning the services. This will ensure that the benefits of joint commissioning, including not only the reduction of duplication and inefficiency as services overlap but also the co-ordination of services for mutual benefit, are spread across the full range of services, for the maximum benefit of children and young people.

¹⁰¹ See paragraphs 3.52 and 3.59 for estimates of this burden in the context of mental health.

- 4.56 The commissioners within the Local Partnership will not just be concerned with healthcare. The team will also consist of those responsible for commissioning the various other services provided locally for children and young people. There will, therefore, be a single, integrated team of commissioners. This is the point of breakthrough for the new holistic approach, and a radical departure for the NHS. There will be a single team of commissioners for all services for children and young people, with a single person responsible for delivering the common agreed agenda as regards those services.¹⁰²

Recommendation 12: The Local Partnership should have a dedicated team drawn from NHS commissioning organisations, Local Authorities and elsewhere, which is responsible for commissioning all services, including health and healthcare services, for children and young people.

- 4.57 Whatever configuration Local Partnerships take, one of their most important objectives must be that, in relation to health and healthcare, the needs of children and young people must no longer be swamped by the claims made on NHS commissioners (whatever form they end up taking) for services for adults. And, as I have already said, healthcare professionals from across the range of NHS services, particularly general practice, but also the acute sector and community services, must engage and be engaged in the commissioning of services. In this way, commissioning by reference to the pathways of care taken by children and young people, so crucial if services are to be well delivered, can be properly reflected and orchestrated. Furthermore, the historic weakness in the commissioning of NHS services for children and young people will be remedied by the active engagement of healthcare professionals, working alongside other professionals.
- 4.58 The commissioning of services from the NHS will sit alongside (literally and figuratively) the commissioning of all the other services for children and young people. The connections and interactions of the various services can be choreographed so as to make them truly complementary. Savings in terms of greater efficiency, early intervention and the avoidance of duplication will be immediately realised.

Recommendation 13: The commissioning of all services, including those of the NHS, called for by the Local Partnership's agenda and plan must be carried out in such a way as to ensure that the services are complementary and efficiently delivered.

¹⁰² I was told by senior officials in Hammersmith and Fulham Council that this bringing together of all commissioning of local services under a single director has "for the first time, vitalised the joint agenda in a way that nothing else has so far achieved".

- 4.59 Turning now to the provision of services, how is this to be organised? Given the need to envisage services holistically, it is important to avoid compartmentalising the services provided by the NHS in the way that they are currently conceived of, divided between tertiary, secondary, primary and community care. And the interaction between the NHS's services and those of other public sector agencies must equally be organised to maximise their integration and co-operation, rather than, as now, the opposite. What this means in essence is that the providers of services should respond to the needs of those commissioning them.¹⁰³ Providers must, therefore, ensure that children and young people are looked after by the right people in the right place at the right time. I will spell out what this means in more detail in what follows. In general terms, it means that the services provided by hospitals must be inextricably linked to and integrated with those provided through community services and then also with general practice and with those provided by other public services.

Changing the NHS

The low profile of children

- 4.60 One of the immediate effects of vesting policy in the hands of a single department or branch of government is that the profile of children and young people will rise. No longer will they be left to compete on unequal terms for attention with adults on whom the large majority of the present DH's funding is currently spent. Rather, they, their interests and needs will be the sole and specific concern of an influential group of policy-makers. All those fighting a difficult and currently unsuccessful war on behalf of children will be brought together. They will find themselves alongside colleagues with the same interests working to the same goal. They will thereby increase both the co-ordination between themselves and their overall influence in the making of policy, for instance as the NHS Board and its role in commissioning services develops.

The complexity of the NHS as a provider of services and its 'atomisation'

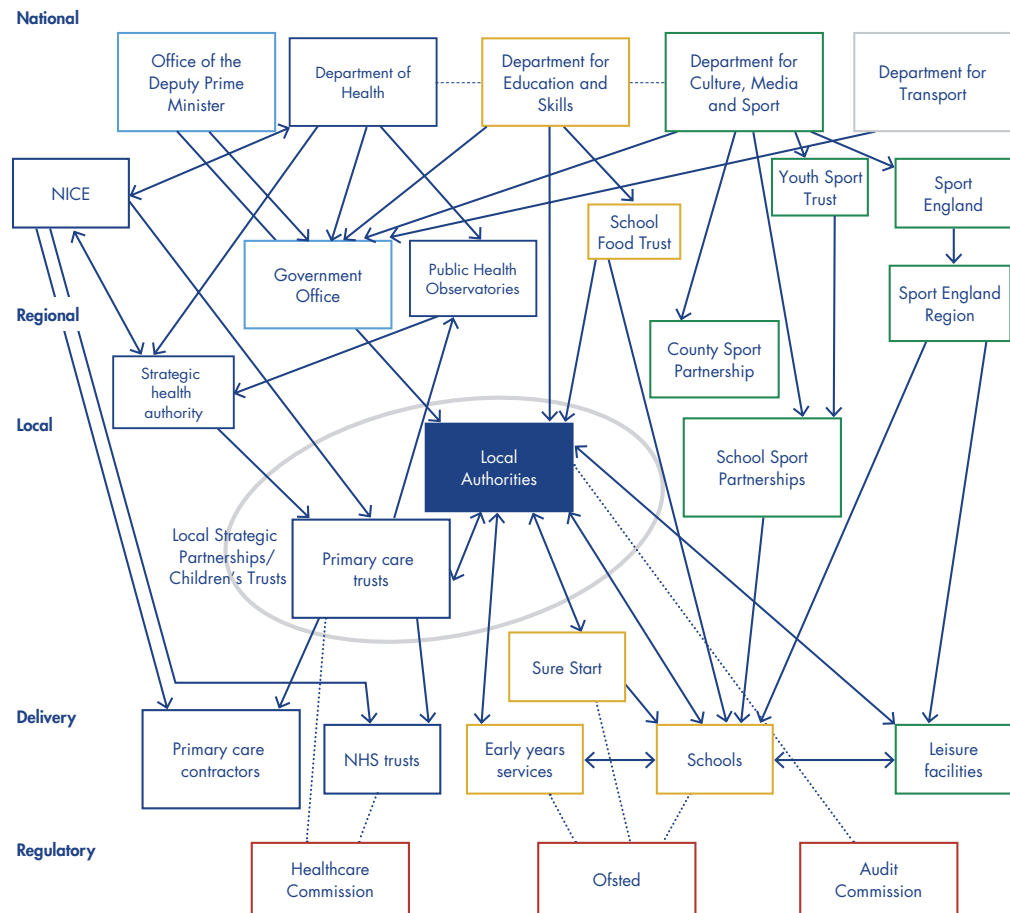
- 4.61 Caring for children is often complex, requiring the involvement of a number of organisations and professional groups. For example, children with long-term conditions such as asthma, epilepsy, or diabetes may have their care managed by a children's community nurse specialist, with contributions and support from paediatricians, the school health team and their GP. In many cases, those providing NHS services must also work with other organisations, for example schools, social services or the police, as I will

¹⁰³ The experience of the NHS organisations I talked to in Newcastle was that organisations providing services arrange what they do and their priorities around the needs and priorities of the Children's Trust. They recognised that it was in their organisational interest to do so.

explore in greater detail later. Treating children and young people can be more complex, and therefore more expensive, than providing equivalent care for adults. For example, children undergoing painful procedures may require play or distraction therapy in addition to their clinical care. They may require specialist equipment, or staff with specialist training, as will young people with long-term conditions

4.62 Services often fail to take sufficient account of this complexity. The services for children and young people suffer because proper account is not taken of the difficulty of planning and commissioning them, as provision must often be co-ordinated along pathways that cross a number of services and settings. The following map of the 'delivery chain' for services aimed at reducing obesity in children and young people is illuminating.

Figure 4.1: Organisational relationships and funding flows for tackling childhood obesity – a complex picture



Source: National Audit Office, Audit Commission and Healthcare Commission analysis
 Note: This diagram was drawn up and published in 2006. It therefore includes a number of organisations that have subsequently been renamed or their functions transferred. But the picture of complexity is clear – and remains.

- 4.63 This complexity also causes problems financially, as additional services, necessary for high-quality care, add further costs. Services such as those provided by play therapists or youth workers are therefore at constant risk of cost-cutting. They are not seen as contributing to clinical outcomes, but this is to fail to appreciate that the child's overall experience of care and treatment is a very important outcome of care.¹⁰⁴
- 4.64 The complexity of the NHS, therefore, as seen both from the inside and the outside, is a major barrier to offering the services that children and young people need and deserve. From the inside it is justified, or at least explained, on the basis that medical care is complex, as are patients. Professionals learn their way around it and become like guerrilla fighters, beating the system on behalf of their patients. From the outside, it is seen as representing a challenge which frequently frustrates the efforts of other professionals.¹⁰⁵ The premise for the future must be that the NHS is there for children and young people, rather than that the child or young person is there for the service. This means that the complexity must be addressed and managed. It means that current ways of working must change both from the inside and the outside.
- 4.65 The starting point must be a network of arrangements. Ordinarily, there should be one point of contact at the centre of the network. The obvious candidate is the general practice. This would have a number of consequences, all of which reflect cultural habits of the past that must be left behind. First, the practice must be accessible. This means that a service must be available around the clock which meets the needs of children and young people. This cannot, of course, mean that each general practice must be open. That would be too expensive and totally inefficient. But we cannot continue to tolerate the existing arrangements whereby, in the absence of real alternatives, children, young people and their parents and carers opt for the A&E department. This is equally too expensive and inefficient. What is needed, therefore, is a better, more efficient system than that which currently exists. And, in discussing what it might be, it is important to draw attention to a cultural barrier which has recently emerged to bedevil efforts to provide services for children and young people. I refer to the concept of 'out-of-hours' services, an expression that owes its origins to an agreement reached between GPs and DH. Leaving aside criticisms of the services that are provided, the concept is bewildering. It is so utterly focused on the world, the needs and concerns of the professional. Children, young people and their parents/carers do not understand the notion of being ill or needing help 'out of hours'. They recognise the idea of the routine and the unusual. And the unusual happens when it happens. And help is needed when it happens.

¹⁰⁴ Lord Darzi, in his report *High Quality Care for All*, identified the experience that patients have of their care as being of central importance in measuring the quality of care provided.

¹⁰⁵ See paragraph 3.51 for evidence of the difficulty which the complexity of the NHS causes for the police.

- 4.66 So, something needs to be done as regards services currently described as ‘out of hours’. I recognise that change will not be easy. But the need is pressing and a solution is needed, even if the mechanism for reaching that solution is not clear. Access to the services provided by general practice (or some form of polysystem¹⁰⁶) must be available at all times. And since such access must form part of the agenda and plans drawn up by a Local Partnership, the Partnerships themselves must have a role in making it happen in the case of children and young people. Whether this is achieved through a grouping or a federation of general practices, through greater use of NHS Direct, or through some other means must be resolved as a matter of urgency. I am aware that discussions are currently taking place to introduce arrangements whereby GPs’ practices will commission services that will provide necessary services at all hours for seven days a week, perhaps, where necessary, through groups or a federation of practices. Whatever the approach adopted, change is long overdue and essential if children and young people and their parents and carers are to get access to care and advice when they need it.
- 4.67 Being accessible also refers to the physical location of the general practice. General practices have been established in schools and children’s centres. They could be ‘branch offices’ of a larger practice co-located in such a way as to offer services without exposing other children and young people in the school or children’s centre to infection. Such developments are essential. Of course I recognise that, in rural areas, the principle holds good, but more creative ways will have to be employed to deliver it efficiently. But such developments reflect what I see as a central cultural shift: that the service comes to the user, rather than the other way around.
- 4.68 What is contemplated is a single point of access, open at all times, at which the child or young person, with a parent or carer or alone, is assessed and routed to the most appropriate professional, whether nurse, counsellor or doctor, for the most appropriate treatment, wherever it is best provided.

Recommendation 14: There should be a single point of access to the NHS’s services for children and young people. This should be through general practice or the hub of some form of polysystem.

¹⁰⁶ Polysystems are described by Hammersmith and Fulham Council as “a network of primary and community clinicians providing an extended range of care; including many treatments currently carried out in hospitals. They are supported by a hub, the polyclinic or general practice, and provide services from GPs’ surgeries, health centres, pharmacies and patients’ homes [and from] schools, children’s centres and leisure centres.” They are described as being “at the heart of the transformation of health services” in the area.

4.69 Secondly, the general practice must be at the hub of the network of services that the Local Partnership, taking account of the views of all those organisations providing services in the area, has determined are necessary. Thus, for example, the various services provided by secondary care must be accessible to the general practice. There must be a point of contact so that the general practice and the child or young person can negotiate their way through the hospital element of the network. The general practice will take on a more positive role: not so much the ‘gatekeeper’ of the past, more the ‘navigator’ of the future. The same requirement of a point of contact must exist as regards other parts of the network, whether it is maternity services, health visiting, the school health team, the care of those with long-term conditions or of the disabled, or the care of those with mental health problems. The general practice has a particularly important role, as the hub of a network of services, to ensure that the services are sustainable over time. I was advised of the need for a critical mass of services and professionals, particularly in any network of hospital services. It is therefore essential that, when considering networks of care, Local Partnerships take into consideration the different geographical areas and distribution of populations so as to ensure that various networks are organised effectively and efficiently, and that services are commissioned and co-ordinated accordingly.

Recommendation 15: The services provided by general practice or a polyclinic should be accessible, available at all times, and at the centre of a network of NHS services for children and young people.

4.70 A critical feature of being the hub, whether it is the traditional general practice or some other mechanism within a polysystem, is the control of information. As has been seen, the weakness in sharing information among those coming into contact with the child or young person is one of the most serious shortcomings in the NHS’s care of children and young people. The solution lies in ensuring that information is received at one central point and is then available to those whose work brings them into contact with the child or young person.

Recommendation 16: Information about the care of children and young people must be collected and consolidated at the central point of access, the general practice or the hub of some form of polysystem, and be available to all who provide services for children and young people.

- 4.71 There will be all sorts of objections raised, including the perennial concerns over confidentiality and cost. I will return to these later, but make the following observations here. I have seen a system in place in Croydon's Family Justice Centre in which a room full of paper records, supplemented by electronic equivalents, is open to all professionals working in the particular unit (concerned with domestic violence and safeguarding children). The professionals included doctors, social workers, lawyers and the police. What made the system work was trust between the professionals and leadership. Confidentiality was a given, but so was the recognition of the need to share information in the interests of those being served.
- 4.72 As regards cost, again the observation can be made that the cost of not collecting information and sharing it according to strict protocols is the mess that currently afflicts how we respond to the needs of children and young people. This mess is far more costly than investing in collecting information, both in human and financial terms. It did not need the most recent horror story of Peter Connelly¹⁰⁷ to tell us this. We already knew. But cultural proclivities to defend professional territories and see information as power have meant that doing the obvious has been defeated by doing the obdurate. This cannot go on.
- 4.73 Of course, some general practices are already far advanced in their systems for sharing information with hospitals and others. Their experience will serve as the basis for building an approach across the whole of the country. Such an approach needs action. And clearly there will be a cost to the general practice in having the responsibility of collecting and sharing information. I propose that there should be a dedicated information officer in every general practice or group of practices, or at the hub of a polysystem.

Recommendation 17: There should be a dedicated information officer in general practices or at the hub of polysystems responsible for the collection, co-ordination and dissemination of information about the care and welfare of children and young people in the relevant area to those providing services and who need to know. This information should ordinarily be made available to children and young people, and their parents and carers. The information officer should also be responsible for managing communication with children and young people and their parents and carers.

107 Also known as Baby Peter.

- 4.74 The benefits in terms of efficiencies that would flow from having an information officer significantly outweigh the costs. Moreover, I propose that the information should ordinarily also be made available to the children and young people, and their parents and carers. To take just one simple example, as I have already said, I heard frequent stories from parents/carers and young people of being asked to go to this and then that place for this or that appointment or test. Oftentimes, they found themselves in the same place on a number of separate occasions. Sometimes, they arrived only to be told that they were not expected or that relevant documentation was missing. On other occasions, they missed appointments because of poor communication, and found themselves criticised for doing so. This is not a service fit for the 21st century. It is a form of bureaucratic purgatory, which professionals lament but preside over. They do not wish it to happen. So, let them work together to stop it. The information officer is an important step and the cost would be readily recouped.
- 4.75 The third point to make is that those in the general practice must have the necessary training and skills to carry out the role that I envisage.¹⁰⁸ This means that all GPs and practice nurses in particular, but also all those other professionals attached to general practice or who form part of the polysystem, must be enabled to make up the gaps in training which I have already referred to. Both initial training and revalidation should include the comprehensive care of children and young people, as should the Quality and Outcomes Framework. Moreover, a general practice should seek to ensure that one GP in the practice has specialised knowledge in this area of care. Such care should, in other words, be a recognised professional pathway, leading, perhaps, to joint appointments between the general practice or polysystem and the hospital. Given that training takes time, in the short term paediatricians from the hospital sector and community paediatricians should be available to general practices or polysystems to provide the necessary service, delivering more care closer to home.

Recommendation 18: All GPs, practice nurses and other professionals attached to general practice or who form part of a polysystem should, as a matter of urgency, receive training in the comprehensive care of children and young people.

Recommendation 19: The initial training for GPs, the Quality and Outcomes Framework and the system of revalidation should all incorporate the need for training in the comprehensive care of children and young people.

¹⁰⁸ One challenge for general practice is to recognise that the inclination to care for children and young people as a member of the family must not prevent the identification of dysfunctional families in which the parent/carer constitutes a risk to the welfare of the child because of alcohol or substance abuse or violence.

Recommendation 20: General practices and those at the hub of polysystems should seek to ensure that there is at least one professional who has specialised knowledge in the comprehensive care of children and young people.

- 4.76 The purpose of the hub is to ensure that the complexity of the NHS confronted by the child, young person or parent/carer is diminished. But complexity takes many forms and it will require concerted effort to eliminate it. One form is the extraordinarily complex systems for organising care, particularly within the hospital sector, but also as between hospitals and other parts of the NHS. Departments of this and that exist. Sub-departments or new departments spring up. The language to describe departments is technical and obscure and excludes people, e.g. cardiac rather than heart, renal rather than kidney. The patient confronts a maze, which sometimes even someone in the hospital may not know how to negotiate. Equally, organisations on the outside, trying to advance the interests of children and young people, complain that it is difficult to get to grips with the system so as to know whom to talk to.¹⁰⁹
- 4.77 One particular feature of the complexity of the NHS is its organisation of services according to the conditions that they treat or the interventions that they provide. As conditions and services are categorised, and thereby differentiated, they become atomised, separated from one another. This process of categorisation or atomisation is then extended to and imposed on patients. They are labelled according to their condition, becoming the 'responsibility' of a particular specialism. A major reason for this is the continuing 'institution-based' view of the NHS, which, as I have already said, defines services around buildings, particular procedures, or professional groups, rather than around the people who use them. And the view is often reinforced by public and political rhetoric: 'hospitals' are the symbol of, and the synonym for, health services more widely.
- 4.78 This imposition of bureaucratic organisation on services has the obvious consequence of imposing an anti-holistic categorisation on the children and young people who use them. Young people told me how they felt dehumanised and "defined by their condition", and that this categorisation by condition led to pressure to "live up to their diagnosis" by conforming to received medical opinion of how those with a particular condition should behave.
- 4.79 This can be particularly damaging when a child or young person has multiple needs. The fact that many disabled children often receive very poor service from GPs can be seen as partly resulting from their being perceived

¹⁰⁹ See paragraph 3.51.

as ‘belonging’ to the specialty that deals with their disability and therefore outside the concern of other clinical groups. As The Newcastle upon Tyne Hospitals NHS Foundation Trust put it:¹¹⁰

“[P]atients know that when they seek help... they are using the national health service. What they are often unaware of is that it is made up of separate elements which have differing policies and practice and hence can communicate ineffectively with each other, duplicate work and in certain respects compete.”

- 4.80 This need not be. As I have suggested, there must be a system of points of contact that can guide the general practice, the polysystem, the child or young person, and the outside organisation to what is needed. That is what service is about. Children and young people need to be under one umbrella with fewer points of access. The many departments and other accretions of hospital life need to be addressed and simplified. The key to this simplification is to identify the pathway of care that children and young people should (rather than currently do) follow, both in and out of the hospital.
- 4.81 This process of rethinking how services are organised and delivered will not be easy for organisations or professionals.¹¹¹ Both tend to prefer the familiar and respond to the exercise of local muscle. But it is essential if children and young people’s needs are to be met. And it can be done. Clear pathways of care for children are essential to avoid the risks of fragmentation of services. There is a need for networks to ensure that, where possible and appropriate, care is delivered close to home, including in primary and community care settings, but delivered in highly specialist centres if clinically necessary. The networks are more effective if formalised and managed. Examples can be found in areas such as newborn care, palliative care and children’s surgery but there is a need to focus on wider aspects of children’s care too including urgent care. Manchester Children’s Hospital is developing these networks alongside their redevelopment proposals as is Newcastle¹¹² and there are examples to be found in most regions. However, a more comprehensive approach needs to be taken.

110 Newcastle upon Tyne Hospitals NHS Foundation Trust (2010) *Better together*.

111 More information on pathways and networks for the care of children and young people, including an analysis of the challenges to changing services successfully, is available in Royal College of Paediatrics and Child Health (RCPCH) (2006) *A guide to understanding pathways and implementing networks*. London: RCPCH.

112 In *Better together*, Newcastle upon Tyne Hospitals NHS Foundation Trust writes: “We seek to once and for all bring about a cohesive pathway of care for patients [all patients including children and young people] from home to hospital and home again. The decision as to how and where to treat patients will be based on their needs and preferences... to ensure that they are seen by the right person, with the right information, the right training, the right equipment, in the right place at the right time.”

- 4.82 I have left till last two further aspects of complexity which should not be overlooked. First, there is in my view a barely detected epidemic of mental health problems in young people.¹¹³ For a variety of reasons, an important one being the fear of stigma, these young people may not be prepared to see general practice as the natural place to go to seek advice and help. Services should ensure that the young person has another door into the system. One such door is through the school health team. It was put to me strongly that children's nurses with particular skills in mental health care, in the prevention of problems and in early intervention could make a significant contribution to addressing the hidden epidemic. Working alongside teachers, and beginning in primary schools, they could reduce the numbers of those subsequently needing CAMHS. Another door is through self-referral. The young person must be made aware and be confident that self-referral to appropriate providers of services, which may include suitably configured general practice, is possible. Self-referral also has implications for those commissioning and providing services. They must ensure that the services are appropriately designed to meet the challenges of self-referral, not least as regards sharing information. The young person then needs help about where to go and how to do it. The voluntary sector has much to offer here.

Recommendation 21: Urgent action is called for to respond to the mental health needs of children and young people. Mental health services must be available and accessible, including through self-referral, and be integrated with other services, particularly through schools.

- 4.83 Secondly, there are those children and young people whom the system does not currently come into contact with, save in some emergency. They may be those living in areas of deprivation, or in some other way on the margins of society. Here, the critical importance of interaction between all the agencies that exist to meet the needs of children and young people so as to work together is most plain to see. Whatever the way in which the child or young person comes onto the radar of a public service and whatever the particular service may be, the information needs to be fed into the central hub, so that an assessment can be made as to whether the

113 See, for example, the report of Barnardo's policy and research unit (February 2010). The report draws attention to groups of children and young people at particular risk: "Looked-after children are around five times more likely to have a psychiatric disorder than the general population... At least 95% of young offenders... in one survey showed evidence of one or more of the main types of disorder, many facing multiple disorders." The Royal College of Nursing described mental health as the biggest health priority for children and young people, with 1 in 4 showing some emotional and behavioural problems by the age of 8. I was told by a senior paediatrician that paediatricians need more training and experience in mental health. He described it as "one of the biggest gaps in their current training". Minor emotional problems were being left unaddressed and were having major effects later.

intervention of NHS services is required. Of particular significance here are programmes for early intervention which I shall discuss at length in due course. Of equal importance are those children and young people who come into contact with the criminal justice system. If ever there was a need for services to come together and work in an integrated fashion, it is here. The child or young person needs education and healthcare and has a range of other needs. If these are provided, there is the prospect of a better future. If not, the cycle of deprivation and damage goes on.

Commissioning

- 4.84 The approach that I have adopted places responsibility for commissioning services on the Local Partnership. In this way, children and young people are given the profile that they have historically lacked, since caring for them is the only responsibility that the Local Partnership has. Commissioning will reflect the Local Partnership's planning, and will therefore ensure that children and young people's health needs are integrated into and seen as part of their needs more broadly. No longer will we have the situation in which the PCT left it to juniors to look after commissioning for children and young people while their seniors wrestle with the important job of meeting the needs of adults. Nor will it be "the loneliest job in the world",¹¹⁴ as felt by one person responsible for commissioning services for children and young people. Instead, commissioners of healthcare services, with their colleagues from other services, will be able to concentrate on and specialise in services for children and young people. Admittedly, there will still be priorities to be argued out, but the argument will only be about what is most needed for children and young people and what best serves their needs. It will not be an argument, in the case of health and healthcare, about the respective needs of children, young people and adults, in which children and young people always come off worse.
- 4.85 Secondly, commissioning can adopt and drive forward a holistic approach to the needs of children and young people.¹¹⁵ Currently, the lack of experience and expertise in commissioning in health and healthcare for children and young people stifles the integration of services. Lacking both the capability and the authority to bring together and shape services across pathways, commissioners are forced to purchase discrete packages of care from individual providers, resulting in a fragmented service. By buying services in this way, commissioners adopt and reinforce an anti-holistic language and outlook.

114 Quoted in a meeting with senior officials.

115 See RCPCH response to *Our NHS, Our Future*, available at www.rcpch.ac.uk/doc.aspx?id_Resource=3374

- 4.86 Moreover, commissioners currently often lack sufficient knowledge of the services that they are commissioning, and so are unable to challenge providers about the quality of the services, or about the integration of one service with others. Quality, therefore, becomes something determined by the local provider's offer rather than the commissioner's insistence. Nowhere is this more problematic than in relation to CAMHS, where both clinicians and managers with experience of providing care expressed concern about commissioners' knowledge, especially of specialist services.¹¹⁶ For the future, as I have emphasised, local healthcare professionals in all sectors of the NHS will be intimately involved in commissioning services from the NHS.¹¹⁷ Their understanding of what is needed and how it should be organised will be crucial. The consequence will be that the commissioning of various public services on the basis that they are integrated will, in turn, require that the services work in an integrated manner.
- 4.87 Thirdly, those charged with commissioning care should ensure that, through their contractual relationship and the volumes of funds at their disposal, they require of the various parts of the NHS that they work in the manner already described: designing services around children and young people, establishing a single portal of access, through the general practice or polysystem, identifying the normal pathways of care and requiring the collection, analysis and dissemination of information. This is what commissioning is about: buying only those services that serve the needs of the community for which the commissioner is responsible and ensuring that the services are both effective (they produce the right outcomes) and efficient (they provide value for money).

Recommendation 22: Those commissioning health services for children and young people should use their influence through commissioning, contracting and funding to require providers to design services around the needs of children or young people, establish a single portal of access, ensure that care is delivered in line with the normal pathway of care, and require the collection, analysis and dissemination of information.

116 One professional body commented that, in relation to CAMHS, "Commissioners are usually inexperienced, junior, or lack clout".

117 Clinicians across primary, secondary and tertiary care should decide how to allocate a shared budget, working in close partnership with patients, managers and local politicians (RCPCH response to *Our NHS, Our Future*, available at www.rcpch.ac.uk/doc.aspx?id_Resource=3374).

Leadership

- 4.88 Children need champions: strong leaders who will advance their interests at all levels in the NHS. I met many inspirational leaders, at all levels. However, within the NHS as a whole, leadership in the cause of children and young people is lacking. Senior staff are focused elsewhere, often on meeting the current priorities for performance management, which largely exclude children and young people. Clinicians who are advocates for children and young people often lack influence. Their lobbying for increasing the priority of care for children and young people has, to date, been broadly unsuccessful. Those caring for children “are not the biggest players in the clinical system”¹¹⁸ and are not well placed within professional hierarchies. They often lose out to other, more powerful, professional and patients’ groups in the contest for resources and the attention of senior management. Designated members of trusts’ boards, or champions on the board for children, are “tokenistic, if they exist at all”.¹¹⁹
- 4.89 It should not be a surprise, therefore, that a recurring theme in the submissions made to me and in the meetings and conversations I have had is the need for effective leadership on behalf of children and young people. It is important to understand what is being said. It is not that there is a shortage of extremely dedicated and thoughtful advocates of the interests of children and young people, from Whitehall to local communities. Rather, it is to observe that, while they make telling arguments (and have been doing so for decades!), they get only limited attention. They are treated as some form of background noise: tolerated and occasionally thrown something, but not regarded as being where the action is in the NHS. As has been seen, a good illustration at the top of the system is the Operating Framework emanating from DH, which sets the direction of the NHS. The needs of children and young people have largely been ignored over the years. They barely feature in what is the managers’ bible. Recently, some progress has been made but it is limited and largely rhetorical, its importance being stressed in narrative but without a link to specific actions or performance measures.¹²⁰ It does not go to the heart of what the NHS should be doing for children and young people. There seems to be a blithe unawareness or lack of interest in the fact that failure to attend to children and young people’s needs just means another generation of adult patients bringing their problems, many of which could have been resolved or mitigated if addressed earlier on. Sisyphus continues, with increasing difficulty, to roll the stone up the hill.

118 View submitted by an NHS senior manager.

119 View submitted at a meeting with a professional body.

120 See paragraphs 4.111–4.116 for an analysis of the current Operating Framework in relation to services for children and young people.

- 4.90 A further illustration is provided by the establishment in 2009 by DH of the National Quality Board, to direct the production of standards relating to quality which are to be observed by the NHS. The first thing that the Board did was to set criteria which would guide the areas or conditions to be given priority in the production of standards. One of the two overarching criteria was identified as being the “burden on the NHS” represented by any condition. Such a criterion immediately prevents the needs of children and young people from ever being given priority. They represent just less than 20% of the population, so the burden of the other 80% is clearly greater. That the burden on this 80% could be reduced by redirecting some attention here and now to children and young people did not register. The approach was centred on adults and the acute sector. Condition-spotting-and-swatting was again at centre stage. As policy is developed by government over the next months, it will be important to reflect on how efforts to establish priorities for the NHS as a whole risk discriminating against children and young people: another reason for separating them off, and the funding that relates to them. Leadership comes in many forms at all levels. For the purpose of this review, I detect the need for leadership in the cause of children and young people, meaning making something happen rather than saying something should happen, from the top to the bottom of the NHS. I have seen what inspired leadership can do, bringing professionals together, getting leaders of services round the same table, negotiating protocols with previously warring professional tribes, having the vision that a local school could become the focal point for a range of services for the health and welfare of a whole community struggling with disadvantage and deprivation.¹²¹ Such charismatic leadership is inspiring but ultimately overdependent on the energy and vision of one person or a small group. Leadership has to be sustained and sustainable.
- 4.91 It should be a duty of the Local Partnership, and one of its most important tasks, to create the environment in which leaders can flourish, realise their vision and bed in progress for the benefit of those who will inherit the vision. They have to be trusted and allowed to innovate (or even fail, if in the failure lessons are learned and acted upon). It is only through such innovation and experiment that the most important improvements in service for the future will be identified and implemented.

121 On my visit to St Stephen’s Children’s Centre in Newham (east London) I was shown a wide range of services, including therapy services (such as speech and language therapy), CAMHS, maternity services, family support services, childcare and parenting classes. The centre recognises its role as the hub of a local community in a deprived area where there are many people who would not normally have access to, or use, services. For this reason, they stress openness, approachability and friendliness.

Recommendation 23: Local Partnerships should identify and foster leaders across the range of NHS services and give them the opportunity to flourish.

- 4.92 Such an approach to leadership seems strangely distant from the style of management in the NHS that was frequently described to me. It was put to me that managers, as leaders, “managed up”, meaning that they looked towards the centre of the system to be told what to do or to check that what was envisaged was alright, rather than feeling free to act for themselves, within acknowledged boundaries.¹²² This was not peculiar to the NHS and, by association, DH. Those who worked within the ambit of DCSF/DfE looked with the same keen eye as to what was expected of them.
- 4.93 This looking to the centre produced at least two unfortunate consequences. First, having two departments of state with different agendas resulted in two sets of professionals sitting down to collaborate and finding that they are being asked to march together but to different tunes. Secondly, it produced an attitude of aversion to risk, to the use of judgement and to innovation. Nowhere is this clearer than in the case of safeguarding children and child protection. A system has been built based on what are called processes and on compliance with procedures. Leadership in the form of bringing teams together and placing the child at the centre of everyone’s concerns struggles to prevail. Instead, there is a retreat behind compartmentalised professional walls, with everyone concerned to show that what is asked for by way of process and procedure has been done. It will surprise no one that the object of the exercise, the actual welfare of the child who may be at risk, may be overlooked from time to time.
- 4.94 Perhaps I should mention in passing two further unfortunate consequences. Firstly, it has been a feature of the NHS that it is constantly subject to reshaping and reorganising from the centre. As it was put to me on a number of occasions, continuity of relationships between professionals is vital in building good services for children and young people. Continuity allows trust between professionals to develop, a feature of which can be a healthy ‘culture of challenge’, as I saw in Sheffield and Leicester.¹²³ Reorganisations force new relationships on professionals, meaning that trust must be built anew. Good services can deteriorate very quickly when good people move on. Secondly, centrism, represented by the Operating Framework, national targets and the like, sits awkwardly with the call issued

¹²² Paragraphs 4.111–4.124 (Priorities and management) explore this issue in more detail.

¹²³ On a visit to Glenfield Hospital in Leicester, it was clear that the sense of support and understanding felt by the parents/carers of very sick babies was due in part to the fact that nurses and staff had worked together for a long time (over 20 years in one case) and trusted each other.

by Lord Darzi in his review of the NHS.¹²⁴ He called for innovation to be given its head at a local level. He was right, but tell that to the local manager or professional. The temptation to try something has to be resisted in the face of the imperative to produce a particular result in a particular timescale. The sound of cultures clashing rings out.¹²⁵

- 4.95 Again, this must change. In the case of safeguarding and child protection, for example, there needs to be a rediscovery of the importance of content over form. Outcomes for children are the only things that matter. The Local Partnership has a central role in ensuring that those who lead those local agencies that could have a role in safeguarding work together and to a common vision. Most important, the Local Partnership and those organisations that make it up must realise that having a plan, or creating a partnership (so-called ‘partnership-working’), are not ends in themselves, warranting congratulation and relaxation once created. They are mechanisms to do a job. Whether the job is done is the only measure of success. As it was put to me, in conversations with the police, the first responsibility of all partners is not to the partnership, but to the children and young people. Agencies and organisations must feel able to challenge each other. They must not resile from their duty out of concern to avoid straining relations in the partnership. Professionals are there for the children and young people, not the partnership.
- 4.96 More generally, as I will explore in the section on professionals working together, leadership rests on an understanding of how professionals of various stripes think and perceive the world; how they work together and why they do not. This argues for greater engagement of professionals as leaders. Too often they cast themselves, or are cast, as outsiders, put upon by ‘the system’. This is an easy position to adopt, if the concern is one of tribal standing and purity. It fails children and young people, however. Professionals of all types need to re-engage with the mission that they chose: to serve children and young people. The system must allow them to do so.

Promoting positive health

- 4.97 The importance of preventing or mitigating ill-health and promoting good health is so obviously central to the NHS, if it is to be a ‘health’ rather than an ‘illness’ service.

124 Darzi, Lord (2008) *High Quality Care for All: NHS Next Stage Review Final Report*. London: DH.

125 I heard a counterview from a senior official in DH that localism was fine, but only if the right people were in place. Currently, it was said, the biggest risk is not that innovation will be squashed, but that poor practice would remain unchallenged. This ambivalence in policy and practice contributes to the malaise I am referring to.

- 4.98 In the case of children and young people, some success has been achieved in securing attention. ‘Public health’ is the one area in which the Operating Framework stresses the needs of children and young people. Obesity, teenage pregnancy and substance abuse are identified as areas for action by the NHS.¹²⁶ But there are significant gaps where the cultural bias of the NHS towards identifying itself with the diagnosis and treatment of disease induces a kind of myopia. Against this background, the new Government’s intention to create an autonomous public health service provides both a significant opportunity and a challenge. The opportunity is to ensure that positive health has the focus and funding that I believe it requires. I set out my reasoning for this below. It is to be hoped that it can be achieved.
- 4.99 The challenge is that the creation of a public health service could see the NHS withdrawing further from the field of positive health and well-being. This must not be allowed to happen. One of the habitual features of the culture of the NHS until now has been to label the prevention of disease and promotion of health as ‘public health’ as a means of pushing it to the edges of the ‘real’ work of the NHS. There has been little or no tradition of adopting a model of positive health in which it is the job of the NHS to keep people, especially children and young people, out of hospital and surgeries as much as possible.¹²⁷ The savings in funds, in productivity gained, in benefits not needed have been calculated an incalculable number of times.¹²⁸ But the culture of the NHS just does not shift. Part of the answer lies in the attitudes of healthcare professionals, defining what people need as being what they provide: ever more technical skills. These skills are, of course, needed and have worked wonders. But, in the greater scheme of things, even greater wonders would be worked by emphasising the pursuit of positive health.
- 4.100 Perhaps one explanation of why the NHS has never committed itself entirely to this cause is because it is clear that the NHS can do only a limited amount about what causes ill-health and what can prevent it. Housing, education, employment, social cohesion, even genes are some of the important ingredient factors. So, the NHS retreats into affecting what it can affect; responding to illness rather than seeking to prevent it, wherever and whenever possible.
- 4.101 It is for this reason that I propose that change at local level must be driven by a Local Partnership with representation from across the full range of relevant public services. The Partnership can call on the NHS, but can look

126 There are Tier 2 Vital Signs in all of these areas. The obesity measure relates specifically to school-age children.

127 *Our health, our care, our say* (2006) represented a step in the right direction in terms of policy from DH, albeit that little change in terms of results from the NHS followed.

128 For example, see Wanless, D (2002) *Securing our Future Health: Taking a long-term view*. London: DH. See paragraph 3.59 for an estimate of the burden in the context of mental health.

beyond it. It can co-ordinate action by all agencies, including education, social services, housing and youth justice as well as the NHS. Currently, as I shall set out in more detail later,¹²⁹ not only is the NHS very limited in terms of what it can do, but it also has little incentive to work with others to provide the integrated services required. Firstly, the benefits of early intervention, for example, usually accrue some years in the future. This means that they are irrelevant to the in-year assessments of organisational performance that feature so significantly in the NHS. Secondly, many of the most significant interventions will primarily benefit organisations other than the NHS. For example, early intervention to tackle behavioural disorders is likely to produce significant long-term benefits in terms of savings in social care and the criminal justice system, but less obvious returns for the NHS.

4.102 The result is that the NHS adopts a range of unhelpful, inward-looking perspectives, focusing only on its particular place in the broader scheme of things. Such an approach would fall away if the services provided by the NHS for children and young people fell within the remit of a Local Partnership, as I have described it. It would be for the Partnership, rather than its individual constituent organisations, to assess overall benefit, and do so by reference to the collective agendas and funding of all the respective agencies. Moreover, ensuring that the views of children and young people themselves are heard, as I have set out earlier, together with appropriate mechanisms for accountability to the local community, will make a further contribution to this overall assessment of benefits. Individual organisations, as a consequence, will be drawn yet further from their narrow, institutional focus which has caused so many of the problems that I have described here.

4.103 As part of the Local Partnership's approach to securing the well-being of children and young people in their community, I would draw attention particularly to the areas of mental health and care in a child's early years. Mental health is significant here, because most adult mental health problems begin in childhood. Doing nothing to combat mental health problems in children and young people is not, therefore, the cheapest option. It is the most expensive option.

4.104 I also mention care in the early years because perhaps the single most important cultural shift that is needed from the NHS is to invest in the development of children in their early years (from minus 9 months to 2 or 3 years old). These early years are absolutely central to the developmental fate of a child. Yet until recently they have received virtually no attention. A huge cultural shift must take place. Resources must be

¹²⁹ See paragraphs 4.114–4.115.

invested in the early years of children, concentrating on those most at risk, whose parents/carers are least able to provide what the child needs.¹³⁰ To those who recoil at the possible cost, there is already evidence of the benefits in financial, let alone human terms.¹³¹ And by investing significantly in early intervention, the cultural context of the discussion of children and young people moves from response to illness to the pursuit of well-being and resilience.

Recommendation 24: A significant shift in the allocation of resources must take place, whereby there must be much greater investment by the NHS, and other agencies, in services for children and young people in their early years, concentrating on those most at risk of not having the opportunity to flourish. Such investment should be a very important consideration for all Local Partnerships as they set their priorities.

4.105 Of particular interest in this context is the development of the Family Nurse Partnership (FNP) programme. In my visit to Tower Hamlets in east London, I was impressed by the energy and enthusiasm of those involved in developing one of the pilots. It is clear that FNPs are labour-intensive and would appear, on the surface, to be expensive. But if the results reflect those obtained in the United States, and there is already evidence to that effect,¹³² the savings, as I have said, will be very significant indeed. In my view the introduction of FNP and other such schemes aimed at early intervention should be a priority for incorporation into Local Partnerships' planning. Equally, I was impressed by the thinking behind 'Total Place'.¹³³ While in its infancy, this initiative, by bringing together agencies across the locality, precisely reflects the position that I am taking here, namely that the focus of services must be on children and young people in a particular area

130 "Disadvantage starts before birth and accumulates throughout life" and disadvantage leads to significant inequalities in health. The Marmot Review (2010) *Fair Society, Healthy Lives: Strategic review of health inequalities in England post-2010*, Executive summary, p. 20. Available at www.marmotreview.org

131 A range of evidence for early intervention is brought together in: DCSF (2010) *Early Intervention: Securing good outcomes for all children and young people*. London: DCSF. See especially chapter 3.

132 I have already mentioned the estimated benefits in relation to social care from the FNP programme in Tower Hamlets. In addition, the evaluation of the first year of FNP in the UK is promising, showing some positive evidence in areas such as smoking cessation, alcohol consumption, breastfeeding and healthy eating. It also showed that family nurses thought that the programme helped their clients to cope better with pregnancy, labour and becoming a parent. (Barnes, J, Ball, M, Meadows, P, McLeish, J, Belsky, J and the FNP Implementation Research Team (2008) *Nurse-Family Partnership: First year pilot sites implementation in England. Pregnancy and the post-partum period.*) Further research is currently being undertaken. The experience of Sheffield's Multi-Agency Prevention and Intervention Services also offers early evidence of savings, through, for example, reductions in teenage pregnancies and in substance abuse (correspondence with Children and Families Service). Evidence gained from operating programmes in the United States suggests that there are a number of positive effects on outcomes, including better maternal health, reduced numbers of accidents, increased readiness of children for school and increased employment. Individual studies also show significant benefits in relation to safeguarding and criminal justice.

133 It is important to note that the policy behind the Total Place approach contemplates significant interaction between central government and local communities. As I remarked earlier (paragraphs 4.9–4.11), policy from central government sets the framework within which local action can take place, and to a degree, for example through the use of financial incentives, seeks to steer what that action may be.

rather than on organisations or institutions. Intrinsic in the concept is that agencies come together to both plan and deliver services in an integrated manner.

- 4.106 At the same time, by concentrating on early intervention and its preventative effects, Local Partnerships will be able to avoid an overemphasis, in terms of the allocation of resources, on child protection, which, because of recent events and the risk-averse mentality produced, has tended to take an increasing slice of available funding. As one professional put it, current decisions about funding are not focused on early intervention: rather, “the money follows the murders”.
- 4.107 Perhaps the strongest argument in favour of co-ordinating services through Local Partnerships is that early intervention can be made central to the overall vision of those commissioning and providing local services. The Local Partnership’s sole mandate will be to care for the needs and interests of children and young people. The need to persuade managers in the NHS of the importance of early intervention falls away. In the prevailing culture in the NHS, preventative strategies and health promotion are at best poor relations; early intervention is barely on the radar of NHS managers (it was variously described as a “luxury” and a “hobby”). By contrast, Local Partnerships can place it at centre stage. And, given that early intervention is best delivered through the integrated efforts of schools, children’s centres and community care, they will be able to focus on the prevention of illness through the variety of services that they offer to parents/carers and young children. I was greatly impressed by my visit to the children’s centre in Croydon where I saw social workers working alongside a general practice and community nurses, with educational facilities available for both young children and their parents/carers. And the focus was not just on children. There was, in addition, a youth club catering to the needs of young people.
- 4.108 It is instructive to note the call issued by the former Children’s Commissioner for England. Adopting the same approach that I set out here, he called for an “ecological” approach to child maltreatment. He urged that focusing “only on preventing maltreatment is less effective than a positive approach of building child-care skills, self-esteem and financial independence”. He went on: “Many of the children at high risk of maltreatment grow up with multiple disadvantages: lack of vital preschool learning opportunities, behavioural problems, harsh inconsistent parenting, poor schools, food insecurity, unhealthy diet causing under-nutrition or obesity and dental disease, and an increased risk of illness and death from sudden infant death syndrome, infections, substance abuse, suicide and violent crime.”¹³⁴

134 Aynsley-Green, A and Hall, D (2008) Safeguarding children: a call to action. *Lancet* 373(9660):280–1.

- 4.109 Perhaps the fact that is most overlooked regarding strategies about early intervention is the use they make of ‘social capital’. Parents, grandparents, siblings and carers are drawn into the strategies and become active participants and agents for involving others, thereby, in turn, creating additional social capital. Properly understood and mobilised, this use of social capital not only saves money but also lays the foundation for a movement towards a healthier environment in which children and young people can grow up. Parents/carers talk to other parents/carers and a wider community of engagement develops. I saw, for instance, a simple example of exposing children and their parents/carers to a healthier diet in the children’s centre in Croydon by recruiting mothers to make smoothies for their children using a variety of fruits. What appeared to be play was in fact an introduction to healthy eating. Using social capital produces social capital. Mobilising and drawing on the resources of families and the wider community in promoting the health and well-being of children and young people achieves results, and is extremely cost-effective.
- 4.110 This same thinking applies to schools. Properly understood, a school, particularly a primary school, is not an island. It is a community and part of a larger community. Schools can be used and at the same time reach out themselves to play a part in social affairs, from children’s centres to criminal justice.

Recommendation 25: Local Partnerships should recognise the value of, and consider ways to promote, ‘social capital’, including involving families and the wider community in promoting health and well-being for children and young people.

Priorities and management

- 4.111 Children and young people are identified as a priority for management in the NHS.¹³⁵ Yet the practice of performance measurement and management has not reflected this rhetoric, and it is to these practices that managers respond.¹³⁶ The NHS’s key performance indicators, the Vital Signs, include (in 2010/11) seven (from a total of 63) which relate specifically to children and young people (including maternity care).

¹³⁵ DH/NHS (2009) *The Operating Framework for the NHS in England 2010/11*. London: DH, pp. 16–18.

¹³⁶ Senior NHS managers explained to me that they interpreted the Operating Framework in conjunction with performance management information and priorities (from strategic health authorities), and that from this a “folklore” emerged about the NHS’s “real priorities”. One manager also quoted a Local Authority Chief Executive’s view that the NHS’s response to nationally-imposed priorities was “awesome”. In a separate meeting, one senior NHS manager said that managers viewed the Operating Framework as their “job description” and that they “want[ed] to be told what to do”. Moreover, a senior official in Whitehall offered the view that managers follow the Operating Framework “so slavishly” that there is no flexibility to respond to the needs or demands of any other organisation or group.

However, none of them is in the most important 'tier one', to which the vast majority of management's attention and resources are devoted. Furthermore, five of the seven are 'public health' measures and therefore outside the mainstream of the NHS's attention.¹³⁷

4.112 The current approach represents a clear expectation, expressed through the chain of performance management, that fulfilling the priorities set out in the Vital Signs should take precedence over all other activity. The Operating Framework itself states that:

“[O]rganisations need to be entirely driven by existing commitments and the NHS Vital Signs tiers 1 and 2.”¹³⁸

4.113 Such a clear indication of priorities means that currently only the most accomplished managers will be able to devote any significant time to other commitments, including the broad range of services not mentioned in the Vital Signs that are needed to care for children and young people. The system is ripe for change. The new Government has this top-heavy centrism in its sights.

4.114 The conflict between rhetoric and reality, in terms of performance management, also applies to the NHS's collaboration with other agencies. It is a feature of the current approach to management and performance in the NHS that the Operating Framework treats the NHS, and encourages those in the NHS to regard themselves, as an island. The need for increased collaboration between the NHS and other services is stated explicitly in the Operating Framework and elsewhere. Indeed, in some cases this requirement to co-operate is enshrined in statute. Yet the performance measures against which PCTs are currently judged give little incentive to take this co-operation seriously.

4.115 Successful collaboration, when translated into effective, integrated services, can be expected to contribute towards the successful achievement of a number of important measures of performance. However, such collaboration does not make a direct and explicit contribution to the most important priorities of performance management. There has remained, therefore, an incentive for the NHS to neglect collaboration in favour of other priorities, which have been designated by the NHS as more

137 The measures relating to children are: percentage of women who have seen a midwife or a maternity healthcare professional, for assessment of health and social care needs, risks and choices, by 12 completed weeks of pregnancy; under-18 conception rate per 1,000 females aged 15–17; obesity among primary school-age children; proportion of children who complete immunisation by recommended ages; percentage of infants breastfed at 6–8 weeks; effectiveness of CAMHS (percentage of PCTs and Local Authorities that are providing a comprehensive CAMHS); and parents' experience of services for disabled children. The last of these is a tier 3 indicator; all the others are tier 2.

138 DH/NHS (2009) *The Operating Framework for the NHS in England 2010/11*. London: DH, p. 46.

important, and which are more wholly within the NHS's control. Funding spent on helping other agencies to achieve desired outcomes is money not spent on achieving outcomes for the NHS. And if money allocated to the NHS is not delivering for the NHS, in the island world of the NHS, this constitutes failure. And failure is to be avoided at all costs (of course, other public agencies fall victim to the same tendency). Performance management (and regulatory) systems, therefore, have reinforced the institution-based view of public services and discouraged collaboration and joint working. As I have said, for a variety of reasons this is particularly likely to disadvantage children and young people.

- 4.116 When children and young people are mentioned in the Operating Framework, it is in the context of reducing their admission to hospital.¹³⁹ This illustrates the narrow focus of the NHS's concern. It addresses the internal needs of the NHS as a system seeking to manage resources. It does not address what the NHS should do for children and young people so as to ensure that they are not admitted to hospital. The consequence is, as I have explained, that those who commission services for PCTs do not give great precedence to the needs of children and young people, driven as they are by the Operating Framework. This again must change.

Recommendation 26: The new Government, when considering changes to the performance management of the NHS, and in designing the mechanisms by which it should in future be held accountable, must ensure that the various organisations providing services at a local level are given incentives to work together, and that the performance management of individual public service organisations calls for and takes into account actions that produce positive outcomes for children and young people, the effect of which may be reflected as the achievements of other public services.

- 4.117 The principal mechanism for indicating what is expected of GPs, the Quality and Outcomes Framework, equally provides little incentive to GPs to give priority to the needs of children and young people. Of 128 indicators of quality, four refer specifically to children (one of which actually refers to antenatal care). There are 1,000 points in all that can be gained by the practice. These points translate into awards of money. Nineteen points relate to children and young people (six of which refer to antenatal care).

Recommendation 27: The Quality and Outcomes Framework should be reviewed so as to include a broad range of measures concerning the health, healthcare and welfare of children and young people.

¹³⁹ DH/NHS (2009) *The Operating Framework for the NHS in England 2010/11*. London: DH, p. 16, paragraph 2.18.

- 4.118 The Local Partnership must use its commitment to integrated working in the interests of children and young people, whereby all organisations and agencies have to collaborate in achieving the Partnership's agenda and plan, so as to break the mould of the NHS's insularity. The approach to management and performance will reflect the plans agreed by all the agencies and managed by the Local Partnership. Children and young people will be the sole concern. They will not be an add-on extra or overlooked group.
- 4.119 Let me now touch on two matters of very great importance for the future management of performance. The first relates to data. Data in many areas of health and healthcare for children and young people is poor or non-existent. This must change. Data is necessary for effective management. It is also crucial for self-critical professional practice and for efficient commissioning. Data sets are currently being developed, that is, bodies of data that tell the story of performance and allow for setting benchmarks for the future. They have been extremely slow in coming, reflecting the low visibility of children's services. It has to be recognised that no self-respecting health service should find itself in the position of being unable in a number of areas of its activity to discover whether its performance is good, bad or indifferent when judged against national or international norms of performance. Data relating to maternity, care of the newborn, and of children and young people, including health promotion, safeguarding, acute care, longer-term conditions, disability and CAMHS, must be generated, used for analysis and published.

Recommendation 28: Data sets must be agreed as a matter of urgency by the NHS and government covering the range of services provided to children and young people by the NHS and data must be collected, analysed and disseminated to those who need it within the Local Partnership. The data must allow services to be held accountable for the quality of the outcomes achieved.

- 4.120 Secondly, data is only worth collecting and analysing if it is about what you want to know. What we need to know is whether the services provided for children and young people are of the appropriate quality. The indicators of successful performance are crucial. Historically, they have been expressed as targets or standards and there have been a large number. I propose that we depart radically from this past.
- 4.121 I propose that there should be only one indicator or criterion of successful performance: satisfaction with the service. The police have recently adopted a similar approach whereby, for the purpose of performance management, the culture of targets has been replaced by one single

strategic objective: public confidence.¹⁴⁰ I substitute the notion of satisfaction for the notion of confidence, but they are broadly the same thing. The point is to focus the minds of those providing the service on meeting the legitimate expectations of those whom they are serving. There are at least two profound arguments in favour of adopting this single criterion of satisfaction. The first is that, although superficially it appears to limit the range of inquiry by being only a single criterion, in fact it achieves the opposite. This is because the concept of satisfaction effectively captures the whole range of factors that children and young people may bring to bear in assessing the quality of the outcome for them. This, in turn, will provoke an iterative process of research and discovery as to what it is that children and young people do in fact value in all of the environments in which they are cared for. Secondly, given this process of research and discovery, professionals will be drawn to, and wish to, meet the elements of satisfaction that are of importance to children and young people.

- 4.122 In the context of healthcare, however, satisfaction needs to be deconstructed. It is crucial to be clear about what is being measured. Children and young people as patients and members of the public are expert in certain areas of care: their needs and desires (whether convenience, or communication, or respect, or privacy); and the longer-term outcomes, such as whether they can walk without a stick, or do without medication. But they are not experts on the technical aspects of their care. There is therefore no point in asking children and young people, as patients or users of services, whether they are satisfied with the technical elements of their care. They cannot take a view because they do not know enough.
- 4.123 So, as regards the technical features of care, the same criterion, satisfaction, should be used, but it should be differently defined. It should be satisfaction by reference to whether the outcomes achieved meet or satisfy the benchmarks of performance developed by professionals (in conjunction with children and young people). This element of satisfaction can be both subjective (was the professional satisfied with the outcome?) and objective (did the outcome meet current benchmarks of performance?). The subjective captures the ambition and commitment of the professional. The objective takes us into the world of data, analysis, norms of performance and benchmarks, and asks, *should* the professional be satisfied. So, standards will not have suddenly disappeared. The huge emphasis currently being placed on such benchmarking across the clinical professions must continue, not least the work of the National Institute for Health and Clinical Excellence (NICE) in developing a range of standards. It must, however, ultimately be focused on one single objective: the

¹⁴⁰ For a more detailed explanation of this work, including further analysis of the advantages of using satisfaction as an indicator of organisational performance, see Halpern, D (2010) *The hidden wealth of nations*. Cambridge: Polity, pp. 42–3 and 208–10.

satisfaction of the children and young people and the satisfactory nature of the outcome reached.

- 4.124 Outcomes for children and young people will occupy centre stage. Satisfaction will be the sole measure: satisfaction from two perspectives, that of the child or young person and that of the professional (in conjunction with the child or young person). The system of performance management within the NHS must reflect this approach, as must the external regulatory system of the Care Quality Commission.

Recommendation 29: There should be a single criterion for measuring the quality of the NHS's services for children and young people – satisfaction. There should be two elements to satisfaction: whether children and young people are satisfied with the outcome achieved, by reference to what they are able to judge; and whether the professional should be satisfied, by reference to the current appropriate benchmarks of performance. The internal performance management and external regulation of the NHS must reflect this approach.

Addressing tensions within the NHS

- 4.125 One of the sharpest tensions in the NHS as regards the care and well-being of children and young people lies in the contrast between various features of the architecture of the NHS, such as competition, choice and payment by results on the one hand, and, on the other, the view of all those involved with children and young people that continuity of care, as regards both people and institutions, is what matters most.
- 4.126 The answer must lie in effective commissioning. Commissioners must seek to ensure that the healthcare that they commission is appropriately organised to provide continuity as the child grows and develops. This is particularly important in the case of children who are disabled or have long-term or complex needs.
- 4.127 Moreover, young people do not engage with services as do adults. Traditional models of providing services may not, therefore, be appropriate. Young people do not respond well to letters. The text message and the internet are their ways of being in touch. Moreover, children and young people, branching out on their own, need guidance as to where to go for services and what may be available. The NHS has not been particularly active or successful in responding to this need. Nor has it felt the pressure to do so, given that children and young people do not represent sufficiently large a group to cause the system to respond to them. Again, it will be the task of commissioners, orchestrated through the Local Partnerships, to ensure that the needs of children and young people are addressed, and in addressing them, that young people in particular are heard and listened to. The importance placed by the new Government on 'patient choice', both

as a good in itself and as a tool for improving services, makes it all the more essential that mechanisms exist to allow children and young people to be heard and for their needs, including particularly continuity of care, to be heard.

Recommendation 30: When designing and implementing mechanisms to give effect to choice within the NHS, due regard must be given to the needs of children and young people, both to be supported in making choices and to receive continuity of care over time.

NHS working with others

4.128 As I have pointed out, providing high-quality services for children and young people requires the NHS to work collaboratively with many other public sector agencies.¹⁴¹ These include primarily social care services, education and (in relation to safeguarding, adolescent mental health and substance misuse) the police and youth justice systems. They may also include others such as housing, planning, benefits services and Jobcentre Plus.

4.129 Each of the institutional differences between these bodies forms a barrier to successful collaboration. Each has a different management structure, framework for performance management and form of regulation. Each has its own budget that may be constrained or ring-fenced in various ways, and for which each alone is accountable. Each answers to different ministers, deals with different stakeholders, and addresses different areas of public concern.

4.130 These formal barriers both delineate and exacerbate differences in organisational perspective or 'world view'. Such views are grounded in the varying professional perspectives of each organisation's staff. Agencies have different views of their relationship with the child or the family, and different 'rules of engagement' with both clients and other agencies. These differences in approach make inter-professional tensions inevitable. For example, some NHS staff expressed frustration that they were unable to discuss cases informally with social workers, because no formal referral had been made. One clinician expressed frustration that "they [social services] are always asking 'is this a referral?'"¹⁴² From the perspective of the child or family using services, such tensions appear not only unnecessary, but also frustrating and confusing. While they remain the same people with the same set of needs, they are viewed, and therefore treated, differently as they fall for examination through different professional lenses.

¹⁴¹ See, for example, principle 5 of the NHS Constitution.

¹⁴² View submitted at a meeting with NHS managerial and professional staff involved in safeguarding children.

- 4.131 An additional factor affecting the NHS's current capacity to work effectively with others is that, as I have pointed out, the sheer size and complexity of the NHS cause problems for other organisations seeking to engage with it.¹⁴³ This is not helped by the internal structure of the NHS, which often means that responsibility for children and young people within any particular organisation is spread across a number of staff. For example, commissioning children's services and safeguarding children might be the responsibility of different directorates in a PCT. This causes confusion for Local Authorities, where responsibility for children is contained in a single management structure and hierarchy. Organisations are also unclear about whom to engage with in the NHS, whether commissioners or providers, or both, about any particular issue. Difficulty in engagement, therefore, makes both the organisation and the practice of working with others more difficult, and less effective, than it should be.
- 4.132 For the future, the first step that the NHS needs to take in working with other agencies is to understand them and how they perceive children and young people and their role in relation to them.¹⁴⁴ Even within the NHS, healthcare professionals take differing views of their responsibilities. The GP may see the child or young person as part of a family and seek to care for the family. Other healthcare professionals may adopt a different stance. These differences of view also exist between healthcare professionals and others, whether social workers, educationalists, housing officials or police, and need to be understood. Social workers, for example, may be neither suitably trained nor sufficiently supported to take action to resolve difficult cases, as they see it as their role to manage cases rather than to seek to improve the circumstances of the children and young people or to solve problems.¹⁴⁵ This is in contrast to the interventionist approach of both the healthcare professional and the police. These differences of approach reflect differences in policy at governmental level and differences in training and ethos.
- 4.133 Against such a background, it is clear that merely agreeing to work in partnership, or making a commitment to do that which is in the best interests of the child, will not take us very far. While all can sign up to it, it will mean different things to different people and the seeds of disagreement and disharmony will be sown. What is needed is a common vision that is strong enough to bind all the agencies together while taking account of different perspectives and different points of departure. This will enable a "rich discussion within a culture of inter-professional respect" which was recognised as a vital prerequisite of effective joint working in this area.¹⁴⁶

143 The call is regularly heard for the NHS to make itself more manageable, consolidating its activities under just a few general headings, e.g. health promotion, accidents, chronic illness and acute illness.

144 One senior manager commented that NHS communications on safeguarding were "completely silo'd". Effective safeguarding will require joint working at local level, but organisations outside the NHS are not involved in formulating national communications.

145 View submitted at a meeting with independent experts.

146 View submitted at a meeting with NHS managerial and professional staff involved in safeguarding children, Sandwell.

It will require significant leadership from the Local Partnership, supported by an acknowledgement by the leaders of its constituent organisations that such a common vision is essential and must take precedence over any individual organisation's concerns. Where apparently irreconcilable differences remain in any particular case, the course of action must be to refer back to the common values of the various organisations and to identify how each can add value to the overall welfare of the child or young person. In this way, differences can be characterised as operational rather than as matters of principle. With a commitment to work together, disagreements will be about a particular approach to a particular case. Progress can then be made.

Recommendation 31: Local public services, led by the Local Partnership, must develop a common vision for all services for children and young people, so as to enable the services to work together.

- 4.134 One illustration of this problem and its possible solution may help. It is clear that healthcare professionals and social workers approach the challenge of child protection from different perspectives. The social worker has a procedure to follow and is disinclined to resort to pragmatism or act on their own discretion. One of the procedures to be followed is that the circumstances of the child about whom concerns are raised must meet a particular threshold. The healthcare professional (and the police) may be more used to the exercise of discretion and consequently more prepared to step in earlier than the social worker.¹⁴⁷ Moreover, the threshold for action that they apply is lower. The risk of arguing about the way forward and overlooking the immediate needs of the children and young people in these circumstances is very real. The aim must be to arrive at an understanding of common responsibility whereby a decision is made that all can accept. The risk taken by one organisation is offset by the responsibility it shares with all the others.¹⁴⁸
- 4.135 Of course, collaboration requires participation. A major complaint raised against the NHS is its poor performance as a partner in joint activities with other agencies.¹⁴⁹ This is so even when its participation is required by law. PCTs are currently described as the local bodies least engaged with Children's Trusts and safeguarding boards. The police have described the NHS as its weakest partner. Others have described the isolation of the NHS in terms of "Fortress Health".

¹⁴⁷ View submitted at a meeting with senior police officers.

¹⁴⁸ Shared responsibility means that all partners are responsible for an agreed course of action, not simply that they agree how responsibility will be passed between them as cases progress (view submitted at a meeting with NHS professionals involved in safeguarding).

¹⁴⁹ It was put to me by a senior official that "health was a poor partner – the most likely organisation not to be at the table". This was compared with the performance of the police service, which in recent years had refocused its activities from policing to "community citizenship". See my reference to the police and measures of performance at paragraph 4.121.

- 4.136 It is true that partnerships have begun to develop at the senior levels of various organisations. Top managers may work well together once they take the plunge. But problems exist lower down in the organisations where staff bring their particular professional/managerial outlooks to their work and are constantly looking over their shoulders at what is expected of them in the form of national targets and performance indicators.¹⁵⁰ Moreover, as funding becomes tighter, the desire or tendency of each organisation to hoard its own money and not to spend it towards a common aim is in danger of becoming entrenched.
- 4.137 With all the agencies responsible for the welfare of children and young people under the overall direction of the Local Partnership and with an obligation individually and collectively to implement the Partnership's agenda and plans, this isolation by and of the NHS should cease. There will still be the challenge of motivating professionals who are actually delivering services to accept a new collaborative way of working, but at least they will all see that they have the opportunity for the first time of being part of a larger organisation dedicated solely to the interests of children and young people. I will consider in due course how this motivation may be inspired.

Changing/challenging how people work

Children and young people

- 4.138 It is axiomatic that, as young people grow and mature, so they must be increasingly engaged in their health and healthcare. I have already stated that the arrangements for the governance of Local Partnerships must include a place for the voices of young people to be heard and listened to. They must have a place in the design and appraisal of the services offered.¹⁵¹
- 4.139 One of the most important tasks for Local Partnerships will be to grasp the nettle of arbitrary boundaries placed around services, based on birthdays. Historically, the line between young person and adult has reflected their legal categorisation. This distinction has been translated into the division of funding as between services for adults and those for young people. Clearly, there has grown up a determination that the budget for adults is protected from the depredations of those responsible for children, and vice versa. Such bureaucratic wrangling may be necessitated by the way in which the

150 The NHS Confederation explained how contrasting regulatory and performance management demands, as discussed above, made it difficult for managers appointed jointly (for example a PCT and Local Authority) to give consistent messages to staff working for more than one organisation. It is for this reason that they argue that joint appointments at senior level must be mirrored lower down organisational hierarchies.

151 I was impressed by the initiative in NHS Central Lancashire where 'Young Advisers' have been appointed. This is part of a larger strategic vision about children, young people and maternal health developed by the Strategic Health Authority in the North West.

system is designed, but they immediately lose sight of the purpose for which the funds exist: to care for the interests of young people as they move into adulthood. And, of course, this is a process that varies from individual to individual. While it may be bureaucratically convenient to draw a clear line between the two streams of funding, it makes no sense at all to the young person. Future arrangements (whether related to organisational structure, funding streams or performance management) must ensure that there is a greater flexibility, allowing for greater continuity of care even into early adulthood. This is a great prize to be won in terms of the future welfare of adults. It is something that must be settled initially by government: what I have previously described as the challenge of transition.

Recommendation 32: Arrangements must be agreed, regarding funding and other matters, to address the changing needs of children and young people as they mature, including greater continuity of care into adulthood. Ensuring a smooth transition between children's and adults' services should be a priority for local commissioners.

- 4.140 Children and young people are entitled to age-sensitive care. Largely, this is a matter of professional expertise and I will address it in due course when I talk about the role of professionals. Here it may be helpful to raise a number of points that have to do with how the NHS deals with children and young people and how children and young people feel that they are dealt with.
- 4.141 It seems an obvious point that services for children should be designed and delivered with the perspective of the child in mind. Where this happens, as in, for example, Sheffield or Manchester Children's Hospitals, the effects are remarkable both as regards the child or young person and their parents or carers, and as regards the staff, who feel that they can provide the service they were trained for and go to work for. Lessons need to be learned. Where it does not happen, the picture is one of children, young people and parents/carers trying to negotiate a maze of services.
- 4.142 It does not take a great deal of insight to realise, for example, that support groups planned for parents/carers which are laid on in the middle of the day will necessarily exclude parents/carers who are at work. Equally, it is just plain common sense that staff in the NHS and indeed in other services should relate to children, young people and parents and carers using language which can be understood and avoid patronising attitudes. Children and young people complain that they are not regarded as active agents in their healthcare but rather as passive recipients. I was told by young people that many professionals currently lack either sufficient expertise, or a suitable professional attitude, to deliver age-appropriate care.¹⁵² As a result, they feel that professionals lack respect for them and

¹⁵² View submitted at a meeting with third sector organisations.

their problems. They feel that they are either treated like children and so feel patronised (one 14-year-old told of how she was asked to colour in pictures to show her feelings), or else treated like adults and, as a consequence, insufficiently supported.¹⁵³

4.143 Engagement with parents and carers is often inconsistent and inappropriate. This was made clear again and again in submissions and meetings. For some older children, parents/carers may be asked their views as proxies for a child or young person who is quite able to express their own view. For example, a parent or carer may be asked for consent, or involved in a child's treatment, when such engagement should be with the child directly.¹⁵⁴ Parents and carers of younger children often feel insufficiently involved and informed about their child's care, or suspect that professionals do not talk to each other. Many parents and carers of disabled children in particular feel responsible for 'co-ordinating' their child's care between a number of professionals, including ensuring that information is shared between them.¹⁵⁵ At the same time, I also came across many examples where parents and carers had not been kept informed about their child's treatment.¹⁵⁶ This must change. The NHS should be required actively to conduct research on a regular basis to determine what children and young people expect and want from it. It is already clear that young people have two fundamental priorities in their dealings with the NHS: that the staff be friendly and that confidentiality be observed.¹⁵⁷

Recommendation 33: NHS services for children and young people should be designed, organised and delivered from the perspective of the child, young person and parent or carer. Relevant NHS services should regularly assess the expectations and views of children and young people using the services, and should take action in the light of the findings, which should be made public.

Professionals

4.144 I have shown already that the way in which professionals within the NHS interact with each other and with professionals in other organisations does not always best serve the interests and needs of children and young people. I heard frequently of professional groups' limited acceptance of the need to work together. Everyone to whom I spoke agreed with the need for more inter-professional working, yet almost all also had examples of where

153 I welcome the recent effort to change traditional ways through the publication by DH of standards designed to make services more 'young people friendly' under the heading of *You're Welcome*.

154 It was put to me forcibly by young people that their parents or carers were asked for contact details but nobody asked them for their details.

155 See paragraphs 3.34–3.35.

156 See paragraph 3.43.

157 View submitted at a meeting with health professionals specialising in the care of young people.

this was lacking. Paralleling the development of specialities within professions, each profession defines itself not only by its own role, but also in opposition to the roles of others. Professional identities are created around a unique domain of knowledge and skills and sphere of influence.

- 4.145 Defined in opposition to one another, professions become 'tribes' which both jealously guard the tasks and the information within their unique domain and, simultaneously, reject involvement with other tasks which are seen as not for them. For example, I was told that teachers can be unwilling to assist pupils with long-term conditions with the medical care that they require in order to stay in school, or that concerns about safeguarding from hospitals may not be passed on to social workers because healthcare professionals think that they can sort out the concerns for themselves. As I have said, these problems stem to some extent from professions' differing 'world views', which determine not only how they approach their daily work, but also their attitude to the children and families they serve and to other professionals.
- 4.146 Children and young people are pupils, patients, social problems, homeless and sometimes also parents or carers. They are victims or potential victims of crime, or potential or actual perpetrators of crime. They need support within their family, or protection from them. All professionals can agree that 'the child' is at the centre of their work, yet each views 'the child' through a different lens.
- 4.147 It goes without saying that there is a clear need for the various areas of expertise that have grown up in healthcare in recent years. But this has led professionals, largely in hospitals, to become more and more specialised. The care and treatment of children have become increasingly atomised. GPs, outside hospitals and with limited training in paediatrics as a consequence of this growing atomisation of care, have tended to refer children and young people to hospital rather than address problems themselves. Clearly, the child or young person who needs long-term care will benefit from such referral. The need will be identified and the care organised so as to ensure that the child or young person is cared for in the most appropriate place, whether at home or elsewhere. But, often, referral is unnecessary. The cost to the system is considerable.
- 4.148 What changes are needed? The future should be designed on the basis of what the child or young person needs from time to time from the services provided by the National Health Service, alone or in conjunction with other agencies. The future must be one of a holistic approach to the child or young person. The future as I have proposed lies in making the general practice or the polysystem the initial point of contact. There, a cadre of frontline staff will assess the child or young person. They will be generalists, but have the necessary training in paediatrics and child health, including mental health, to determine when to care for the child or young person

themselves, when to refer them elsewhere and, in keeping with the holistic approach, when to engage other agencies. The savings in efficiency as well as the avoidance of unnecessary anxiety or upset to the child or young person will be considerable.

- 4.149 Of course, the holistic approach should not be limited merely to general practice and the first point of contact. It should pervade the approach taken by all professionals, even the most specialised. I saw a good example of this on the wards of a large teaching hospital (University College Hospital) where members of different professions, including the play specialist, take turns to lead a ward round. The effect is as much symbolic as practical. It says that all the staff are there together, working for one common purpose: the good of children and young people. What is required to produce this sort of approach? The answer is professional leadership and vision.
- 4.150 A contrast can be found in the current approach to child protection. Given the high visibility of this area and the aversion to risk that pervades professional actions, professionals tend to retreat into their professional silos, secure in the knowledge that they have ticked the relevant boxes and ready to blame someone else if something goes wrong. It is an area crying out for leadership, common vision, and understanding and trust between the professionals involved. The Local Partnership can make a significant contribution.
- 4.151 It has become clear to me that training lies at the heart of making a better future for children and young people.¹⁵⁸ I have already said that those in general practice, nurses as well as doctors, must, as a matter of urgency, receive appropriate training in children and young people's health and healthcare. This should be reflected in the Quality and Outcomes Framework and in the process of professional revalidation.¹⁵⁹ But the need for training goes much wider: there should be a common curriculum to which all those who come into contact with children and young people, not just health professionals or those working in NHS organisations, should be exposed. It should address not only matters specific to the care and welfare of children and young people, but also matters such as how to work in teams, how to see the child or young person holistically, an understanding of the development of children and young people, how to identify mental health problems, an understanding of what other professionals dealing with children do, and how local services are commissioned, co-ordinated, provided and held to account. It must be a central feature of this training that professionals should learn to understand their fellow professionals as

158 The importance and potential of training was a major theme of my discussions with both the Royal College of General Practitioners and the Royal College of Nursing. It was also referred to by nearly every other person to whom I spoke, as well as in a large number of written submissions.

159 It was urged on me that the Quality and Outcomes Framework should be expanded to include a reference to participation in safeguarding and child protection cases.

a first step towards being able to trust and rely on them. Of course, the purpose of such training is not merely to build trust, but also to improve outcomes for children and young people as a consequence of such increased trust. Indeed, there is much to be said for the Local Partnership identifying a champion for the various professional groups whose job is to explain what the profession does and how it sees the world.

Recommendation 34: All those involved in providing services for children and young people, including but not limited to NHS services, should receive training together according to a common curriculum, developed with the involvement of the Royal Colleges and other professional bodies, a principal purpose of which must be to enable professionals to understand each other's roles and work together.

- 4.152 It has also become clear to me that an intrinsic element in the process of moving professionals from a default position of distrust to one of trust of each other is the need to show each of them how working with others will in fact make their job easier and, by extension, more rewarding as they can achieve more for the children and young people whom they serve. It seems that the natural propensity of professionals of all stripes is to assume that collaboration is some kind of betrayal of their tribal identity. In fact, collaboration is a mature response, recognising that the multi-factoral challenges presented by their responsibility for the welfare and well-being of children and young people can only be met by a multi-professional response (and professional here includes managers).
- 4.153 One aspect of the relations between professionals both within and across professions which causes significant concern is the difficulties associated with sharing information about children and young people and, on occasion, their families. The need to address the circumstances of children and young people holistically, to be aware of the pathways of care that they follow both within the NHS and in contact with other agencies, and to plan services around the journeys they take, are fundamental premises in my approach to this review. These premises can be and often are undermined by a failure to share information. An example can serve to make the point. I heard from a number of young people about how frustrating and depressing it was to have to tell the same story to a succession of professionals, none of whom seemed to have passed it on to the next.¹⁶⁰ And I have already referred to parents and carers of disabled children who had to tell the same story on numerous occasions only to find that one specialist had not written to another, such that one parent ended up writing letters to consultants herself.

¹⁶⁰ View submitted at a meeting with young people.

- 4.154 I have already stressed the importance of creating a climate of trust in which information may automatically pass from professional to professional. This may be an important task for the Local Partnership. It is not impossible to create such a climate. I have already referred to the example of the Family Justice Centre in Croydon.¹⁶¹ I was equally impressed by what I saw in Sheffield. All those responsible for the care and well-being of children and young people had access electronically to a common database. The information was recorded in accordance with a protocol. Everyone, from the school health team, to the A&E doctor, to the health visitor, to the GP could check on the child or young person and also record information for the benefit of others. Clearly, one significant benefit this system provides is in the area of safeguarding and child protection. But its value goes far beyond this. If professionals are to be there for the child or young person as they develop and come into contact with various public services, then sharing information is essential. It allows the best choices about the care and well-being of the child to be made and it allows services to target those who most need help.
- 4.155 Of course, trust, though essential, is not the only factor necessary to facilitate the proper exchange of information. Two other matters are of particular relevance. The first is technical. Systems for storing and allowing access to information have to be aligned. This would mean that those entitled to enter data would have access to the data of other professionals. Currently, this may not be the case. As the NHS Confederation reported, the NHS's system of Connecting for Health does not recognise the systems used by Local Authorities. A health professional may be unable to gain access to records relating to the safeguarding of a child because the information is held on a different system or on premises occupied by another public service, such as the education department, as I encountered in Newham.¹⁶² Or, as happened in Haringey, the hospital staff could gain access in principle to records on safeguarding, but could only do so in the presence of social workers.
- 4.156 Such a state of affairs is the opposite of integrated services: it epitomises services which have disintegrated. The solution lies in developing local networks for sharing data electronically, rather than simply seeking to create some overarching national solution. Protocols can be agreed locally as to what is to be stored and who may have access. National databases can be referred to when useful, but given that their creation has taken on the quality of the search for the Holy Grail (which, it needs to be recalled, has never been found!), it is better to think in less grand terms and get on with doing something which can be made to work locally. As it happens, the NHS Confederation has expressed the view that, of all local agencies, Children's Trusts have historically been the most successful in fostering the

¹⁶¹ See paragraph 4.71.

¹⁶² The benefits of the co-location of services again comes through.

sharing of information between the various organisations that are a part of it.¹⁶³ This shows that progress can be made. It must be made faster, and more consistently, across and between all services.

Recommendation 35: There should be local networks through which services can share information electronically and protocols should be agreed by the networks to provide for this.

4.157 The other matter of concern is confidentiality.¹⁶⁴ This is not the place to explore the nature of confidentiality when dealing with children and young people (an exceedingly complex subject). Nor is it the place to seek to understand why the translation of information into electronic form surrounded with protection creates a level of concern not associated with the recording of information on paper, which routinely gets lost, is read by many, and the sharing of which is difficult at best. Nor is it the place to notice that, when asked, most members of the public, rather than those who claim to speak for them, say they are anxious that information be shared between professionals, recognising that it is in their interests that this be so. Of course, they wish for appropriate safeguards to be in place. Such safeguards are well understood and exist. Nor is it the place to notice that information is power and that professionals may be inclined on occasions to raise the flag of confidentiality to refuse access to ‘their’ data by others. Nor, finally, is it the place to remark that much of the controversy over sharing information relates to what is recorded, rather than to the fact of its being recorded. If a standard template were used by all that limits information to the factual and removes opinion and speculation, then objections to sharing would become less strong.

4.158 Instead, what I propose here is that there is a general understanding that confidentiality is a relative not an absolute obligation. That being so, local networks must agree on the protocol to be followed, share it with their local community (with the relevant arguments) and then get on with developing a system of sharing. Without it, services for children and young people will always be less good and children and young people, particularly in the context of safeguarding, will suffer. Of course, one part of such a protocol will include those circumstances in which respect for confidentiality has a very high priority, for example in the case of mental health problems or sexual behaviour in young people. But, even here, the objection of the young person usually relates to sharing information with family members not other professionals, including the school health team. Indeed, properly understood, the issue is largely one of privacy rather than confidentiality.

¹⁶³ NHS Confederation’s submission to the review.

¹⁶⁴ It was put to me by senior officials that, as regards obtaining personal information in the context of providing a wide range of services for children, the NHS was rated as the most difficult organisation by professionals working in other agencies, with GPs being described as particularly difficult. A ‘culture of confidentiality’ was said to exist in the NHS and DH, with very limited leadership at senior level leaving professionals unsure of how to respond to requests for information, and therefore reluctant to share it.

- 4.159 Before I leave this section about professionals, it is important for me to recognise one central and immovable point. The services provided to children and young people are delivered by professionals on the ground. They are at the centre of everything. Unless they are encouraged and empowered to adapt the culture in which their services are provided and received, nothing will change.
- 4.160 Thus, perhaps, the most important agents for change to advance the interests of children and young people are the professional commitment and ethos of those who serve them. Many professionals feel beleaguered or beaten down, frustrated that they cannot achieve what they signed up to do and what they have spent their professional lives trying to accomplish. Many professionals have turned inwards, seeing the outside world of 'the system' as somehow hostile and designed to frustrate them. Many do the best they can and settle for that, in the knowledge that it is not what they would wish. The system must reconnect with its professionals. As mentioned above, this applies to managers as much as to technical (in the case of healthcare, clinical) professionals.
- 4.161 At the heart of such a proposition is leadership and vision. At all levels, from the government and policy-maker to the nurse on the ward, the professionals must recognise in the changes that I am proposing a way of re-committing themselves to the design and delivery of services for children and young people. The natural conservatism of all professions will draw them towards a reluctance to change. The natural commitment to service should draw them out. School nurses must see that, by working with the general practice and the health visitor, they are doing, and doing better, what they, as school nurses, trained to do. They will be better school nurses, as well as provide a better service to children and young people. GPs must see that being at the hub of the service for children and young people is not a further burden for which they must negotiate appropriate terms and conditions (though these are not unimportant). Rather, it is the chance to become a more fulfilled GP, caring for families and young people and working collaboratively with others. GPs must see the collection of information as an affirmation of the care based on evidence which was at the heart of their motivation for joining the profession. Managers must see themselves as facilitating the provision of services around the needs of, and therefore for the greatest benefit of, those who use them. Surgeons in the hospital must see themselves as part of a pathway of care. That is, after all what they trained to be and now they can make it happen.
- 4.162 Changes in the care of children and young people will not take place without the engagement of professionals. Once professionals realise that what I am proposing allows them to be how they see themselves, good and fulfilled nurses and doctors, they will want to make sure that change takes place. Those who are proposing to change how healthcare services

for children and young people are organised and provided would do well to bear this in mind. Whatever the scale or the type of the proposed change, ultimately it has to be delivered by those who work in and dedicate their lives to these services. The motivation and conviction of professionals, unlocking their passion for the services that they provide, are, I believe, the most powerful tools that exist to bring about improvement, especially in the current climate of financial constraint. It behoves us all to recognise and mobilise this motivation and conviction.

Workforce

- 4.163 Within the NHS, perhaps the greatest and most pressing need is for an increase in the workforce trained in paediatrics and the care of children. In the hospital sector, it is still the case that, apart from environments dedicated to paediatric care, the level of skill and expertise in dealing with children and young people is not what it should be. A concerted effort must be made by all the Royal Colleges, professional bodies and the NHS to address this weakness.
- 4.164 Government, employers and professional groups must make the development of the workforce a very high priority. Endangered species such as psychologists, who perform a crucial role in hospitals and in the community, speech and language therapists who can rescue a child from uncomprehending exclusion, and play specialists in hospitals, should not be seen as expendable luxuries to be got rid of when the money is tight. They are part of the necessary complement of staff. They are crucial to the experience that a child may have of care in and out of hospital, and thus of the attitude to healthcare generally that that child will carry into later life, for example in their attitude to the self-management of a long-term condition. The fear of the school dentist of 50 years ago, which persuaded generations of children that dentists were to be avoided, with adverse consequences for health, offers a cautionary parallel.

Recommendation 36: Government, employers and professional groups must address the need for more professionals trained in the range of skills required in the comprehensive care of children and young people as a matter of urgency.

- 4.165 It must be recognised that significant shortages of professionals trained to care for young people with mental health problems exist at a time when an epidemic of such problems lies beneath the surface of society. This gap must be closed. I am aware of the concerns expressed about resources. My answer is that if we really care about young people and if we want to reduce the burden on adult services in the years to come, action now is the only option. I heard pleas for increased numbers of specialists (particularly

in the area of cognitive behavioural therapy)¹⁶⁵ and for more generalists, particularly school nurses. It is not my place to arbitrate among these pleas. These decisions must be taken at a local level, on the basis of an understanding of the needs of each community.

- 4.166 As regards general practice, I have pointed out the need to train GPs and others who work with them. This need is increasingly pressing, for two reasons. The current level of training is poor and getting worse. Secondly, if general practice is to be at the centre of arrangements for caring for children and young people, as I propose, such training is required as a matter of urgency. As one senior GP put it to me, “Some GPs now don’t even know how to hold a baby”. The temptation to refer children and young people elsewhere from lack of knowledge or confidence must be resisted by GPs. They will be able to resist it only if they are properly trained.
- 4.167 As regards the NHS’s workforce more broadly, I have urged the development of joint curricula and joint training. This is something that the relevant Royal Colleges, professional bodies and regulators need to address urgently.¹⁶⁶ The purpose is obvious. Working in a team is a central feature of modern healthcare. Training together breaks down cultural tendencies towards professional isolationism. It also fosters an understanding of each other’s role and contribution. And it sets the basis for a more holistic approach to the care of children and young people. Indeed, the ultimate goal must be to shift the focus away from single professional units and identities with their particular goals, to a single-minded concern only for the outcomes which are needed for children and young people: that is, work backwards and start with the child or young person, “I exist to provide for you”, rather than forwards from “This is what I, as a professional, do”.
- 4.168 Joint training is of particular benefit as regards safeguarding. Of particular importance is an understanding of what constitutes a risk factor. We know more about these risk factors than ever before, but this understanding, and how to apply it in making professional judgements, needs to be more widely taught to relevant staff.¹⁶⁷ It is clear that different professional groups use what appears to be a common language in different ways (for example, the degree of evidence called for to allow a view that abuse may be suspected). The value of training together is that these differences can be identified and a way forward found that puts the interest of the child or young person first, rather than any particular professional group’s sense of what is right. By training together, professionals come to understand how

165 View submitted at a meeting with Lord Layard.

166 Both the RCPCH and the Royal College of Nursing stress the need for broader programmes of education, to include such matters as safeguarding, in the case of nurses or, as the RCN describes them, “the Child Health Nurse of the future”. While this is welcome, it still envisages the nurse being educated in isolation. The need to avoid these silos, whether in practice or in education and training, is what is being urged here.

167 This was mentioned to me both by officials and independent experts working in the area.

their views of the world differ, how that affects their behaviour, how this might cause confusion or tension between them, and how this might be resolved. In this way professionals can understand how their differing perspectives can add to the richness of understanding particular cases and to the subtlety of agencies' response.

Recommendation 37: There should be joint training of professionals involved in the care and welfare of children and young people, according to agreed curricula, particularly in the area of safeguarding.

- 4.169 Equally, as regards safeguarding, different professionals operate different thresholds to justify action. Again, these need to be explicitly identified and a common approach agreed. Such a solution will be made easier should my broader proposals be accepted, given that policy will emanate from only one department of state and will be translated into action at the local level by a single Local Partnership that brings together all of the relevant organisations.
- 4.170 One of the consequences of an integrated approach to the workforce in providing services to children and young people is the quite proper reflection that some jobs are better done by this rather than that professional. One such example is the recognition that there is a difference between a health visitor and health visiting. The latter job may be carried out perfectly well by someone who is not a health visitor but is part of their team. Such developments are essential to produce an efficient and effectively integrated workforce. They will be resisted by those who think in terms of their professional identity rather than in terms of what all professionals are there to achieve: the best possible service for children and young people. The task of all who can influence the shape of the future workforce must be to redesign the workforce around the child or young person. The reverse has for too long been the story. One way of achieving this, which is worth considering, is to create not just an integrated approach but an integrated workforce for children and young people, whereby all those involved in health and healthcare in the local community are employed by the same organisation, preferably the Local Partnership. Such professionals might include the health visiting team, the school health team, community nurses and others. In this way, inter-professional barriers are broken down as organisational barriers which keep professions apart are removed.

Recommendation 38: Consideration should be given to the creation of an integrated workforce for children and young people, in which all those involved in health, healthcare and welfare in the local community are employed by the same organisation, preferably the Local Partnership.

- 4.171 I have referred several times already to the challenge of managing the care of young people as they pass to adulthood. It is clear that the process of 'transition' is both entirely artificial and, at the same time, entirely real.
- 4.172 The artificiality lies in the arbitrary boundaries drawn between the services offered to young people and those offered to adults, with all the unfortunate consequences that flow from this. As I have said, it is essential that local organisations come together to ensure that the young person can enjoy a continuity of care which ignores birthdays and concentrates on needs.
- 4.173 The reality lies in the fact that young persons are, of course, in a process of development and that the services offered to them need to reflect and take account of this. To begin to address this reality, I propose that there should be a cadre of professionals who are trained in both paediatrics and the care of young adults. These would be available to the Local Partnership to enable it to commission services which manage the process of growing up, putting the young person at the centre and addressing the needs of 16- to 25-year-olds.

Recommendation 39: There should be a cadre of professionals who are trained in both paediatrics and the care of young adults. Government, employers and professional groups should work together in order to ensure that such a cadre is established and receives appropriate training.

5: Conclusion

- 5.1 There is no doubt that many children and young people receive better care from the NHS than ever before. There is no doubt that up and down the land, every day, children and young people receive good care from good caring professionals. But there is also no doubt that services for children and young people could be significantly better. That is the premise on which I was asked to conduct this review.
- 5.2 The influence of cultural factors on the performance of the NHS is very great. If these factors are not identified and addressed, the scope for improving the services which the NHS provides for children and young people is limited. If they are addressed, a major step forward is possible. The long decades in which reality always fell short of rhetoric will be over. Children and young people, tomorrow's future, will get what they deserve and what we owe them.
- 5.3 I have adopted an approach in this review which seeks to address this historical problem. I have proposed that the care of children and young people must be seen in the round rather than from the narrow perspective of the acute sector (healthcare as intervention). I have further proposed that care should be unified and co-ordinated at two critical levels: as regards policy, in a single department of state; as regards the commissioning and provision of services locally, by a Local Partnership which, while it could take a variety of forms, must operate according to certain principles, the most important of which is that it be wholly dedicated to the needs and welfare of children and young people.
- 5.4 If services for children and young people provided by the NHS are to improve, the barriers to collaborative working, both within the NHS and between the NHS and other agencies, must be overcome. Services must be integrated within the NHS along pathways of care. They must interact successfully and seamlessly with other public agencies. The NHS is not an island. We fail children and young people if we perpetuate a system in which they (or their parents or carers) need to knock on the right door in search of care and risk going unhelped if they get it wrong. We fail children and young people if their needs and concerns are not at the centre of everything that is done: easy rhetoric but very difficult to pull off. Being held accountable by reference to the sole criterion of whether the outcome of the service provided was satisfactory will mark a new beginning: that the NHS intends to respond to children and young people, rather than expecting them to respond to the system.

- 5.5 We must invest. We must invest to save and we must invest because it is right to do so. To those who say that the times are not propitious for investment in anything, that disinvestment is the only way forward given the state of the public finances, I say the following. The new approach that I propose contemplates the integration of services, working collaboratively within the NHS and across the other agencies. Savings will be made through greater efficiency, through co-location and the benefits it brings, and through the joint planning and commissioning of services. They will also be made through the reduction of the current complexity which particularly surrounds the services provided by the NHS. A system that still relies on multiple appointments for different things in different places, or, worse, by returning to the same place, is expensive. It does not meet the standards that children and young people are entitled to expect. As regards early intervention and a shift towards health promotion and the prevention of disease, the pay-off is obvious. What has been lacking at times has been the political will.
- 5.6 Finally, at the centre of any system for providing services are the professionals. The challenge for them is to re-engage with the system so as to change it for the better. It cannot change without them. The prize at stake is the chance to be the professionals they want to be. The greater prize is services for children and young people that they and the NHS can be rightly proud of.

Summary of recommendations

Recommendation 1: Responsibility for policy relating to the health and well-being of children and young people should be brought together in a single government department. In addition to health and healthcare, this responsibility should extend to include as many other aspects of public services used by children and young people as possible.

Recommendation 2: Relevant elements of government and national organisations must clearly establish, and agree on, their respective responsibilities in relation to the care of children, young people and adults, how these responsibilities interact, and how services for them can be appropriately aligned.

Recommendation 3: Funding for the health and healthcare of children and young people and for 'transition' to adulthood must be identified, separated from the funding dedicated to the care of adults, and transferred to the responsible government department for further distribution to organisations at local level.

Recommendation 4: There should be a dedicated Local Partnership in every Local Authority or similar area which is responsible for the planning and delivery of children and young people's health and healthcare at the local level and for integrating these services into all of the services provided.

Recommendation 5: The Local Partnership must establish mechanisms to ensure that there is local accountability to the public.

Recommendation 6: The Local Partnership must have the power to require that a Children and Young People's Plan is drawn up and implemented.

Recommendation 7: The Local Partnership's plan must set out the agenda for children and young people's health and healthcare.

Recommendation 8: The Local Partnership's plan must integrate the agenda for children and young people's health and healthcare into the overall plan for all the services that the Local Partnership is responsible for providing, so as to ensure that a holistic approach to the care and welfare of children and young people is adopted.

Recommendation 9: The Local Partnership must create structures whereby the views of children and young people can be sought and taken account of in the planning and delivery of health and healthcare services.

Recommendation 10: The Local Partnership must operate according to the following principles:

- There should be a holistic focus on children and young people.
- There should be a duty to ensure that local organisations work together.
- There should be appropriate ways of ensuring accountability to the public.
- There should be an emphasis on efficiency in the provision of services.
- Children and young people should be actively engaged and involved.

Recommendation 11: The funding of health and healthcare services, and all other services for children and young people, must reflect and give effect to the Local Partnership's agenda and plan.

Recommendation 12: The Local Partnership should have a dedicated team drawn from NHS commissioning organisations, Local Authorities and elsewhere, which is responsible for commissioning all services, including health and healthcare services, for children and young people.

Recommendation 13: The commissioning of all services, including those of the NHS, called for by the Local Partnership's agenda and plan must be carried out in such a way as to ensure that the services are complementary and efficiently delivered.

Recommendation 14: There should be a single point of access to the NHS's services for children and young people. This should be through general practice or the hub of some form of polysystem.

Recommendation 15: The services provided by general practice or a polysystem should be accessible, available at all times, and at the centre of a network of NHS services for children and young people.

Recommendation 16: Information about the care of children and young people must be collected and consolidated at the central point of access, the general practice or the hub of some form of polysystem, and be available to all who provide services for children and young people.

Recommendation 17: There should be a dedicated information officer in general practices or at the hub of polysystems responsible for the collection, co-ordination and dissemination of information about the care and welfare of children and young people in the relevant area to those providing services and who need to know. This information should ordinarily be made available to children and young people, and their parents and carers. The information officer should also be responsible for managing communication with children and young people themselves, and their parents and carers.

Recommendation 18: All GPs, practice nurses and other professionals attached to general practice or who form part of a polysystem should, as a matter of urgency, receive training in the comprehensive care of children and young people.

Recommendation 19: The initial training for GPs, the Quality and Outcomes Framework and the system of revalidation should all incorporate the need for training in the comprehensive care of children and young people.

Recommendation 20: General practices and those at the hub of polysystems should seek to ensure that there is at least one professional who has specialised knowledge in the comprehensive care of children and young people.

Recommendation 21: Urgent action is called for to respond to the mental health needs of children and young people. Mental health services must be available and accessible, including through self-referral, and be integrated with other services, particularly through schools.

Recommendation 22: Those commissioning health services for children and young people should use their influence through commissioning, contracting and funding to require providers to design services around the needs of children or young people, establish a single portal of access, ensure that care is delivered in line with the normal pathway of care, and require the collection, analysis and dissemination of information.

Recommendation 23: Local Partnerships should identify and foster leaders across the range of NHS services and give them the opportunity to flourish.

Recommendation 24: A significant shift in the allocation of resources must take place, whereby there must be much greater investment by the NHS, and other agencies, in services for children and young people in their early years, concentrating on those most at risk of not having the opportunity to flourish. Such investment should be a very important consideration for all Local Partnerships as they set their priorities.

Recommendation 25: Local Partnerships should recognise the value of, and consider ways to promote, 'social capital', including involving families and the wider community in promoting health and well-being for children and young people.

Recommendation 26: The new Government, when considering changes to the performance management of the NHS, and in designing the mechanisms by which it should in future be held accountable, must ensure that the various organisations providing services at a local level are given incentives to work together, and that the performance management of individual public service organisations calls for and takes into account actions that produce positive outcomes for children and young people, the effect of which may be reflected as the achievements of other public services.

Recommendation 27: The Quality and Outcomes Framework should be reviewed so as to include a broad range of measures concerning the health, healthcare and welfare of children and young people.

Recommendation 28: Data sets must be agreed as a matter of urgency by the NHS and government covering the range of services provided to children and young people by the NHS and data must be collected, analysed and disseminated to those who need it within the Local Partnership. The data must allow services to be held accountable for the quality of the outcomes achieved.

Recommendation 29: There should be a single criterion for measuring the quality of the NHS's services for children and young people – satisfaction. There should be two elements to satisfaction: whether children and young people are satisfied with the outcome achieved, by reference to what they are able to judge; and whether the professional should be satisfied, by reference to the current appropriate benchmarks of performance. The internal performance management and external regulation of the NHS must reflect this approach.

Recommendation 30: When designing and implementing mechanisms to give effect to choice within the NHS, due regard must be given to the needs of children and young people, both to be supported in making choices and to receive continuity of care over time.

Recommendation 31: Local public services, led by the Local Partnership, must develop a common vision for all services for children and young people, so as to enable the services to work together.

Recommendation 32: Arrangements must be agreed, regarding funding and other matters, to address the changing needs of children and young people as they mature, including greater continuity of care into adulthood. Ensuring a smooth transition between children's and adults' services should be a priority for local commissioners.

Recommendation 33: NHS services for children and young people should be designed, organised and delivered from the perspective of the child, young person and parent or carer. Relevant NHS services should regularly assess the expectations and views of children and young people using the services, and should take action in the light of the findings, which should be made public.

Recommendation 34: All those involved in providing services for children and young people, including but not limited to NHS services, should receive training together according to a common curriculum, developed with the involvement of the Royal Colleges and other professional bodies, a principal purpose of which must be to enable professionals to understand each other's roles and work together.

Recommendation 35: There should be local networks through which services can share information electronically and protocols should be agreed by the networks to provide for this.

Recommendation 36: Government, employers and professional groups must address the need for more professionals trained in the range of skills required in the comprehensive care of children and young people as a matter of urgency.

Recommendation 37: There should be joint training of professionals involved in the care and welfare of children and young people, according to agreed curricula, particularly in the area of safeguarding.

Recommendation 38: Consideration should be given to the creation of an integrated workforce for children and young people, in which all those involved in health, healthcare and welfare in the local community are employed by the same organisation, preferably the Local Partnership.

Recommendation 39: There should be a cadre of professionals who are trained in both paediatrics and the care of young adults. Government, employers and professional groups should work together in order to ensure that such a cadre is established and receives appropriate training.

Annex A

Terms of reference: Review of NHS services for children

1. **Goal:** to identify the cultural obstacles that inhibit sustained improvement in frontline NHS services for children, and in particular NHS action to safeguard children; and to make recommendations to support sustained improvement for the medium and longer term in outcomes for children receiving services.
2. **Context:** improving children's health and wellbeing, including action to safeguard children, are identified as clear priorities for the NHS, and policies and guidance are in place. But successive HCC [Healthcare Commission] and CQC [Care Quality Commission] reports and other evidence indicate that good practice is not always embedded effectively. While the NHS responds positively to specific initiatives and reports, short term improvements tend not to be sustained. Child health is established as a priority through the NHS Operating Framework more firmly than ever before, and a comprehensive programme of action is being put in place in response to Lord Laming's recent report on child protection. So it is important to take the opportunity to secure the cultural change that will lead to lasting improvements in outcomes for children through improvements in practice and in the leadership of organisations.

The review will need to reflect the principles of change management in the NHS following the NHS Next Stage Review, and the focus on Quality, Innovation, Productivity and Prevention as key drivers as we enter tighter economic circumstances.

3. **The task** is to explore with staff and local leadership what are the cultural obstacles to improvement in outcomes to children, and how these can be addressed.
4. The scope covers:
 - dedicated children's services (including health visiting and other community services, paediatrics, CAMHS [child and adolescent mental health services]);
 - services dealing with children as part of their wider responsibilities, including primary care, A&E, ambulance and out of hours services; and some aspects of surgery; and
 - services working with adults whose condition may create pressures or risks for their families, including mental health, alcohol and substance misuse and domestic violence.

5. The review will need to explore with staff and local professional and organisational leaders the factors that inhibit change. This will need to be shaped by their views, but potential issues to explore include :
 - perceptions of health services' role in child health and wellbeing, and in safeguarding;
 - the challenges to professional practice and how these can be met;
 - challenges to leadership, especially given the disseminated responsibilities across the NHS on children's health and their healthcare and safeguarding and between departments of state/government departments;
 - the balance between personal professional responsibilities and wider team responsibilities across the NHS and LA [Local Authorities'] children's services for safeguarding;
 - wider social/cultural factors, for example concerning professional training and development, and the status of children and families.
6. The project should have a practical focus, and include workshops and discussions across SHA [strategic health authority] regions. A short report with recommendations for action should be submitted to David Nicholson by end March 2010.
7. **Wider engagement.** While the review is specific to the NHS, it will need to take account of the requirements for cross sector working on children and on safeguarding. At national level, the Government has recently put in place arrangements to strengthen cross sector co-ordination through creation of a cross-government National Safeguarding Delivery Unit, and the appointment of Sir Roger Singleton as National Adviser to Government on the Safety of Children. This project will be of interest to Sir Roger and the NSDU and appropriate involvement and sharing of insights will be agreed.

Annex B

Sites visited

Allens Croft Children's Centre, Birmingham: Meetings with clinical and managerial representatives from primary care trusts (PCTs) and NHS providers from across Birmingham, along with representatives from West Midlands Strategic Health Authority (SHA) and the Allens Croft Children's Centre. Visit organised by West Midlands SHA.

Brandon Centre, Camden: Discussion with centre management and commissioners from the PCT and the Local Authority about the centre's range of services and its approach to engaging with young people and approach to transition between children's and adult services.

Croydon Council/NHS Croydon: Discussions with Caroline Taylor (Chief Executive of NHS Croydon) and Dave Hill (Director of Children's Services, Croydon Council) about collaboration between the PCT and the council and the Croydon Total Place project.

Family Justice Centre, Croydon: Tour of the centre and discussions with centre managers and staff including health, social care and police professionals, and representatives from third sector organisations working in partnership with the centre. Visit organised by Croydon Council.

The Great North Children's Hospital, Newcastle: Tour of the hospital facilities and discussions with clinical and managerial staff about the trust's systems, procedures and facilities for safeguarding children. Visit organised by NHS North East.

London Borough of Hammersmith and Fulham/NHS Hammersmith and Fulham: Discussions with Geoff Alltimes (Chief Executive), Andrew Christie (Director of Children's Services) and Carole Bell (Programme Manager – children), about integrated governance of the Local Authority and the NHS, and its benefits for children and young people's services.

NHS Tower Hamlets Community Health Services: Discussions with the Tower Hamlets Family Nurse Partnership (FNP) team, and commissioners from Tower Hamlets PCT, about the FNP programme.

Peppermint Centre, Croydon: Discussions with staff and parents/carers using the centre, followed by a tour of the facilities including the GP surgery, IT suite and nursery.

Queen Alexandra Hospital, Portsmouth: Discussions with community children's nurses, specialist nurses, child and adolescent mental health services (CAMHS) clinical staff, divisional management for children's services and senior

management. Tour of the hospital including children's services and the paediatric emergency department.

Royal Manchester Children's Hospital: Discussions with managers and professional staff, and visits to a number of departments, particularly oncology and intensive care. Discussion of arrangements for safeguarding.

Sandwell General Hospital: Discussions with hospital and community-based staff about safeguarding, especially how acute, community and social care organisations work together and share information.

Sheffield Children's Hospital: Discussions with trust management, clinical staff responsible for and involved in safeguarding, the specialist CAMHS team, health visitors, school nurses and other community staff with clinical links to hospital services, PCT and Local Authority staff working with the hospital and parents/carers. Tour of hospital facilities including intensive care, high-dependency unit, the A&E department and the sexual assault referral centre.

St Nicholas Hospital, Newcastle/Northumberland, Tyne and Wear NHS Foundation Trust: Meeting with PCT and Local Authority commissioners and NHS providers of CAMHS. Tour of medium-secure ward for adolescents with mental health problems and learning disabilities, including discussion with managers, staff and service users.

St Stephen's School and Children's Centre, Newham: Discussion with centre leadership team and representatives from Newham Council and the PCT. Tour of the facilities including meetings with community midwifery staff based in the centre and with a group of parents/carers using the centre.

Swindon Borough Council: Presentation and discussion about the Swindon Life programme with Local Authority and PCT managers, and staff involved in organising and running the programme. Accompanied by Irene Lucas, Director General for Local Government and Regeneration, Communities and Local Government.

University College Hospital: Tour of children and young people's services wards, including specialist services, play therapy suite, and dedicated outpatients departments. Discussions with clinical and managerial staff.

Annex C

Review meetings

Professor Sir George Alberti, Taskforce on the Health Aspects of Violence Against Women and Children, Department of Health

Alliance for Access to Education

Professor Sir Al Aynsley-Green, former Children's Commissioner for England

Ed Balls, former Secretary of State for Children, Schools and Families

Francine Bates, former Special Adviser to Ed Balls

Dame Christine Beasley, Chief Nursing Officer, Department of Health

David Behan, Director General for Social Care, Local Government and Care Partnerships, Department of Health

Alan Bell, Team Leader – Vulnerable Children, Department of Health

Sir Michael Bichard, Institute for Government

Kate Billingham, Project Director, Family Nurse Partnerships, Department of Health

Professor Ann Buchanan, Director, Oxford Centre for Research into Parenting and Children, University of Oxford

Sir Ian Carruthers, Chief Executive, NHS South West

Dr Peter Carter, General Secretary and Chief Executive, Royal College of Nursing

Harry Cayton, Chair, National Information Governance Board for Health and Social Care

Department for Children, Schools and Families Joint Partners Group

Department for Children, Schools and Families Board of Stakeholders

Department of Health Senior Children's Nurses Stakeholder Group

Jackie Doughty, Deputy Regional Director for Children and Learners, Government Office for the North East

Sue Dunstall, Policy Adviser – health, NSPCC

Jim Easton, National Director for Improvement and Efficiency, Department of Health

Sir Paul Ennals, Chief Executive, National Children's Bureau

Professor Steve Field, Chair, Royal College of General Practitioners

Dr John Goddard, British Pain Society

Heather Gwynn, Director, Chief Nursing Officer Directorate, Department of Health

Cathy Hamlyn, Director, National Support Teams, Department of Health

Dr Lesley Hewson, Child and adolescent psychiatrist and Vice Chair, National Advisory Council for children's mental health and emotional well-being

Christine Humphrey, Safeguarding Adviser, Department of Health

Anne Jackson, Director of Child Well-being, Department for Children, Schools and Families

Tom Jeffrey, Director General for Children and Families, Department for Children, Schools and Families

Dr Anna Johnson, Consultant, Plymouth Hospitals NHS Trust

Professor Lord Richard Layard, Emeritus Professor, London School of Economics and Political Science

Christine Lenehan, Director, Council for Disabled Children

Irene Lucas, Director General for Local Government and Regeneration, Communities and Local Government

Professor Michael Marmot, Professor of Epidemiology and Public Health, University College London

Dr Janet McDonagh, Young People's Health Special Interest Group, Royal College of Paediatrics and Child Health

Dr Andy Mitchell, Medical Director, NHS London

Trish Morris-Thompson, Chef Nurse, NHS London

National Children's Bureau Children and Young People's Inter-Agency Group

National Children's Bureau National Participation Forum

National Conference on Safeguarding Children for Named and Designated Clinical Professionals

NHS Confederation (members representing children and young people's mental health services)

NHS Institute for Innovation and Improvement

NHS South West and local government partners

Sir David Nicholson, Chief Executive, NHS

Una O'Brien, Director General, Policy and Strategy, Department of Health

Sir Denis O'Connor, Her Majesty's Chief Inspector of Constabulary

Claire Philips, Taskforce on the Health Aspects of Violence Against Women and Children, Department of Health

Hilary Samson-Barry, Deputy Director, Children, Families and Maternity, Department of Health

Dr Sheila Shribman, National Clinical Director for Children, Young People and Maternity Services, Department of Health

Sir Roger Singleton, Chief Adviser on the Safety of Children, HM Government

Fiona Smith, Children's Nursing Adviser, Royal College of Nursing

Dr Terence Stephenson, President, Royal College of Paediatrics and Child Health

Diana Sutton, Head of Policy and Public Affairs, NSPCC

Sue Sylvester, National Children's Services Adviser for Health, Department for Children, Schools and Families

Peter Todd, Her Majesty's Inspectorate of Constabulary

Dr Gill Turner, Young People's Health Special Interest Group, Royal College of Paediatrics and Child Health

Caroline Twitchett, Senior Policy Lead – children and young people, Offender Health Division, Department of Health

Anne-Marie Walsh, Young Adviser to NHS Central Lancashire

Lesley Warrender, Her Majesty's Inspectorate of Constabulary

Jo Webber, Deputy Policy Director, NHS Confederation

Dame Jo Williams, Chair, National Advisory Council for children's mental health and emotional well-being

Rob Willoughby, former Children's Services Adviser, Department for Children, Schools and Families

Young Minds Very Important Kids (VIK) group (Lisa Baird, Hannah Bilverstone, Kat Cormack, Simone Dewis, Rhiannon Godden, Celeste Ingrams, Gary Watts)

Annex D

Written submissions

David Abbott, Bristol University

Dr Liz Adamson

Pel Ahmet

Julie Alexander

Michelle Avon

Katie Barnes, Liverpool John Moores University

Rachel Bartlett, NHS London

Allen Bewley

Dr Cliona Ni Bhrolchain

Bliss

Jakki Blueitt

Anne Bowers

British Association for Community Child Health

British Medical Association

British Youth Council

Care Quality Commission

Central Lancashire Primary Care Trust

Children's Hospices UK

Children's Surgical Forum

Chronic Pain Policy Coalition

CLIC Sargent

Janet Cobb

Nancy Cohn

Lesley Coles, Portsmouth Hospitals NHS Trust

Commission for Rural Communities

Commissioning Support for London

Contact a Family

Dr Felicity Cooper

Council for Disabled Children

Croydon Council

Dr Mary Cunliffe

Sophie Daws

Machita Denny

Diabetes UK

Jackie Doughty, Government Office for the North East

Dr Peter Ehrhardt

Susan Fairclough

Family Planning Association

Margretta Finnegan

Foundation for People with Learning Disabilities

Elizabeth Fradd

Diane Fuller, Sheffield Children's Hospital

Dr Mandy Gamsu

Dr John Goddard, British Pain Society

Government Office for Yorkshire and The Humber

Alyson Grayson

Linda Griffiths

Jean Gross, Government Communication Champion

Karon Hollis

Interface (forum for parents and carers of children with ADHD)

Dr Anna Johnson

Gary Jones

Steve Jones, Clinical Psychologist, Sheffield Children's Hospital

Dr Raphael Kelvin, Professional Adviser, Department of Health

Jo-Anne Keys, Autism Anglia

Dr Sebastian Kraemer

Professor Lord Richard Layard

Young people from the London Borough of Barking and Dagenham

Dr Elaine Lunts

Liz McArthur

Kerry Ann McKenna

Mrs D Molesworth

Tussie Myerson

Reverend Paul Nash, Birmingham Children's Hospital

National Children's Bureau

Newham Primary Care Trust

NHS Confederation

NHS Institute for Innovation and Improvement

NHS North West

NHS Sickle Cell and Thalassaemia Screening Programme

NHS South West

NHS West Midlands

Lauraine Nicholson, Peppermint Centre, Croydon

North Bristol NHS Trust

North West Play Network

NSPCC

Jackie Orr

Dr Gina Palumbo

Queen's Nursing Institute

Paul Rawson

Regional directors of public health

Royal College of Nursing

Royal College of Paediatrics and Child Health

Royal College of Paediatrics and Child Health, Young People's Health Special Interest Group

Royal College of Speech and Language Therapists

Nicholas Royle

Molly Sage

Dr Geoff Sharp

South Birmingham PCT

Professor Stephen Singleton

Sue (mother of disabled child)

Sue Sylvester, Government Office for the North East

Kate Thompson

Dr Mike Tomson

Tower Hamlets Family Nurse Partnership Team

Tracee (mother of disabled child)

Nicy Turney

UK Public Health Association

University College Hospital

Helena Vernon-Jackson

Helen Wheatley

Angela White

David Widdas

Dr Jeannette Wilkes

Rob Willoughby

Young Equals

