PALLIATIVE CARE SERVICES FOR CHILDREN AND YOUNG PEOPLE IN ENGLAND

An independent review for the Secretary of State for Health by Professor Sir Alan Craft and Sue Killen
## CONTENTS

**Foreword**  
2

**Executive summary and summary of recommendations**  
3
- Introduction  
3
- The review  
3
- What did we find?  
3
- What do we recommend as a way forward?  
6

1. **Introduction**  
11
- Purpose of the review  
11
- Approach to undertaking the review  
11

2. **Setting the scene**  
15
- What is children’s palliative care?  
15
- The development of children’s palliative care services  
15
- Palliative care services  
16
- Policy context  
16

3. **Findings**  
21
- Numbers and expected trends  
21
- Services and accessibility  
25
- Funding and sustainability  
30
- Effective and efficient service provision  
36

4. **Important elements of a good service**  
41
- What would this mean to the children and their families?  
43

5. **Making a difference – the changes we would like to see happen**  
45
- Improved planning and commissioning  
45
- Improved data collection and needs assessments  
47
- Improved consistency in service provision  
47
- Improved resources and more effective use of existing spend  
48
- Improved use of levers  
49
- Regulation and audit  
50
- Other improvements  
51

**Annexes**

A ACT Care Pathway  
52
B Organisations which hosted visits and meetings  
55
C Individuals and organisations providing assistance to this review  
56
D Consultation respondents  
58
E Bibliography  
61
We are pleased to present this independent report on palliative care services for children and young people in England, which was produced at the request of the Secretary of State for Health.

Our findings are based on wide consultation with stakeholders, including children and young people and their families, commissioners and providers of services. We found a mixed picture, with examples of excellent provision in spite of the constraints of insecure funding, but we also saw evidence of inadequate provision and real need. As with many such reviews, if the best current practice could be universal many of the problems would be solved.

We were concerned at the lack of information that many Primary Care Trusts (PCTs) and commissioners were able to provide and it is not surprising that services are poor in some parts of the country when needs are neither assessed nor effectively recognised. Families told us that they faced a constant struggle to get the best for their child and support for the rest of the family.

A constant theme was the lack of connection between the different statutory sectors. From a national to a local level there was only limited evidence of health, social services and education working together. Voluntary sector providers play a key role in delivery but are too often left out of the planning and commissioning process.

Our stakeholder reference group was of great help in keeping us focused on the task in hand and we could not have produced this report without the help of all the families and professionals who freely gave of their time and effort, in spite of the enormous pressures on them. We would in particular like to thank Ivan Lewis MP, the Parliamentary Under Secretary of State for Care Services, and Hilary Samson-Barry and Rob Dickman at the Department of Health for their help and support.

We do hope that this report will be a catalyst for a step change in access to services and to their sustainability. We were enormously impressed with the commitment of all those involved in delivering services. It would take a relatively small amount of additional resources and improved planning and commissioning to turn this commitment into excellent services for an extremely vulnerable and deserving group of children and young people.

Professor Sir Alan Craft  
Sue Killen
EXECUTIVE SUMMARY AND SUMMARY OF RECOMMENDATIONS

Introduction

Children’s palliative care is concerned with symptom control and maintaining quality of life, not just in the dying stages, but in the weeks, months and years before a child’s death. Although it has been developed to support children and young people who are diagnosed with life-limiting or life-threatening conditions, there are strong overlaps between these children and those with disabilities. Children typically move into and out of different services depending on the progress of their condition. Palliative care needs therefore to form a thread through the lives of many children with severe disabilities and complex needs.

Services for children and young people with palliative care needs have developed over the last twenty-five years in a largely unplanned way. Funding for the sector has also been ad hoc and often short-term. Children’s hospices rely heavily on voluntary giving whilst other services rely on a combination of statutory funding and short-term grants.

The biggest single impetus to service development were grants provided by the Big Lottery Fund (BLF), which started in 2003 for periods of up to three years. These grants supported the development of both hospice services and specialist palliative care community nursing teams.

In May 2006, concern about what would happen to hospice services once the BLF grants finished led to the Secretary of State for Health pledging £27m over a three-year period to support children’s hospices, and the commissioning of this independent review of children’s and young people’s palliative care services in England. One of the main aims of the review, therefore, has been to find a more sustainable way of developing and funding services as well as looking at the availability and accessibility of these services.

The review

Between November 2006 and January 2007 we consulted widely, bringing together views and ideas from those involved in planning, commissioning, providing and using services. In addition, we commissioned Department of Health (DH) analysts to review prevalence and mortality data and the York Health Economics Consortium to look at funding flows, sustainability and the benefits of providing children with a planned care pathway.

What did we find?

In general

There is an enormous overlap between children with disabilities and complex health needs and those requiring palliative care. Services for these groups of children need to be planned together. HM Treasury (HMT) and the Department for Education and Skills (DfES) have been undertaking a review of services for children and young people, including those with a disability. Recommendations from their report will also benefit children with palliative care needs.

We found a lack of understanding of what children’s palliative care involved, most assuming it was just about end of life care. This lack of understanding and lack of recognition of children’s palliative care as a specialism have added to its Cinderella status.

There was also a lack of clarity about who was responsible for leading the planning and development of services at national, regional and local level. Meeting children’s needs requires health, education and social services to work together. Although progress has been made in joint working in children’s services as a whole, we found little evidence of this in the planning, commissioning and delivery of palliative care.

* When we refer to children and young people in this review this includes every child and young person aged 19 years and under except for neonates, i.e. babies in the first 28 days of life
Overall, we found hard-pressed parents who were exhausted, but utterly committed to caring for their children. They are willing to shoulder the burden of care provided they are supported; without that support, family stresses inevitably lead to costs being picked up by the State. We found a committed workforce who spent too much of their time battling the system, and worrying about the long-term funding of the services they were providing rather than being able to concentrate on the job they were trained to do.

Numbers and expected trends

We found a poor information base with no nationally-agreed figures on prevalence and little evidence of good needs assessments at either regional or local level. Services are generally commissioned at PCT level, but our evidence indicates that numbers requiring services at PCT level are generally too low to support sustainable services.

We also found little evidence of trend data being used in the planning of services. Advances in medical care mean that children and young people with conditions requiring palliative care are living for longer. We heard of young adults arriving at hospitals with conditions only paediatricians were trained to deal with. Concern about the lack of transition services to manage the transfer to adult services, which themselves are poorly developed, was raised at almost every meeting and discussion group we attended.

The regional Paediatric Palliative Care Networks,² which were launched by the DH in 2006, have excellent potential for bringing all the key players together, including the voluntary sector, but their development has been patchy and there is a danger that they will founder without greater support.

Services and accessibility

There is huge variation in the availability of services across England. We found examples of excellent practice but there was too little sharing of good practice and no apparent system for holding commissioners to account for the quality of services delivered to these families. There were many areas where services were inadequate; there was little strategic planning, or evidence of using commissioning to develop a sustainable service.

Families and the children and young people themselves were often subjected to multiple assessments, and then often received no resulting service. Families felt they had to fight for the services they did receive and too often found themselves falling into the gap between health services and social care.

We found strong support for children having access to the full range of services on the pathway of care developed by the Association for Children’s Palliative Care (ACT).³ In particular, families wanted more community services able to offer help and advice 24 hours a day, 7 days a week, including end of life care. Very few teams were able to offer this, resulting in families having to make unplanned (and expensive) use of A&E and inpatient hospital care. End of life is a particularly difficult time for families. Most families would like their child to be supported in dying at home. However, currently three-quarters of them die in hospital.

The voluntary sector is providing vital support to families both in hospices and in home-based community support, but is often not effectively engaged in the planning and commissioning process.

² The aim of regional Paediatric Palliative Care Networks is to support the effective planning and delivery of a full range of palliative care services on a regional basis, thereby ensuring that those who need these services have access to them

³ ACT is a UK-registered charity for children and young people with life-threatening or life-limiting conditions and their families
Funding and sustainability

There are large variations in funding across England, and overall funding is not sufficient to provide the range of services on the ACT Care Pathway. Money is also not being spent as effectively as it should be. Our economic analysis shows that investment in the kind of community-based services families are asking for has the potential to pay for itself through savings in hospital services.

Statutory funding from the NHS and Local Authority Children’s Services (LACS) is the most sustainable funding, but too many key services are reliant on short-term grants or voluntary provision.

Effective and efficient service provision

The funding that is available for children’s palliative care should be focused on the most cost-effective services. As well as being much better for children and their families, we found that supporting children in the community is far more cost-effective than waiting until a family reaches crisis point or a child reaches a medical crisis, resulting in inappropriate and costly time in hospital.

The most sustainable and cost-effective teams are those which are planned and commissioned across total populations of at least 1 million, are capable of providing a range of services, including end of life care and bereavement support, and can provide support and advice 24 hours a day, 7 days a week. Key workers are essential to co-ordinate services and maintain the strong personal contact that families value.

We found a hugely committed workforce but lack of recognition of palliative care as a specialism, and concern about the funding of posts made it difficult to build a sustainable workforce.
Important elements of a good service

Those we spoke to were in favour of the development of a range of accessible services, including: specialist paediatric care; core palliative care services, including community nursing teams, hospices and specialist respite care; and more access to universal children’s services.

These services need to be co-ordinated by key workers and the core community teams.

What do we recommend as a way forward?

Transforming services requires changes in every aspect of delivery. Planning and commissioning needs improving at every level. We therefore recommend that:

- the DH should take the lead, working with stakeholders, including other Government departments, to develop a national strategy for children’s palliative care, to raise its status, improve understanding and provide a framework within which services can be planned and delivered in a joined-up way
- the DH and the DfES should work together with Strategic Health Authorities (SHAs) and the Government Offices for the Regions (GOs) to clarify who has lead accountability at each level – nationally, regionally and locally – for planning and delivery of services

- SHAs and GOs should take the lead in planning services at regional level, ensuring there is an established, functioning and effective Paediatric Palliative Care Network and that PCTs and Local Authorities (LAs) form sub-regional groups covering the right population size and geography for effective commissioning of sustainable services. Commissioning some elements of the specialist provision will involve Specialised Commissioning Groups
- the voluntary sector providers should be seen as key partners at every level of planning and delivery. Given their vital role in developing palliative care, the two main bodies representing the voluntary sector, ACT and the Association of Children’s Hospices (ACH) should consider the scope for providing an even stronger national voice for children and young people with palliative care needs

Urgent improvements are needed in data collection and needs assessments if services are to be commissioned effectively and resources allocated equitably and effectively. We therefore recommend that:

- the DH should take the lead in ensuring that national data on prevalence and trends is collected and collated
- the DH and the DfES, involving ACT and ACH, should expand the work currently under way on the National Child Health Mapping exercise to urgently develop a simple framework for improving regional and local needs assessments for children’s palliative care

---

1 PCTs and LAs should form “sub-regional” groups or clusters and work together to plan and develop service provision across total populations of around 1 million but taking account of local geography, with one PCT taking the lead in commissioning those services which need to operate across more than one PCT/LA area

2 The National Child Health Mapping Exercise aims to create an inventory of all dedicated child health services provided in England and the investment in them
There needs to be greater consistency across the country in the services children have access to and a single assessment process for children with palliative care needs with services to follow. We recommend that:

- children and young people with palliative care needs and their families should have access to the full range of services on the ACT Care Pathway after an appropriate professional needs assessment

- commissioners should ensure an increased focus on community services to help manage and support children with palliative care needs to stay at home. Every sub-region needs to ensure it develops community teams capable of providing support and advice, including end of life care, 24 hours a day, 7 days a week

- the Government needs to give the same priority to end of life care for children and young people as for adults, at every level of planning and service provision

- the DfES and the DH should consider whether children’s palliative care should form a special pilot, looking at how the Common Assessment Framework (CAF) can be further developed to meet the needs of this particular group of children, or whether some other approach is needed to ensure an effective single multi-agency assessment by health and social care

- based on the ACT Transition Pathway, there should be a greater focus on services for managing the transition to adult services, linked to a better understanding of trends in life expectancy for those requiring palliative care

- children and young people with palliative care needs should have access to the same range of general services as other children, including universal services

More resources are needed for children’s palliative care, both to develop services and to strengthen the planning and commissioning system. However, this money needs to be targeted at the right services and much can also be achieved by more effective use of the existing spend. We recommend that:

- increased spend on palliative care should be linked to sustainable statutory funding being targeted at the most cost-effective services. Top of the list for funding should be community-based teams offering support and advice 24 hours a day, 7 days a week

- most services should be delivered jointly by health and social care. Increased funding should therefore be linked to evidence of joint planning involving the National Health Service (NHS) and LACS

- the DH and the DfES should work with ACT, ACH and commissioners to develop model contracts and best practice guidelines for dealing with the voluntary sector

---

6 The Common Assessment Framework is a shared assessment tool for use across all children’s services, which aims to help early identification of need and promote co-ordinated service provision

7 The ACT Transition Care Pathway provides a clear framework for young people, families and professionals to help them plan for and move on from children’s palliative care services to adult services
• the DH should also facilitate the development of training courses and best practice information sharing for commissioners on palliative care services, and for the voluntary sector on how to deal with commissioners. (It may be possible to link this with initiatives under way at the Office of the Third Sector)

There needs to be an improved use of levers, including regulation and audit to support a greater focus on palliative care and to ensure that money that should be spent on children’s palliative care services is not allocated elsewhere. We recommend that:

• a national indicator should be established for services for disabled children, including those with palliative care needs, should be included in Children and Young People’s Plans (CYPPs), and that continuing care criteria are strengthened for children to ensure that they match those for adults

• there should be greater sharing of best practice, including the development of benchmarks and standards for services, which can be used by regulators, as well as those commissioning services. We recommend that ACT and ACH (working with the DH) take this forward, building on the work in this review, including work by the York Health Economics Consortium. ACT and ACH will need some support with resources

---

8 All areas should produce a single, strategic, overarching plan for all local services for children and young people. The plan is designed to support more integrated and effective services to improve outcomes for children and young people
• given that ring-fencing of funds is no longer acceptable, the NHS needs to consider what other approaches may be needed in addition to the above to ensure a reasonable level of spend on palliative care. Mechanisms need to be found to ensure that any new money is targeted appropriately

• there is a thematic review of children’s palliative care by relevant regulators (currently the Healthcare Commission, the Commission for Social Care Inspection (CSCI) and Ofsted) and the Audit Commission in two years’ time to judge progress in developing services

To support the development of services, there also needs to be greater recognition of palliative care as a specialism along with an appropriate workforce strategy. This is to ensure children have access to appropriate specialist services but also better access to general services. We recommend that:

• there is a formal recognition by the Royal College of Paediatrics and Child Health (RCPCH) and the Postgraduate Medical Education and Training Board (PMETB) of children’s palliative care as a sub-specialty of paediatrics

• the RCPCH and Royal College of General Practitioners (RCGP) should ensure that basic competencies in children’s palliative care services are part of generic training for all paediatricians and GPs

• the Royal College of Nursing (RCN) should lead work on developing a career pathway for nurses specialising in palliative care for children and young people

• the DH should lead the development of a workforce strategy, including the development of training in palliative care for those working with children and young people
“Sometimes, being the very, very best parent does not mean fighting to cure, but fighting to do the best you can for your child’s quality of life.”
INTRODUCTION

Purpose of the review

1.1 The Secretary of State for Health requested an independent review of services for children and young people in England who have life-limiting conditions and require palliative care. In the research for and the writing of this review we were asked to focus, in particular, on the availability, accessibility and long-term sustainability of these services.

1.2 Services for children and young people with palliative care needs, including children’s hospices, family support services, home-based community services and specialist medical and nursing teams, have developed over the last twenty-five years in a largely ad hoc and unplanned way.

1.3 Funding for this sector has also been ad hoc and often short-term. For example, hospices are mainly funded by voluntary fundraising whilst other services have relied on a combination of statutory funding and short-term grants. Funding is explained in more detail in section 3.

1.4 Short-term grants were provided by the BLF from 2003 and were available for periods of up to three years. These grants supported the development of both hospice services and specialist palliative care community nursing teams (known as “BLF teams”). However, these grants were only available for a limited amount of time.

1.5 Concern about what would happen to hospice services once these BLF grants finished resulted in the Secretary of State for Health pledging £27m over a further three-year period to support children’s hospices, as well as the commissioning of this independent review.

1.6 This independent review takes place within the wider context of the Government’s Comprehensive Spending Review (CSR) for 2007. The CSR is being informed by a series of cross-government policy reviews. One of these is a wider review of children and young people – including, as an important subset, disabled children – and is being taken forward jointly by HM Treasury (HMT) and the Department for Education and Skills (DES). We have worked with these departments to achieve a common understanding of the issues.

Approach to undertaking the review

1.7 Our main information gathering took place between November 2006 and January 2007. We consulted widely, bringing together views and ideas from a wide range of people involved in planning, commissioning, providing and using services.

1.8 The review included the following elements:

- a reference group
- consultation letter and events
- visits and meetings
- commissioned research

Reference group

1.9 This included a cross-section of stakeholders who provided valuable oversight of our work and help with shaping the review and testing out our conclusions. Membership of the group is highlighted in Annex C. We are very grateful to them for their help and support.

Consultation letter and events

1.10 Our consultation letter went to over 200 stakeholders and we received around 150 responses. We asked people to tell us their experiences of how things were currently working, and the changes they would like to see.9
1.11 We discussed the findings from the written consultation at a series of separate events with nurses, service providers, clinicians and commissioners. Again, we asked them to tell us their experiences of the current system and the changes they wanted to see. In particular, we asked them to tell us what they saw as the ideal range of services, what changes needed to happen to ensure that children and young people and their families had access to this range of services in future, and what the barriers to change were.

Visits and meetings

1.12 A full list of organisations which hosted visits and meetings is available at Annex B. We spoke to as wide a range of people as possible. This included a number of visits to different regions of England where we were able to see varying levels of service provision and degrees of engagement between commissioners and providers and between hospital-based and community services. We were also able to talk to parents, and to children and young people themselves, and to see examples of excellent service provision from both the voluntary and statutory sector.

Commissioned research

1.13 Given that one of the main issues we were asked to look at was sustainability, we commissioned the York Health Economics Consortium (the consultancy and research arm of the University of York) to take an independent look at funding flows and sustainability.
We also asked them to test our hypothesis that delivering a good care pathway for children, with early intervention and support within the community, was the most cost-effective approach as well as the one that delivered the best outcome for families.

1.14 To support the York work, and provide us with the best possible estimate of the numbers of children in England with palliative care needs, we also commissioned Department of Health (DH) analysts to review available data on children with palliative care needs, including an assessment of mortality and hospital admission data.

1.15 The York report and the report by DH analysts are published in parallel with this report.

1.16 We found a strong level of agreement amongst those we consulted on the problems with the current system and the changes needed. We are therefore confident our recommendations are soundly based.

---

1 Reports by the York Health Economics Consortium can be accessed via www.york.ac.uk/inst/yhec/projects.shtml#nhs_consulting
2 Reports by DH analysts can be accessed via www.dh.gov.uk/en/publicationsandstatistics/statistics/statisticalworkareas/statisticalhealthcare/index.htm
“The goal is to add life to the child’s years, not simply years to the child’s life.”
What is children’s palliative care?

2.1 Children’s palliative care is concerned with the treatment of children with life-limiting or life-threatening conditions. It is the need to maintain quality of life, not just in the dying stages, but also in the weeks, months and years before death and is characterised by concern for symptom relief, promotion of general well-being, and psychological and social comfort for the child and family.

Children’s palliative care

Palliative care for children and young people with life-limiting conditions is an active and total approach to care, embracing physical, emotional, social and spiritual elements. It focuses on enhancement of quality of life for the child and support for the family and includes the management of distressing symptoms, provision of respite and care through death and bereavement.

Life-limiting conditions

Life-limiting conditions are those for which there is no reasonable hope of cure and from which children or young people will die. Some of these conditions cause progressive deterioration, rendering the child increasingly dependent on parents and carers.

Life-threatening conditions

Life-threatening conditions are those for which curative treatment may be feasible but can fail, such as cancer. Children in long-term remission or following successful curative treatment are not included.


2.2 The range of illnesses and symptoms, many of which are rare, make it hard to define and predict care needs and it is clear that a strong overlap exists between the needs of children and young people requiring palliative care and those with disabilities and other complex care needs. However, whereas disability is generally a constant state, meaning that services may be planned and managed more effectively around the individual, the needs of children requiring palliative care are in many cases such that they dip in and out of services according to their condition at the time. It is helpful to think of palliative care as a strand running through the lives of many children and young people with complex needs and disabilities.

2.3 Children and young people with palliative care needs and their families also require more specialised services such as end of life care and bereavement services. Caring for a child with a life-limiting or life-threatening condition impacts on the family as a whole, creating enormous strains on parents, siblings and wider family members. Services therefore need to provide support to the whole family.

The development of children’s palliative care services

2.4 Children’s palliative care is a relatively recent development and is not yet widely recognised as a specialism in its own right. Adult palliative care and the provision of adult hospices, particularly for those with cancer, developed in the 1960s, though it was not until the 1980s that the need for specialist palliative care services for children was recognised. The growth of children-specific palliative care services soon followed, and included the development of teams of outreach nurses from paediatric oncology units, the appointment of the first consultant in paediatric palliative care at Great Ormond Street Hospital, London and the opening of the first children’s hospice in the
world at Helen House in Oxford. The voluntary sector, and the children’s hospice movement in particular, have been leaders in the development of services and have remained a vital partner in service delivery and innovation ever since.

Palliative care services

2.5 Children’s palliative care is provided through statutory services such as health, social services and education and voluntary services such as hospices and other charitable organisations. A wide range of palliative care services exist which children and their families may need to access at different stages depending on the child’s clinical condition.

2.6 The ACT Care Pathway (detailed in Annex A) proposes an approach which links children and young people with palliative care needs and their families with community services, hospital-based services, social services, education and the voluntary sector in one joined-up planning process to ensure continuity of care and promote partnership working.

2.7 Although access to services will depend on local availability and funding, all children will have a general practitioner and usually a paediatrician at a local hospital. Figure 1 on page 17 outlines the main providers of palliative care services and the key role and services that each provides.

2.8 Co-ordinating the numerous services that a child and their family may require is an increasingly difficult and complex task for those involved in front-line delivery of care. There may also be overlap between the services some of the teams provide. An overview of our findings of the reality of service provision, equality of access and the experience of staff, children and young people who have palliative care needs together with their families, is outlined in section 3.

Policy context

2.9 Children’s palliative care services are delivered within an overall policy framework set by the Government. Responsibility for delivery is devolved largely to the local NHS and Local Authorities (LAs) and requires effective collaboration between government departments and local organisations to develop and provide equitable, high-quality and effective palliative care services for children, young people and their families.

2.10 The key policy initiative which addresses children’s palliative care issues is the National Service Framework (NSF) for children, young people and maternity services. This policy sets out the direction for the future of children and young people’s services and highlights developmental standards which are to be delivered by 2014. NSF Standard 8 is the most relevant for children’s palliative care and sets out an expectation that:

Children and young people who are disabled or who have complex health needs receive co-ordinated, high-quality child- and family-centred services which are based on assessed needs, which promote social inclusion and, where possible, enable them and their families to live ordinary lives. Palliative care is available to those who need it and a range of flexible, sensitive services is available to support families in the event of the death of a child.

2.11 The DH supported this with the publication of a practical guide for PCTs and practice-based commissioners, Commissioning children’s and young people’s palliative care services, and through support for the development of Paediatric Palliative Care Networks.

---

3 Department of Health and Department for Education and Skills, October 2004
4 Department of Health, November 2005
Figure 1: Children’s palliative care service providers and key services provided
2.12 The NSF standards are at the heart of the Government’s *Every Child Matters* agenda, which sets out the principles of co-operation and integration between services and sectors as key to delivering improved outcomes for all children and young people. The agenda is underpinned by the Children Act, which sets out duties of co-operation and joint inspection arrangements, and introduces the concept of children’s trust arrangements, through which local partners can come together to plan and commission services. There are also a number of tools which have been rolled out or are in development which support integrated working and are relevant to the recommendations in this report. This includes the Common Assessment Framework (CAF) and Children and Young People’s Plans (CYPP).

- The CAF is a shared assessment tool for use across all children’s services, which aims to help early identification of need and co-ordinated service provision. All LA areas are expected to implement the CAF before the end of 2008.
- CYPPs are single, strategic overarching plans for all local services for children and young people. They form the basis of the children’s trust approach to service delivery and should be designed in partnership with health and other local partners.
2.13 The DH’s commitment to this approach was reiterated through its White Paper *Our health, our care, our say*. The White Paper sets a requirement for PCTs to ensure that the right model of services is developed for children with disability/complex health needs. PCTs are expected to audit capacity and delivery of integrated care pathways against the NSF standards, and agree service models, funding and commissioning arrangements with their SHA.

2.14 Recent policy developments therefore have the potential to be supportive of the needs of children and young people requiring palliative care. The aim of this review, however, was to find out what the impact had been so far on service delivery.

**Key messages**

- Children’s palliative care is concerned with the treatment of children with life-limiting or life-threatening conditions by maintaining quality of life, not just in the dying stages, but also in the weeks, months and years before death.
- There is a wide range of services potentially available to children and young people with palliative care needs and their families. This is complex to manage. Whether these services are actually available depends on local availability and funding.
- There are a number of policy areas and wider initiatives which, when implemented, will help to strengthen children’s palliative care services as well as developing children’s services as a whole. However, NSF Standard 8 is not due to be fully implemented until 2014.
“The only reason I survive Friday to Monday is having the doctor’s mobile number.”

Parent
3. FINDINGS | PALLIATIVE CARE SERVICES FOR CHILDREN AND YOUNG PEOPLE IN ENGLAND

FINDINGS

3.1 This chapter sets out the main findings from the research carried out for this review of palliative care services for children and young people in England.

3.2 Ensuring that children and young people with palliative care needs and their families receive the services they need and deserve requires those responsible for planning and commissioning to be aware of the following:

- **Numbers and expected trends**: how many children and young people there are with palliative care needs, where are they located, and what the likely future trends are

- **Services and accessibility**: current availability and accessibility of palliative care services and where gaps exist

- **Funding and sustainability**: current levels of funding and how sustainable this funding is

- **Effective and efficient service provision**: which services deliver both the best outcomes for children and their families and represent the best value for money

This chapter examines each of these points in detail.

**Numbers and expected trends**

**Numbers**

3.3 Obtaining reliable figures on the numbers of children and young people with palliative care needs has proved difficult. Core estimates on prevalence had been developed by ACT, and these were based on a number of key pieces of local research that had taken place over the last fifteen years. DH analysts had also produced some figures in advance of the launch of the regional Paediatric Palliative Care Networks in 2006. However, there was no universally agreed figure. We therefore commissioned DH analysts to review the available data on children with palliative care needs.

3.4 There is a strong overlap between services required by children and young people with a disability and those with palliative care needs. Although all children and young people requiring palliative care services do not have a physical disability they do fall within the wider legal definition of children with a disability.\(^5\)

3.5 Our estimates indicate that there are around 20,000 children and young people in England living with conditions likely to require palliative care. This is based on a prevalence rate of 6 per 10,000 if neonatal\(^6\) conditions are included and 5 per 10,000 if they are excluded.

3.6 For the purpose of this review we decided to concentrate our analysis on palliative care services for non-neonates. This is because most neonates who die as a result of conditions which require palliative care services are born, treated and subsequently die without leaving hospital so there is less demand for palliative care services in the community.

3.7 It is clear from the information above that the overall numbers of children and young people suffering from conditions requiring palliative care are small. The volumes break down to even smaller numbers at a local – particularly PCT – level, as is shown in Figure 2 on page 22.

---

\(^5\) Further information on the definition of disability can be found in Department for Work and Pensions (2006) *Disability Discrimination Act: Guidance on matters to be taken into account in determining questions relating to the definition of disability*. London. TSO

\(^6\) The term ‘neonates’ refers to babies within the first 28 days of life
“Young people should not be transferred fully to adult services until they have the necessary skills to function in an adult service and have finished growth and puberty.” Royal College of Paediatrics and Child Health (RCPCH)

3.8 The large variation in numbers of children and young people with palliative care needs, and in the numbers dying both at SHA and PCT level, emphasises the importance of carrying out local needs assessments. The small numbers of children and young people with palliative care needs at PCT level mean services need to be configured across a wider geographical area if they are to support the range of services needed and be sustainable. This is true particularly when planning services for end of life, given the low numbers and large variation.

Expected trends

3.9 There are strong indications that, due to advances in medical care, children are living longer and subsequently requiring more palliative care services. Evidence suggests that many of them can maintain a good quality of life if they and their families have access to and are properly managed using appropriate services. However, these children do require increasingly complex levels of support.

3.10 The example of Duchenne Muscular Dystrophy (DMD) below is replicated across other chronic diseases, meaning that it is no longer appropriate to look on some life-limiting conditions as inevitably fatal in childhood, since the majority of children may now be expected to reach adulthood. This profound change in life expectancy has implications for all areas of management, from the time of diagnosis onwards and also for services to support the individual.

Planning for transition to adult care

3.11 Clearly, if more children and young people with palliative care needs are living longer and surviving into adulthood this will affect the services and infrastructure required. In turn, this poses significant challenges to those commissioning services in taking account of these changing trends.

3.12 Current approaches are rarely ideal. The most likely options are the abrupt transfer to adult services or staying in the paediatric setting longer than is appropriate. Effective transition to adult care must allow for the fact that adolescents undergo changes far broader than just their clinical needs.

3.13 To support this difficult and complex process, ACT has developed a new resource to guide and support young people, families and professionals through the transition to adult services. This is based around an early collaboration between paediatric and adult services to improve transition and help services to better support young people in this critical adjustment to their lives. However, there is a real problem with the availability of appropriate adult services.
3.14 Our research indicates that from 2002–2005, 74% of those aged 19 and under suffering from conditions likely to have required palliative care (excluding neonates) died in hospital, while 19% died at home, and 4% died in a hospice. Figure 3 on page 24 summarises these findings.

3.15 Despite the fact that the majority of children and young people with palliative care needs currently die in hospital, most families would prefer death to take place at home. For many parents, the home provides the security and comfort of a familiar environment, free from the disruption of hospital routines. Children generally prefer to be at home among their own toys, pets, family members and friends. At home, privacy and normality is enhanced, siblings can be included, and parents feel more in control.
“One of the things we know is that from the moment we set the [Great Ormond Street Community Nursing] team up and were able to offer people much more support at home, the number of families who chose for their child to die at home increased from about 30% to 70 or 80%. This occurred even though our goal was not to encourage people to care for their dying child at home, but rather to improve palliative care wherever the family wanted that to be. But ‘wherever’ turned out to be at home, if you offered the right service. So, I suppose that is a very clear measure of providing something that didn’t exist before.” Palliative care specialist and paediatric oncologist

Figure 3: Place of death for children and young people aged 0–19 (excluding neonates) likely to have required palliative care, by SHA (2002–2005)

<table>
<thead>
<tr>
<th>SHA of usual residence</th>
<th>Home</th>
<th>Hospice</th>
<th>Hospital</th>
<th>Other$^{37}$</th>
</tr>
</thead>
<tbody>
<tr>
<td>East Midlands</td>
<td>128</td>
<td>20</td>
<td>424</td>
<td>8 (1%)</td>
</tr>
<tr>
<td>East of England</td>
<td>161</td>
<td>58</td>
<td>487</td>
<td>15 (2%)</td>
</tr>
<tr>
<td>London</td>
<td>174</td>
<td>21</td>
<td>988</td>
<td>19 (2%)</td>
</tr>
<tr>
<td>North East</td>
<td>69</td>
<td>4</td>
<td>229</td>
<td>6 (2%)</td>
</tr>
<tr>
<td>North West</td>
<td>197</td>
<td>64</td>
<td>734</td>
<td>20 (2%)</td>
</tr>
<tr>
<td>South Central</td>
<td>122</td>
<td>24</td>
<td>331</td>
<td>6 (1%)</td>
</tr>
<tr>
<td>South Coastal</td>
<td>108</td>
<td>19</td>
<td>361</td>
<td>22 (4%)</td>
</tr>
<tr>
<td>South West</td>
<td>121</td>
<td>21</td>
<td>380</td>
<td>11 (2%)</td>
</tr>
<tr>
<td>West Midlands</td>
<td>125</td>
<td>35</td>
<td>574</td>
<td>21 (3%)</td>
</tr>
<tr>
<td>Yorks and Humber</td>
<td>167</td>
<td>49</td>
<td>568</td>
<td>36 (4%)</td>
</tr>
<tr>
<td><strong>All SHAs$^{38}$</strong></td>
<td><strong>1,372</strong></td>
<td><strong>315</strong></td>
<td><strong>5,076</strong></td>
<td><strong>164 (2%)</strong></td>
</tr>
<tr>
<td><strong>England total$^{39}$</strong></td>
<td><strong>1,449</strong></td>
<td><strong>331</strong></td>
<td><strong>5,487</strong></td>
<td><strong>180 (2%)</strong></td>
</tr>
</tbody>
</table>

[Source: Department of Health statistical analysis. Cochrane et al. 2007]

3.16 Although home-based care of a child with a slowly progressive condition can be an onerous task (particularly for the parents, who may need to administer multiple medications and learn nursing tasks), this type of care is preferred by families and is normally more cost-effective than acute/inpatient care in hospital. Yet we also know that a home-based death is currently only a reality for a small proportion of patients.

Trend data – mapping exercise

3.17 In researching numbers and trends for this review, it was clear to us that the current evidence base for children’s and young people’s palliative care is not well developed.

3.18 The need to collect epidemiological data identifying the number of children with life-threatening and life-limiting conditions, the palliative care needs of

$^{37}$ The “Other” category includes, for example: nursing home, residential home, private home that is not the usual residence of the deceased

$^{38}$ Percentages may not sum to 100% due to rounding

$^{39}$ The England figures include deaths in England of people not usually resident in England
these children and patterns of referral to and utilisation of services has now resulted in the development of a mapping project. This is a joint project between ACT and ACH and the intention is to develop a tool to enable the standardised collection of data on the numbers of children with life-limiting and life-threatening conditions and the services that are available to support them. The tool is currently being piloted and will then be rolled out across the UK over a timescale of three to five years.

**Key messages: numbers and expected trends**

- There is a general lack of accurate figures and data on prevalence and trends; however, the DH analysts worked with ACT and ACH to provide updated estimates.
- These estimates show that relatively small numbers of children and young people suffer from conditions requiring palliative care.
- The geographical spread of those requiring palliative care varies, so accurate local needs assessments are essential.
- Given the small numbers of children and young people with palliative care needs at PCT level, services should be configured across a number of PCTs and LAs (sub-regional) to ensure they are able to support the range of services needed in a sustainable way.
- Children and young people with palliative care needs are now living longer and displaying increasing complexity of care needs.
- These trends present significant challenges to those planning and commissioning services.

**Services and accessibility**

**3.19** In section 2 on page 15 we outlined the range of services that exist for children and young people with palliative care needs and their families, though we highlighted that access to services is dependent on local availability and funding. This section looks at what families want from palliative care services and the reality of availability and accessibility of these services across England.

**What families want**

**3.20** Throughout the review, we took every opportunity to ask parents, young people, and service providers what services they believed were the most important. At the group discussions with parents, the same issues continued to be raised and overall they told us that they wanted:

- more community-based services
- more respite care, particularly more respite available within the community
- key services available 24 hours a day, 7 days a week – this was particularly important for dealing with crises and for end of life care
- assessments co-ordinated between health and social care, with services to follow
- more responsive services able to deal swiftly with changing circumstances – e.g. the need for a new wheelchair, a deterioration in a child’s condition, transition to adolescence and adulthood
- more bereavement support and support for siblings
- confidence that the services they valued most would be sustained

**Review of availability and accessibility of services**

**3.21** Inequity of service provision and access emerged as a key issue. Problems include:
“Our Children’s Home Care Team currently provide a 24 hour on-call support service for end of life care for children and young people at home on an ad hoc basis. Staff provide this service as a ‘goodwill’ gesture, and as a result of this, the existing workload of the community team is either delayed or managed in some other way while providing ‘end of life’ care. There is no additional funding to provide for this end of life service, meaning that other patient visits are cancelled and only emergency visits provided.” Consultant Paediatrician

3.22 These difficulties have the potential to lead to many patients being doubly disadvantaged, not only because of their life-limiting/threatening disease and the distress associated with that, but also by being excluded from the benefits of palliative care.

3.23 Children with complex needs are likely to access several specialties, across local general hospitals and tertiary centres, hospices and community nursing teams. However, very few hospitals have paediatric palliative care consultants on site, while at a local hospital, a general paediatrician may (or may not) have an interest in palliative care. There is wide variation in the extent to which children and young people have access to tertiary centres with expertise in palliative care and symptom control.

3.24 Where specialist centres have developed, these have acted as a catalyst for service development in the surrounding region. For example, the Great Ormond Street Symptom Control Team provides specialist support to community teams, hospices, local hospitals and GP services and even NHS Direct across the South East.

3.25 However, the number of specialist tertiary centres and specialist palliative care consultants, on a national basis, remain small. There are currently six consultant specialists in paediatric palliative medicine, of whom one is a nurse and five are doctors. In addition, there are very few academic centres of research excellence in palliative care in children, and only one consultant senior lecturer.
ii) Hospices

3.26 The provision of hospice and hospice-at-home services is very variable across the country. This is often due to local perception of need and charitable effort, resulting in uneven geographical distribution.

3.27 Experience suggests that the desire to set up a new children’s hospice is driven by a specific event – typically, the struggle a family has experienced in caring for a sick child and a fervent desire to ensure others should not have to struggle in the same way.

3.28 This ad hoc planning has led to duplication and overlap of services in some areas and lack of provision in other geographic areas. ACH has become increasingly concerned about this situation and has recognised the importance of positively influencing the planning and development of future services. This move towards better planning has been encouraged by the Government and the DH, who have sponsored the commissioning of a toolkit to better inform potential developers.

3.29 Children’s hospices and hospice-at-home services offer an incredibly important service to both parents and children and also help alleviate considerable pressure on the statutory sector – particularly hospitals – by providing respite care and complex symptom management. However, not every family has ready access to a children’s hospice and some hospices themselves operate different entry criteria (such as age limit and the expected life span of the child), again meaning that some families cannot gain access.

3.30 Diverse communities, such as black and minority ethnic (BME) communities, asylum seekers and socially deprived families, may also find it hard to access children’s hospices for cultural or language reasons. Some, for example, have problems with the concept of a short break in which children are cared for by people outside the family, while different translations can also create a barrier, for example, in some languages “hospice” translates as “orphanage”.

3.31 Progress is being made: for example, Rainbows Children’s Hospice in Loughborough and Acorns in the Midlands focus on providing culturally acceptable models of care and have appointed community workers to help build the capacity of ethnic minority families to engage with the hospice services. Acorns has also published multi-faith literature on enhancing the quality of care for families. We strongly endorse these developments and believe more needs to be done to ensure the effective inclusion of all communities, thereby increasing referrals.

iii) Community Children’s Nursing Teams

3.32 Most areas have a Community Children’s Nursing (CCN) Team but the size and sustainability is variable. The very specialist elements of palliative care – symptom advice and control, 24-hour crisis support, end of life care and bereavement support – are then “bolted on” to the CCN teams. However, due to funding and difficulties in service configuration, the accessibility of such specialist care is variable across the country.

3.33 The size of these teams is often very small and this means that the nurses often have an excessive caseload and are, therefore, vulnerable to sickness, high staff turnover and stress or burnout. Accordingly, they may not be able to offer a service to the community outside of “normal hours”. We found that even in the areas of good practice, services are existing on the bare minimum and cannot offer crisis cover or end of life care and support on anywhere approaching a consistent or sustainable basis. There were examples of local teams putting huge effort into supporting a child dying at home but this was often at a cost to their regular work and to themselves.

iv) Social care and education

3.34 We found a lack of joint working between the NHS and Local Authority Children’s Services (LACS), with the consequence that assessments often identify care needs which cannot be met locally – for example,
“We had to wait 18 months for access to specialist equipment and an occupational therapist. It’s always a battle.” Parent

These struggles are not, however, confined just to parents and families:

“I never again want to be in the position of arguing about whether this is a ‘health’ bath or a ‘social care’ bath.” Director of Public Health (talking about which agency should fund a particular piece of equipment)

children and young people being unable to take up offers of specialist short breaks because transport is unavailable.

3.35 Accessing services is a constant battle for parents and families. We heard repeatedly from families caught up in bureaucratic disagreements about funding – particularly for equipment such as wheelchairs, housing adaptations and respite care.

3.36 Parents reported problems with multiple assessments, different eligibility criteria, local priorities, referral systems and statutory requirements across health, education and children’s social care, which continue to challenge the development of a single service – with the main driver appearing to be a desire to avoid paying rather than meeting the needs of the child or young person.

3.37 Education was another area that parents were concerned about due to a lack of services and a lack of co-ordination. We heard from parents who were struggling to get their children into school due to the lack of medical support to feed children with, for example, a gastrostomy. Other parents reported their experiences with schools that were concerned about taking children who required regular medications – one example being the controlled drug Diamorphine. One family even took the education service to the High Court to enable their child to receive a good education from a school that could cater for her needs. The family won the case, but only after a battle.

3.38 Against this, we did see some good examples where community-based services came together to provide an excellent outcome for the child. One such example is “Sarah”, whose case is handled by the Lifetime service in Bath:

Case study – “Sarah”

Sarah is a six-year-old with idiopathic pulmonary hypertension. This is the most severe form of pulmonary hypertension and Sarah is dependent on her medication being consistently delivered via an infusion pump, which she carries in a backpack. Sarah’s condition is such that she could collapse at any time and may not recover. The family have been approached about the possibility of Sarah having a heart and lung transplant.

Sarah became acutely unwell very shortly after her diagnosis and the decision about her medication was made very quickly. Her parents were then faced with an intensive training programme to ensure they were competent and confident to draw up the correct amount of medication and understand the infusion pump. This initial training was undertaken by the pulmonary hypertension team at Great Ormond Street Hospital and then supported by the Lifetime Community Children’s Nurse.

To enable the family to continue providing such a high level of complex health support for Sarah at home they have had the support of professionals from several agencies. Social services provide support from both a social worker and an assistant social worker to help the parents in their day-to-day living and parenting skills. Ongoing support is provided by a children’s community nurse and psychologist to help the family come to terms with having a child with a life-limiting condition. Sarah has since started school and has the support of the education staff, including the head teacher, teacher and learning support assistants (LSAs).
v) Other voluntary providers

3.39 In addition to hospice and hospice-at-home services, there are a range of voluntary sector providers delivering support to families. For example, the Jessie May Trust provides respite and palliative care services in the home and often works in partnership with the Lifetime service, and the Rainbow Trust also provides family support.

Case study – Rainbow Trust Children’s Charity

Established in 1986, Rainbow Trust Children’s Charity provides practical and emotional support to families who have a child with a terminal illness. They have teams that are widely dispersed in the North and South of the country. They have over 40 care staff in the field and an army of volunteers who work all over the country. Regional Family Support Workers provide care in the families’ own homes through diagnosis, treatment and beyond bereavement. They may attend hospital appointments with parents, sit by the bedside of the sick child to give parents a break and take worried siblings out for the day. Support is available 24 hours a day at times of crisis. Families can also take respite breaks at one of two Rainbow Houses – in Surrey and Northumberland.

The Rainbow Trust Children’s Charity supports 1,000 families each year and relies on voluntary donations to raise £2.3m in funding each year.
Key messages: services and accessibility

- There is wide variation and inequity of service provision across England
- There is duplication of services in some areas and lack of provision in other areas due to an unco-ordinated approach to planning services
- There is an overall shortage of community-based services, particularly 24 hour crisis support, end of life care and respite at home
- There are too many organisational, budgetary and geographical boundaries to overcome when attempting to secure services for disabled children and children and young people with palliative care needs
- Good, integrated services exist in part due to the quality of personal contact, interaction and liaison but they are very resource-intensive
- We found a committed but frustrated workforce and stressed parents who are willing to take on the main role in providing care for their children provided they are supported

Funding and sustainability

3.40 One of the key drivers for this review was the lack of sustainable funding and resources. In order to support our analysis on sustainability we commissioned work from the York Health Economics Consortium. Their full report20 is made available in parallel with this report. The comments in this section are therefore based in part on the conclusions of the York work. In particular, we thought it was important to:

- review current levels of funding from both statutory and voluntary sources
- review how effectively statutory money was being spent

Statutory sector funding

3.41 Children’s palliative care has benefited from a series of one-off injections of funding: the Diana teams, BLF funding and most recently the £27m grant to hospices from the DH. However, it has been less successful at attracting long-term statutory funding. Statutory funding from PCTs or LAs is the most sustainable source of funding and we believe that steering this towards the most effective services is the best way of building up sustainable services in the long term.

3.42 As we have discussed, many children and young people with palliative care needs fall within the broader category of disabled or those with continuing care needs. Most funding for palliative care is therefore provided through the funding of services for disabled children and continuing care.

i) Primary Care Trusts (PCTs)

3.43 The York team attempted to find out how much PCTs were spending on disabled children. Their principal source of information was the returns from PCTs to the DH National Child Health Mapping exercise. As part of this exercise, PCTs were asked to provide information on services provided for children with disabilities and complex needs, including palliative care needs.

3.44 Of the PCTs that provided returns, 45% did not provide any data on children with disabilities. The quotes below list some of the reasons they gave:

- “We have not been able to accurately identify the number of children with disabilities and complex health needs”
- “We have no robust figures on these children”

20 Reports by the York Health Economics Consortium can be accessed via www.york.ac.uk/inst/yhec/projects.shtml#nhs_consulting
3. FINDINGS | PALLIATIVE CARE SERVICES FOR CHILDREN AND YOUNG PEOPLE IN ENGLAND

• “We are unable at such short notice to provide this data. This is not currently mapped by any single entity”

• “Not known. This work has not been undertaken and will be a major piece of work and will involve inter-agency working to obtain accurate assessment”

• “Do not understand what is meant by the conditions causing childhood disabilities, complex health needs and palliative care needs”

• “The PCT has done no recent analysis of childhood population need”

3.45 The inability of so many PCTs to provide information on spend on services for disability and palliative care points to major failings in the current system. There is an urgent need to raise the priority afforded to services for disabled children and those with palliative care needs and to improve PCTs’ ability to assess the needs of these children and to monitor and assess what they are providing and how much they are spending.

3.46 The York team was able to review the information provided by those PCTs that did provide sufficient data, which showed huge differences in levels of spend across the country. This ranged from over 100 PCTs who calculated that they spent less than 5% of their child health spend on disabled children to a small number of PCTs who spent between 35–40%. Overall, York concluded that there is up to a 10-fold difference in funding levels by PCTs, and it is likely that many PCTs are not providing sufficient funding across the whole range of services for disabled children.

3.47 This variation in spend, leading to considerable variation in service provision, was supported by the evidence we collected at regional meetings and discussions.

• ii) Local Authority Children’s Services (LACS)

3.48 We found very little evidence of LACS being engaged in the provision of palliative care services, or of providing funding. The evidence provided in responses to our consultation letter and at regional meetings suggests that what is needed is a multi-sectoral approach spanning health, social care and educational support. Where this was done most effectively was where PCTs and social services were involved in joint commissioning, or operated pooled budgets.

3.49 In Cambridge, for example, a local agreement had been reached between the community nursing team and social services to share assessments and funding. However, this kind of arrangement, and the excellent example of Halton (see case study on page 32) were the exceptions.

3.50 In their report, York highlight “a lack of support from Local Authority Social Service Departments”. Parents also reported to us the problems they faced when caught in the gap between health and social care. One of the worst examples of this we came across was when visiting one of the community nursing teams. A girl they were dealing with had entered the end of life phase. The family had been waiting for an assessment from social services for the extra support they needed over this difficult period. In spite of regular pressure from the nursing team, social services failed to speed up their processes or share the nursing team’s assessment and finally arrived to assess the family on the day the girl died.
Case study – pooled budgets in Halton

In 2002, Halton Local Authority identified the need to develop joint strategic planning in relation to disabled children’s services. The first Multi-Agency Strategy was published in 2003 and signalled a commitment from the LA and the PCT to work towards integrating services for disabled children and their families, including the development of a limited pooled budget.

Halton Children’s Disability Services were well placed to respond to the integration agenda of the Children Act 2004 and the Children’s Disability Mini Trust was established in 2006 with a vision of integrating services for disabled children, including services for children and young people with palliative care needs. The strategic plan has been revised and joint management arrangements are in place with the joint appointment of a Children’s Disability Manager. Plans are in place to build on the success of the pooled budget, expanding it further to provide increased flexibility in the provision and commissioning of services. The Mini Trust has a vision of developing co-ordinated multi-agency services through multi-disciplinary teams with integrated processes that provide a seamless service to families on a continuum with universal and preventative services.

The success so far in Halton has been achieved through the strong partnerships that have been developed and which are underpinned by a robust strategic planning framework that brings together all stakeholders through the Children and Young People’s Alliance Board. The partnerships in relation to disabled children’s services are one of the most mature and are further underpinned by the Multi-Agency Strategic Plan for Disabled Children with Complex Needs which covers palliative care and the formal Partnership Agreement governing the pooled budget.

Voluntary sector funding

3.51 There are a variety of voluntary sector organisations providing services for children and young people with palliative care needs, including hospices, hospice-at-home services and a variety of family support and bereavement services.

3.52 Information from ACH reveals it costs an average of £2.5m to run a children’s hospice service each year. Prior to the recent £27m government cash injection, children’s hospices in England received an average of just 3.6% of their income from statutory sources. Nearly half of all children’s hospices (16) receive no statutory funding whatsoever. As a result, children’s hospices are dependent on fundraising for most of their day-to-day needs.

The end of BLF funding and its effect on sustainability

3.53 From 2003 the BLF provided grant funding to 24 children’s hospices, 64 community teams and 39 bereavement services. However, there was no ongoing commitment past the three-year grant period. It was assumed that where the community teams and services failed to attract mainstream NHS funding they would close.

3.54 BLF funding enabled hospices to cope with increasing demand for their services at a time when a number of them faced a fall-off in donations following major international fundraising appeals in 2004 and 2005, including the aftermath of the Asian tsunami. The ending of the BLF funding therefore raised major problems of sustainability.

3.55 The recent £27m grant money made available for hospices has helped provide short-term relief for hospice services which faced the loss of BLF funding. However, this is only a temporary solution (as demonstrated in the East Anglia Children’s Hospice case study on page 33).
“Long-term funding has not yet been secured for this service. Funding through the New Opportunities Fund (NOF – now the BLF) ceased at the end of September 2006, and whilst commissioners agreed funding for the continuation of this service up to end of March 2007, this has not been committed beyond that date. The continuation of funding is being considered by the local PCT within the Local Delivery Plan for 2007/08, however, due to considerable financial constraints facing the local commissioners, there is a high risk that funding will not be available.” Trust Clinical Nurse Manager

### Case study – Hospice funding in East Anglia

East Anglia Children’s Hospice (EACH), which operates three hospices in East Anglia, had to introduce cutbacks in the services they were able to offer families, including cutbacks in respite care, as a result of the loss of their BLF funding of £640,000 a year. The £27m of funding for hospices announced by Ministers last year has enabled them and a number of other hospices to reinstate services, but there is clearly a need to find more secure sources of long-term funding.

3.56 In January 2006, a snapshot survey undertaken by ACT of the financial security of the BLF-funded teams revealed that of the 104 respondents less than 10% felt that their funding was secure. In August 2006, a further ACT snapshot confirmed these fears. Of the 44 respondents:

- 15 were making staff redundant
- 27 had put in place a freeze on recruitment
- 25 had been forced to put restrictions on the types of services offered
- 13 had introduced a waiting list

3.57 As outlined in the York report, the most recent BLF evaluation undertaken by Warwick University in January 2007 show that only 14 out of the 47 schemes that provided information (30%) had definitely secured ongoing funding from their PCT. Whilst the eventual picture is likely to be more positive, this protracted period of uncertainty is unlikely to have helped the confidence of staff and service users, or contributed to their sustainability.

Hospices and voluntary sector providers

3.58 As outlined above, hospices receive very little statutory funding and must rely heavily on charitable donations and grants. The amounts they do receive and the extent to which they are involved in the statutory commissioning process vary enormously across the country. The average hospice service receives 5% or less, but this is a slightly misleading figure – some services receive more, or more often none at all.

3.59 Whilst collecting evidence for this review we heard comments in favour of more central government funding to provide short-term help for services in financial difficulty. We believe this could just provide further encouragement for leaving palliative care outside statutory funding.

3.60 Short-term funding has therefore proved effective at building up innovative services, but it has not proved effective at enabling them to attract long-term funding.

3.61 The basis on which hospices are funded varies enormously. Although some hospices decide not to engage with local commissioners as they wish to preserve their independence, an increasing number of hospices spend a growing amount of time talking to PCTs and LACS but with variable benefit in terms of additional funding or influence over local service development.

3.62 For those hospices that are successful in attracting statutory funding, a range of different contracting methods are used. Some commissioners agree a set amount of funding or an agreed percentage, whilst others align funding to actual services used. Payments may be made on receipt of an invoice, at regular intervals by reference to an indicative bed charge, or by way of an up-front annual payment for services. St Oswald’s in Newcastle has one of the clearest and best co-ordinated contracts we found and forms an integral part of the partnership model in place in the North East (see case study on page 34). However, the partnership model and contract were achieved by St Oswald’s funding a full-time partnerships and policy lead post.
3.63 Some providers, like The Children’s Trust in Tadworth, have developed an approach which means they receive most of their funding from statutory sources. They, like St Oswald’s, only accept children for whom funding has been secured in advance – in effect, they have become a commissioned service. However, most hospices accept all children referred to them that meet their criteria. This approach can “encourage” PCTs and LACS not to fund them, since they know that a service will be made available whether they pay for it or not. It is difficult for a hospice or a family support team to refuse to accept a child because funding is not available.

The Children’s Trust is a voluntary sector organisation that provides a comprehensive range of services for children with profound and multiple disabilities and complex health needs, including those requiring palliative care. It provides respite care and palliative care alongside a range of other services, including rehabilitation, transition from acute hospital care to home, community outreach and a school for children with profound and multiple learning difficulties and complex health needs.

3.64 Some hospices argued that they should be guaranteed a fixed percentage of their costs. However, what children need are specific services rather than a particular provider. The emphasis should be on commissioning the services on the ACT Care Pathway according to an individual child’s needs assessment. Hospices, along with other providers, need to decide what services on that pathway they are best equipped to provide.
Although adult hospices differ from children’s hospices, they do provide a comparator in terms of statutory funding and in commissioning of end of life care. Although many adult hospices also face problems through lack of sustainable funding, in 2000 NHS funding for adult hospices averaged 28%. By 2004, this had increased to 38%, mostly as a result of the extra £50m per annum made available for adults under the Cancer Plan. This extra £50m is now recurrent in PCT baseline allocations ensuring it is available on a long-term basis for palliative/end of life care. There is therefore a sharp contrast between the funding and priority given to hospice services for adults and for children.

Statutory and voluntary sectors working together

To some extent the provision of grants and the growth of voluntary sector providers who manage with only minimal statutory funding has enabled commissioners to avoid taking responsibility for services.

The findings suggest that what is needed is not more short-term crisis funding, but for statutory funding to be targeted towards the most cost-effective services whether they are in the statutory or voluntary sector, and for those responsible for planning and commissioning services to have more information on what they should be providing and to be held accountable for what they deliver.

The DH has recently published updated guidance aimed at health and social care about commissioning services including services from the voluntary sector. However, during our review we saw very little sharing of best practice of how to deal with the voluntary sector, and the extent to which the voluntary sector is brought within the commissioning process is a complete lottery. Far more needs to be done to set standards for how the statutory sector should engage with the voluntary sector. The voluntary sector also needs to consider which elements of the care they provide sit most appropriately within the commissioning process.

It is a waste of time and effort for service providers to have to negotiate a multiplicity of different contractual and funding arrangements. The problem of having to deal with multiple numbers of PCTs and LAs that each plan and commission separately rather than as part of a co-ordinated group or cluster also affected statutory teams like the Lifetime service in Bath, which covers six different PCT areas.

There was strong anecdotal evidence that investing statutory money in good community-based teams not only provides better quality of care for children and their families, but is also far more cost-effective than allowing children to spend inappropriate time in hospital attending outpatients or A&E. This is explored in more detail in the next section.

Further guidance is available at www.dh.gov.uk/en/publicationsandstatistics/lettersandcirculars/dearcolleagueletters/DH_072604
Key messages: funding and sustainability

- Funding for services for children and young people with palliative care needs has thus far been largely ad hoc and reliant on short-term injections of cash
- The inability of many PCTs to provide information on services for disability and palliative care highlights major failings in the current system and an urgent need to improve their capacity to undertake local needs assessments
- As most children and young people with palliative care needs require social care as well as medical support there are strong arguments for greater support from LACS
- Although children’s trust arrangements are supposed to drive joint planning between health and social care for children’s services, there is only limited evidence of this being the case for palliative care services
- Short-term grant funding has proved effective at building up innovative services but it has not proved effective at enabling services to attract long-term funding
- Planning and commissioning need to be co-ordinated in a way that supports both voluntary and statutory sector providers to develop services that operate over total populations of at least 1 million, and therefore makes better use of scarce resources

Effective and efficient service provision

3.71 The limited amount of funding available for children’s palliative care services must be focused on the most cost-effective services. We invited York to undertake a cost benefit analysis of children’s palliative care services to test the hypothesis that developing good community-based services and a planned care pathway could deliver savings for the NHS as a whole as well as being better for children and their families.

The value of community-based services

3.72 The York analysis confirmed our hypothesis and identified that as well as being much better for children and their families, supporting children in the community is far more cost-effective than waiting until a family reaches crisis point or a child reaches a medical crisis, resulting in inappropriate and costly time in hospital. Specialist community teams can prevent:

- unnecessary admissions to hospital during evenings, overnight and at weekends, when families are unable to access 24-hour support (where there are concerns about, for example, drug regimes or respiratory problems)
- longer lengths of stay (delayed discharge) as a result of problems in putting together complex packages of care. Community or outreach key workers are critical in this role and also act as co-ordinators to ensure care packages are efficiently and effectively organised
- children having to attend outpatient clinics on a regular basis for simple tasks, such as blood tests, and management of technology-dependent children
- death in a hospital environment (three-quarters of children with palliative care needs die in hospital) when families would prefer this to be at home

3.73 Parents value all community-based services and see respite care, including hospices, as essential to enable the family to continue to cope. In an ideal world, a full range of community-based services would be available in all areas, but given that finances will always be limited and the need to build up services from a very low base in some areas, cost effectiveness becomes a major issue. The following are what we believe are the essential services that should be in place:
Paediatric palliative care nursing team (including 24-hour/end of life/crisis support). Paediatric community palliative care teams can deliver services which reduce the dependency on hospital-based services and achieve savings which will fund the entirety of the team. All families with palliative care needs should be able to access such a team, which should receive statutory funding. The model and composition of the team would depend on the availability of services in a locality.

Access to specialist support services (e.g. therapists, psychologists etc.). Families are likely to access these services in an outpatient setting already, although not necessarily at the level which will afford maximum benefit. Specialist support services need to be part of the community-based team and work within an agreed and integrated care package for a child and family. A good example of a community palliative care nursing team working collaboratively with specialist services is the Camden and Islington Lifeforce team.

Hospice at home/community respite and support team. These enable families to cope with managing a child with complex needs at home rather than in a residential or hospital setting.

Hospice, residential and short break facilities. Access to hospice care is greatly valued by families, and inpatient hospice care is probably the gold standard for the provision of respite care for children with palliative care needs, yet the majority of hospices receive only a small proportion of their funding from statutory sources. Whilst the development and funding of community palliative care teams ought to be the top priority, PCTs must do more for hospices, and should also encourage hospices to develop hospice-at-home care, and to be part of Paediatric Palliative Care Networks.

Case study – Camden and Islington Lifeforce team and Great Ormond Street Hospital for Sick Children

Lifeforce is one of the BLF-funded palliative care teams which provide home-based, family-centred palliative care support to families, including respite at home and a play/youth worker. The team is led by a specialist nurse and includes a respite nursery nurse, play worker and a psychologist one day a week. The service is a bolt-on to the CCN Team. There is a well-established parents group that gives regular feedback to the team.

The Great Ormond Street (GOS) team provides specialist paediatric palliative care and medical support for these children and families and advises the Camden and Islington team on medical management via the symptom control team at GOS. The GOS team also provides 24-hour back-up telephone support and, alongside the Lifeforce team, undertakes joint home visits and works closely with the CCNs to build a team around the family. There is another NOF/BLF team in Chelsea, Westminster and Hammersmith that offers a similar service and works with the GOS team in a similar, although less formal, way.

The GOS team provides specialist medical and nursing support and advice to families and professionals and accepts referrals from anywhere in South East England. Because of the large catchment area, day-to-day care of children and families is provided by local services and GOS provides more specialist palliative care support.
3.74 The York analysis demonstrates in particular how providing community-based services could not only enable children to die at home, which is what the majority of families want, but that supporting children to die at home reduces costs. Figure 3 on page 24 shows the variation across SHAs of children dying at home. Increasing the numbers of children dying at home would release funds to help pay for the development of community-based services.

3.75 There is the opportunity for current levels of statutory funding to be spent more effectively. Investment in community services is not only better for children and their families, but also better value for money.

The value of a team-based approach to providing children’s palliative care services in the community

3.76 The York analysis indicated that, given the current investment in service, a team-based approach to providing children’s palliative care services across a wider geographical area than just a PCT or LA is the most effective and sustainable approach to providing services. This is based on the following findings:

- services which meet the needs of small population numbers are unsustainable – they are both less cost-effective and less able to deliver an excellent service than those that cover larger populations

- the cost of BLF community-based nurse-led teams and their ability to provide a full range of services varied greatly depending on how many families they supported and how much funding they had

- small teams were extremely vulnerable to sickness and maternity leave. Many reported problems with recruitment, staff turnover and staff burnout

3.77 York’s evaluation, and the experiences of those setting up the Diana teams and the teams funded by the BLF, indicate that a cost-effective palliative service could be set up for a total population of around 1 million, representing about 200–300 children and young people with palliative care needs and their families. This would provide the opportunity for more effective strategic planning, sustainable services, better economies of scale and the scope for providing services 24 hours a day, 7 days a week. Most of the community-based teams we spoke to only operated 9am–5pm, five days a week, and even so were often stretched.

3.78 The most sustainable and cost-effective way of building up services is by the merger of smaller teams or the expansion of existing teams rather than starting from scratch. Any change to current service provision should start with a review of the local services available, funded by both the statutory and voluntary sector.

3.79 The York analysis also concluded that the most sustainable and effective teams were those that provided a range of services within a single team, with key workers or lead professionals providing a co-ordination and contact point for parents.
Key messages: effective and efficient service provision

- Investment in community-based services has the potential to pay for itself through savings in hospital services
- Investment in community services is not only better for children and their families, but also better value for money
- The most sustainable and cost-effective community teams are those which are capable of delivering support 24 hours a day, 7 days a week for a total population of at least 1 million
- It is important that teams provide families with a key worker to co-ordinate services and maintain a strong personal contact
- Children’s palliative care services should be planned and commissioned across a total population of at least 1 million
“Long-term funding has not yet been secured for this service...”

Trust Clinical Nurse Manager
4.1 Given the findings set out in the previous section, we have pulled together what we believe are the most important elements of a good service for children and young people with palliative care needs.

4.2 This approach is based upon the existing ACT Care Pathway involving access not only to specialist palliative care services as required, but also to those universal services that are available to all children. Developing the right joined-up approach provides confidence to all concerned that services will be available and accessible when needed, to enable the child or young person to live as full a life as possible.

4.3 Not all palliative care services will be required at the same time. Children and young people with palliative care needs and their families have varying needs, and will therefore dip in and out of services as and when appropriate. However, in order for this to happen, those planning and commissioning services have to ensure that they develop the right range of specialist services as well as improved accessibility of universal services. Figure 4 below sets out the three categories of service – universal, core and specialist – which need to be available and accessible according to need.

Figure 4: Different levels of palliative care services which should form the basis of a children’s palliative care service

- **Specialist Palliative Care Services**
  - Tertiary specialist paediatric care and symptom control

- **Core Palliative Care Services**
  - These form the majority of services required by children and young people with palliative care needs and their families, e.g. community nursing teams, hospices, bereavement services, sibling support

- **Universal Services**
  - The foundations for a good palliative care service includes services which are available to all children and young people, e.g. GPs, education, playgroups

A key worker will be responsible for ensuring joined-up and co-ordinated service provision.
A joined-up, three-tier system could make a real difference to the lives of children and young people with palliative care needs and their families. In order to ensure the three levels complement each other, we believe the following key elements need to be in place:

- Key workers who would be responsible for ensuring that children, young people and their families are able to access the right services at the right time and that care is planned, co-ordinated and appropriate to their needs

- Access to a nurse-led community-based team with specialist knowledge of palliative care, which is able to offer support and advice 24 hours a day, 7 days a week and co-ordinate access to other services

- Services which are planned and commissioned based on the ACT Care Pathway, and that support both voluntary and statutory sector providers

- Day-to-day care that is generally provided in the community, with specialist children’s community teams working in conjunction with GPs, hospitals, social services and education

- At least one person who is a specialist in palliative care for children, who will act as a source of specialist knowledge for children across the region and who will take the lead to ensure the development of services

- A range of flexible respite care which is accessible to families, including respite at home, in a children’s hospice and through social services
4. IMPORTANT ELEMENTS OF A GOOD SERVICE | PALLIATIVE CARE SERVICES FOR CHILDREN AND YOUNG PEOPLE IN ENGLAND

- the views of service users, including parents and, where possible, children and young people themselves, forming an important part of the planning process, either through Paediatric Palliative Care Networks or some other means

**What would this mean to the children and their families?**

4.5 This would mean that from the point of diagnosis onwards, families would have a clear idea of the range of services they would have access to, and the key workers and key services they could turn to in order to co-ordinate their needs. Knowing services will be available when needed will reduce stress and ensure that families can get on with their lives.

4.6 Children and young people will have access to specialist services but will also have access to universal services, meaning that, if possible, they will be able to go to school and to play, and to get as much as possible out of life.

4.7 Families will be supported as a whole, including support for siblings, bereavement support, and respite available to the whole family, to ensure that families are able to stay together and enjoy activities together.

**Key messages**

- Not all palliative care services will be required at the same time, but suitable services must be available when they are needed
- The suggested approach pulls together a range of services which fall into three levels – universal, core and specialist. These would be accessed at different stages of the illness and according to need
- Such an approach could make a real difference to the quality of the lives of children and families with palliative care needs
“We had to wait 18 months for access to specialist equipment and an occupational therapist. It’s always a battle.”

Parent
5. MAKING A DIFFERENCE – THE CHANGES WE WOULD LIKE TO SEE HAPPEN

5.1 There has been some excellent work on the planning and delivery of services for disabled children and those with palliative care needs, but this has not yet achieved the step change in delivery hoped for. Transforming the planning, commissioning and delivery process in the way we propose requires changes across the system at every level, including better use of levers, such as regulation and audit, to persuade people within the system to focus on services for children and young people with palliative care needs and their families.

5.2 Overall, our recommendations should deliver a much stronger emphasis on delivery for these children:

- at national level, with a clear national strategy and the information needed to plan the allocation of resources effectively
- at a regional level, with regional Paediatric Palliative Care Networks and strategic decisions on the right geography and numbers to commission services effectively
- at a local level where parents would have access to better focused services

5.3 We therefore hope that the Government, in collaboration with stakeholders, will take the lead in developing a delivery plan and a monitoring process for taking forward the recommendations in this report so that lasting improvements happen.

5.4 Our conclusions and recommendations are outlined as follows.

Improved planning and commissioning

5.5 Service providers and commissioners told us that children and young people’s palliative care suffered because it had a low profile and we also found many people who did not know what it was, assuming it was only about end of life care.

5.6 There was little evidence of LACS being engaged in the commissioning of palliative care services or providing funding, even though children and young people with palliative care needs require both healthcare and social care services.

5.7 There was confusion about how responsibility for developing policy and strategy was managed at national level, and although the DH and the DfES have made great strides in more effective joint working, this was not widely understood by those we spoke to on the ground.

5.8 The voluntary sector has played a leading role in establishing and developing children and young people’s palliative care. Much of the innovative work at national level in developing a care pathway and analysing national prevalence rates has been co-ordinated by ACT and ACH. We believe the voluntary sector should be recognised as key players at every level of delivery. The best outcomes for children are achieved where voluntary and statutory services work seamlessly together. The fragmented way in which the voluntary sector has developed, with no major national players and two key representative bodies makes it important that ACT and ACH continue to work together closely so that they can campaign as effectively as possible on behalf of children and young people.

5.9 We therefore recommend that:

- the DH should take the lead, working with stakeholders, including other government departments, to develop a national strategy for the delivery of palliative care services for children and young people, to raise its status and profile, drive a better understanding of what palliative care involves and set a framework within which services can be delivered in a joined-up way. Included within the strategy, stakeholders would like to see clearly identified “champions” for children’s palliative care
- the DH and the DfES should work together with SHAs and GOs to clarify who has lead accountability at each level, nationally, regionally and locally, for planning and delivery of services

- SHAs and GOs should take responsibility for leading planning at regional level, and ensuring that there is an established, functioning and effective Paediatric Palliative Care Network in place. They need to be supported, with some resources for administrative support. They should also ensure that PCTs and LAs form sub-regional groups covering the right population size and geography to ensure the effective commissioning of sustainable services. Commissioning some elements of the specialist provision will involve Specialised Commissioning Groups

- the voluntary sector should be recognised as a key partner at every level of planning and delivery from the development of national strategy and policy to the commissioning of local services. Given their vital role in developing palliative care, the two main bodies representing the voluntary sector, ACT and ACH, should consider the scope for working even more closely together to provide an even stronger national voice for children and young people with palliative care needs and promote greater understanding of children’s palliative care

5.10 These recommendations would improve planning and commissioning at national, regional and local level as set out in Figure 5 below.

Figure 5: Improvements to planning and commissioning at a national, regional and local level

<table>
<thead>
<tr>
<th>Level</th>
<th>Planning and commissioning</th>
</tr>
</thead>
<tbody>
<tr>
<td>National</td>
<td>• A published national strategy on children and young people's palliative care</td>
</tr>
<tr>
<td></td>
<td>• A delivery plan for the recommendations in this report and a delivery mechanism and monitoring process involving stakeholders</td>
</tr>
<tr>
<td></td>
<td>• A national indicator for services for disabled children which includes distinct measures to cover palliative care services</td>
</tr>
<tr>
<td></td>
<td>• The DH taking the lead in ensuring national data on prevalence and trends is collected and collated</td>
</tr>
<tr>
<td></td>
<td>• A national champion to take the lead in monitoring the needs of children and young people with palliative care needs</td>
</tr>
<tr>
<td></td>
<td>• A national workforce strategy, including the development of training in palliative care</td>
</tr>
<tr>
<td>Regional</td>
<td>• Identification of regional champions for palliative care services for children and young people</td>
</tr>
<tr>
<td></td>
<td>• SHAs and GOs to take the lead in planning services at a regional level, ensuring there are established, functioning and effective Paediatric Palliative Care Networks (including the voluntary sector and views from service users)</td>
</tr>
<tr>
<td></td>
<td>• Improved needs assessments underpinning more effective commissioning</td>
</tr>
<tr>
<td></td>
<td>• Core palliative care services commissioned by groups of PCTs and LAs</td>
</tr>
<tr>
<td>Local</td>
<td>• Children and Young People's Plan to include details of services for disabled children, including those with palliative care needs</td>
</tr>
<tr>
<td></td>
<td>• Universal children’s services developed in a way that improves accessibility for those with palliative care needs</td>
</tr>
</tbody>
</table>
Improved data collection and needs assessments

5.11 To date there have been no definitive numbers on children and young people likely to require palliative care in England. Developing national estimates has fallen to the voluntary sector. This has led not only to confusion about numbers overall, but also to a failure to pick up trends. Children and young people are living for longer and surviving in the community with more complex needs, leading to greater demand for all services, including improved transition to adult palliative care services. If services and commissioners are to respond to this, then the starting point has to be the collation of trend data.

5.12 Better collection of robust data will improve a PCT’s ability to assess the needs of children and young people who require palliative care, to monitor and assess what services they are providing and how much they are spending. Better needs assessments are the cornerstone of improved commissioning. The data from the National Child Health Mapping exercise shows how urgently improvements are needed. The ACT/ACH mapping exercise has the potential to improve things in the medium term but we believe this needs to be addressed urgently.

5.13 We therefore recommend that:

- the DH should take the lead in ensuring that national data on prevalence and trends is collected and collated. Data on children and young people with palliative care needs should be collected on a national basis from now on, including overall numbers, numbers dying and trends, to support the forward planning and commissioning of services

- the DH and the DfES, involving ACT and ACH, should expand the work currently under way on the Child Health Mapping exercise to urgently develop a simple framework for improving regional and local needs assessments for children’s palliative care

Improved consistency in service provision

5.14 Commissioners need to ensure that a full range of services is available to drive effective palliative care and ensure that children have access to the full range of services on the ACT Care Pathway. These services include those that sit alongside mainstream children’s services like classroom support, childcare and play therapists, and more specialist support like 24-hour, end of life nursing care.

5.15 Most services that we saw are planned and commissioned at a local PCT level. However, given the small numbers of children requiring specialist palliative care in any PCT area, and the difficulties of building sustainable teams of a size and range of skills capable of providing support and advice 24 hours a day, 7 days a week, we believe services should be planned and commissioned at regional or sub-regional level. These should also be jointly commissioned by PCTs and LACS, given that children and young people with palliative care needs require high levels of both medical and social care. Some of the best and most effective services are jointly commissioned and cover more than one PCT area.

5.16 The DH has already started to encourage regional planning through the development of regional Paediatric Palliative Care Networks. These have the potential to ensure the right people work together, sharing best practice and planning services effectively. They also offer potential for the views of service users (including parents and children and young people themselves) to have an impact at a more strategic level. However, the development of the networks has been patchy to date and we think they would benefit greatly from some central support and resource.

5.17 At present, it is a lottery as to which services children have access to across the country. The proposed improvements in commissioning and planning, the focus on the most cost-effective services and more resources overall should help improve
things, but it is also important to set benchmarks and standards for the services children should receive.

5.18 To ensure that their children receive the right services, parents want more effective assessments of their child’s needs and joint assessments involving health and social care. We did find some good examples of this but in many parts of the country they were the exception rather than the rule. The CAF is attempting to address this, but progress has so far not been sufficiently rapid to make a difference for children and young people with palliative care needs.

5.19 We therefore recommend that:

- children and young people with palliative care needs and their families should have access to the full range of services on the ACT Care Pathway after a single appropriate professional needs assessment
- commissioners should ensure an increased focus on community services to help manage and support children with palliative care needs to stay at home. Every sub-region needs to ensure it develops community teams capable of providing support and advice including end of life care, 24 hours a day, 7 days a week. Such teams can be developed in either the statutory or voluntary sector
- the Government needs to give the same priority to end of life care for children and young people at every level of planning and service provision as for adults. Most parents would like their child to be supported to die at home and services need to be developed to enable this to happen
- the DfES and the DH should consider whether children’s palliative care should form a special pilot, looking at how the CAF can be further developed to meet the needs of this particular group of children, or whether some other approach is needed to ensure effective multi-agency assessments by health and social care
- based on the ACT Transition Pathway, there should be a greater focus on services for managing the transition to adult services, linked to a better understanding of trends in life expectancy for those requiring palliative care
- children and young people with palliative care needs should have access to the same range of general services as other children, and in many cases, where they do need extra support to enable them to access education, playgroups etc., their needs are similar to those of disabled children and others with complex needs. Universal services should therefore be made more accessible to children with palliative care needs

Improved resources and more effective use of existing spend

5.20 Our analysis and the work by York Health Economics Consortium indicates that there are huge variations in the level of spend by PCTs on services for disabled children, including those with palliative care needs. This suggests that not enough money is being spent on these services as a whole and what is spent is not being used as effectively as it should be. York’s cost benefit analysis indicates that shifting resources to the kind of community-based teams parents want could pay for itself in terms of savings in hospital care. We believe children’s palliative care needs more resource overall, but it is important to ensure that PCTs and LACS are aware of the best way to spend it.

5.21 It will also be important to develop improved means of sharing best practice about planning and commissioning palliative care services for children across PCTs. We found very little evidence of sharing of best practice in commissioning, and considerable resources being wasted through providers which operate across more than one area having to negotiate
with a large number of PCTs and LACS, all of which contract in different ways and take different approaches to funding. This is a particular problem for hospices and community nursing teams.

5.22 We therefore recommend that:

- increased spend on palliative care should be linked to sustainable statutory funding for children and young people’s palliative care and focused on the most effective services that deliver the best outcomes. The additional funding should be used in particular to support the development of sustainable services able to offer appropriate support and advice 24 hours a day, 7 days a week;

- most services should be delivered jointly by health and social care. Therefore, additional funding that is provided should be linked to evidence of joint planning involving health and social care, i.e. PCTs and LACS. This should provide an incentive to develop pooled budgets covering health, social care and education;

- the DH and the DfES should work with ACT, ACH and commissioners to develop model contracts and best practice guidelines for dealing with the voluntary sector, instead of every PCT in the country developing a different approach to contracting with them. The range of model contracts should indicate the fairest and most effective way of doing business with the voluntary sector;

- the DH should facilitate the development of some training courses and information-sharing for commissioners on palliative care services, and training/best practice should also be developed for the voluntary sector to advise them on the best way to deal with commissioners. There may be scope for developing this alongside the Office of the Third Sector initiative for training commissioners who deal with the voluntary sector;

- the work the York Health Economics Consortium have already undertaken should be further developed so that Paediatric Palliative Care Networks and commissioners can be given a clearer idea of what a sustainable cost-effective service looks like.

**Improved use of levers**

5.23 Given the need to grow services, the paucity of information on current levels of spend and the vulnerability of current services to budget cuts, we also heard strong arguments for ring-fencing money for specialist palliative care services. However, given that this is not an approach currently in favour, and the delays likely to result from trying to resolve what should be included in the ring-fence, we recommend that other means are found to ensure that PCTs give sufficient priority to palliative care services for children and young people.

5.24 The view expressed strongly in our consultation meetings and in the responses to our consultation letter was that the reason services for children and young people with palliative care needs were not given priority was because there was no target for them. Commissioners explained to us that they have to focus on “must do” priorities and services for children and young people with palliative care needs just did not feature. NSF Standard 8 was warmly welcomed but was viewed as lacking teeth. It had not yet driven the hoped-for improvement in services.

5.25 The HMT/DfES review of services for children and young people, including disabled children, has also noted that variations in how well local areas are accommodating national standards and local priorities may mean that those most in need are not always getting the support that they need. The review is considering how best to use the evolving performance management framework, including exploring the potential for a national indicator focused on improving
services, to prioritise disabled children at both local and national level.

5.26 Tools for improving the focus on children’s palliative care at local level already exist in the form of the criteria used for children requiring continuing care and CYPPs, which are the main planning document for LACS and Children’s Trust Arrangements. However, commissioners told us that the continuing care criteria lacked the legal status of similar criteria for adults, and the CYPPs we looked at made very little reference to even general services for disabled children, never mind services for children and young people with palliative care needs.

5.27 We therefore recommend that:

- a national indicator should be established for services for disabled children which includes distinct measures to cover palliative care services
- services for disabled children, including children and young people with palliative care needs, should be included in CYPPs. Disabled children should be dealt with as a strand in each of the five themes in Every Child Matters which form the core of the CYPPs. Continuing care criteria for children and young people need to be given the same statutory basis as those for adults, so that both PCTs and LACS jointly focus on delivering appropriate services for these children
- there should be a greater sharing of best practice, including the development of benchmarks and standards for services, which can be used by regulators as well as those commissioning services. Work should be taken forward on developing standards/benchmarks for:
  1. effective Paediatric Palliative Care Networks
  2. the commissioning of palliative care services
  3. the range of services that should be provided
  4. the treatment of voluntary sector providers

This will enable greater clarity over which PCTs are spending their resources effectively and which are not. We need to bring all PCTs up to the standard of the best. We recommend that ACT and ACH (working with the DH) take this forward, building on the work in this review, including work by the York Health Economics Consortium. ACT and ACH will need some help with resources

- given that ring-fencing of funds is no longer acceptable, the NHS needs to consider what other approaches may be needed in addition to the above, to ensure a reasonable level of spend on palliative care. Mechanisms need to be found to ensure that any new money is targeted appropriately

Regulation and audit

5.28 Regulation and audit has an important role to play in driving improvements in services, as well as in holding PCTs and LACS to account for what they deliver, and is therefore a potentially strong lever for driving change.

5.29 One of the issues for inspection is the split of responsibilities between CSCI and the Healthcare Commission. The majority of children’s hospices are registered and inspected by the Healthcare Commission, yet hospice-at-home services fall largely under the responsibility of CSCI. CSCI and the Healthcare Commission do work closely together, but we believe it would improve delivery if palliative care services could be dealt with by a single regulator. Given the small numbers involved, the fragmented nature of services, the need to use regulation to drive improvements in services, and the fact that we need health and social care to work jointly to deliver what is needed, it clearly does not help to have split responsibilities between regulators.
5.30 However, all the regulators, when we spoke to them, recognised the need to improve palliative care services for children and young people and were supportive of what the review was trying to achieve. They were all willing to make use of standards or benchmarks that were developed. We also discussed with them the possibility of a thematic review\(^2\) of palliative care services. Given that much of what we have found relates to poor use of resources (alongside a lack of investment in the most cost-effective services), we believe that such a review should include the Audit Commission.

5.31 We believe that regulation and inspection could be used to drive improvements in services.

5.32 We therefore recommend that:

- the Healthcare Commission, CSCI and Ofsted should all use the agreed standards and benchmarks for palliative care services once these are developed and should judge LA and PCT performance against these when carrying out their routine inspections
- all relevant regulators (currently the Healthcare Commission, CSCI and Ofsted) and the Audit Commission should commit to jointly holding a thematic review of palliative care services for children and young people in 2009. This will allow some time for PCTs and LAs to develop services and respond to the recommendations in this report
- more should be done to drive a seamless joined-up inspection process, either through one regulator taking the lead on palliative care services or joint teams and inspections

Other improvements

5.33 The lack of status for palliative care, and lack of recognition of it as a specialism, makes it more difficult to develop expertise amongst doctors and nurses. The medical staffing of hospitals also needs further development. This can be provided by GPs but increasingly consultants, often with joint appointments with hospices are taking on this role. Medical support for hospices also varies across England and can be a significant cost for the voluntary sector to bear.

5.34 We therefore recommend that:

- paediatric palliative care should be developed as a recognised sub-specialty. This needs the support of the RCPCH and PMETB
- the RCPCH and the RCGP should take the lead in ensuring that the principles of paediatric palliative care are taught to all trainee paediatricians and GPs. Each region should have at least one specialist in paediatric palliative care and each locality should have someone who takes a special interest in this area
- the RCN should lead work on developing a career pathway for nurses specialising in palliative care for children and young people
- as part of the work on developing model contracts and best practice for dealing with the voluntary sector, work should take place on the right approach to payment for medical staffing in hospices and the reimbursement for the cost of medicines given in hospices
- the DH should lead the development of a properly-supported workforce strategy for nurses and other staff, including social workers, play therapists and other support workers

\(^2\) A thematic review would be a review of the quality of delivery of children’s palliative care based on an assessment of delivery in a cross-section of areas across the country
ACT Care Pathway (1)

**IDENTIFICATION OF CONCERN**
(Referred to paediatrician)

**CLINICAL ASSESSMENT OF THE CHILD**

**DIAGNOSIS OR RECOGNITION OF LTI OR LLI PROGNOSIS**

**BREAKING NEWS**

**FAMILY CARERS**
Immediate needs:
- Information
- Training
- Transport

**CHILD/YOUNG PERSON**
Immediate needs:
- Symptom control
- Medication
- Equipment
- Information
- Follow-up

**FAMILY HOME**

**FULL MULTI-AGENCY ASSESSMENT**
(continues Pathway 2)
ACT Care Pathway (2)

MULTI-AGENCY ASSESSMENT OF CHILD AND FAMILY NEEDS

<table>
<thead>
<tr>
<th>FAMILY CARERS</th>
<th>CHILD/YP PERSON</th>
<th>ENVIRONMENT</th>
</tr>
</thead>
<tbody>
<tr>
<td>Information needs</td>
<td>Symptoms/pain</td>
<td>Home assessment</td>
</tr>
<tr>
<td>Financial review</td>
<td>Personal care needs</td>
<td>Equipment needs</td>
</tr>
<tr>
<td>Emotional needs</td>
<td>Therapies</td>
<td>Transport needs</td>
</tr>
<tr>
<td>Sibling well-being</td>
<td>Emotional support</td>
<td>School</td>
</tr>
<tr>
<td>Family functioning</td>
<td>Information</td>
<td>University/college</td>
</tr>
<tr>
<td>Respite/short breaks</td>
<td>Short breaks</td>
<td></td>
</tr>
<tr>
<td>Quality of life</td>
<td>School/leisure</td>
<td></td>
</tr>
<tr>
<td>Interpreter</td>
<td>Quality of life</td>
<td></td>
</tr>
<tr>
<td>Transition to adult services</td>
<td>YP Transition plan</td>
<td></td>
</tr>
<tr>
<td>Genetic counselling</td>
<td>Independent living needs</td>
<td></td>
</tr>
</tbody>
</table>

Clinical Lead
Family GP

MULTI-AGENCY CARE PLAN

Interventions

<table>
<thead>
<tr>
<th>FAMILY CARERS</th>
<th>CHILD/YP PERSON</th>
<th>ENVIRONMENT</th>
</tr>
</thead>
<tbody>
<tr>
<td>Psychological support</td>
<td>Symptom management</td>
<td>Home adaptations</td>
</tr>
<tr>
<td>Training</td>
<td>Personal care</td>
<td>Aids/equipment</td>
</tr>
<tr>
<td>Access to benefits</td>
<td>Nursing support</td>
<td>Motability</td>
</tr>
<tr>
<td>Parent support group</td>
<td>Educational support</td>
<td></td>
</tr>
<tr>
<td>Sibling group</td>
<td>Social and leisure activities</td>
<td></td>
</tr>
<tr>
<td>Respite/short breaks</td>
<td>Short breaks</td>
<td></td>
</tr>
<tr>
<td>Pharmacy/supplies</td>
<td>Psychological support</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Independent living advice (YP)</td>
<td></td>
</tr>
</tbody>
</table>

Acute or planned admission
Discharge back to Community team

REVIEW OF NEEDS

REVIEW OF PROGNOSIS

RECOGNITION OF END OF LIFE

(continues Pathway 3)
ACT Care Pathway (3)

**RECOGNITION OF END OF LIFE**

**ASSESSMENT OF END OF LIFE NEEDS AND WISHES**

**END OF LIFE PLAN**

**ENVIRONMENT**
- Place of death
- Ambience
- Place after death

**FAMILY CARERS**
- Practical support
- Sibling involvement
- Emotional support
- Spiritual issues
- Cultural/religious issues
- Funeral planning
- Organ donation
- Grandparents

**CHILD/YOUNG PERSON**
- Pain/symptom control
- Quality of life
- Friends
- Emotional support
- Spiritual issues
- Cultural/religious issues
- Funeral planning
- Organ donation
- Resuscitation plan
- Special wishes/visits
- Memory box

**DEATH**

**FAMILY CARERS**
- Family Support
- Practical help
- Sibling care
- Contacts
- Bereavement support

**CHILD/YOUNG PERSON**
- Funeral
- Burial/Cremation

**ENVIRONMENT**
- Place to be with the body
- Ambience

**POST DEATH**
ANNEX
ORGANISATIONS WHICH HOSTED VISITS AND MEETINGS

• Association for Children’s Palliative Care
• Association of Children’s Hospices (ACH)
• British Association of Community Child Health
• British Association of Paediatric Palliative Care
• Cambridgeshire PCT and the East Anglia Children’s Hospice, Cambridge
• Camden and Islington Lifeforce Team, London
• Centre for Child and Adolescent Health, Bristol
• CHASE Children’s Hospice Service, Surrey
• Children’s Hospice South West
• East Midlands Palliative Care Network
• Great Ormond Street Children’s Hospital NHS Trust, London
• Helen House and Douglas House, Oxford
• London Children’s Community Nursing Group
• Rainbow Trust Children’s Charity, Surrey
• Rainbows Children’s Hospice, Loughborough
• Richard House Children’s Hospice, London
• Royal College of Nursing
• Royal College of Paediatrics and Child Health
• Royal Liverpool Children’s NHS Trust, Alder Hey
• Specialist Paediatric Oncology Outreach Team, Royal Victoria Infirmary, Newcastle upon Tyne
• St Oswald’s Children’s Service, Newcastle upon Tyne
• The Children’s Trust, Tadworth
• The Lifetime Service, Bath and North East Somerset

We are also extremely grateful to all those who travelled some distance to attend meetings and consultation events.
ANNEX
INDIVIDUALS AND ORGANISATIONS
PROVIDING ASSISTANCE TO THIS REVIEW

Those who are members of the reference group for the review are indicated with a *.

Al Aynsley-Green – Children’s Commissioner
Andrea Cail – Scottish Executive
Andrew Ross – Chief Executive, The Children’s Trust
Andrew Webb – ADSS
Angela Thompson – Palliative Care Lead Paediatrician, Warwickshire Primary Care Trust
Anne Jackson – dfES
Anne Thompson – Paediatric Oncology Outreach Nurse Specialist, Newcastle RVI
Barbara Evans – Head of Safeguarding and Corporate Parenting, Association of Directors of Social Services
*Barbara Gelb – Chief Executive, Association of Children’s Hospices
Becca Riley – Director, Rainbow’s Hospice, Loughborough
Bernadette O’Gorman – Palliative Care Nurse for Camden, Islington and Haringey
Carole Easton – Chief Executive, CLIC Sargent
Carole Stone – Ellenor Shining Lights
Christine English – Paediatric Oncology Outreach Nurse Specialist, Newcastle RVI
Christine Lavery – Chief Executive, Society for Mucopolysaccharide Diseases
*Christine Lenehan – Council for Disabled Children
Clare Tester – Scottish Executive
David Behan – Director of Social Care, DH
David Widdas – Consultant Nurse, Pool Bank House, Coventry and Warwickshire Partnership NHS Trust
Dr Lynda Brook – Macmillan Consultant in Paediatric Palliative Care, Royal Liverpool Children’s NHS Trust, Alder Hey
Dr Sheila Shribman – National Clinical Director for Children, DH
Dr David Vickers – Consultant Paediatrician, Cambridgeshire Primary Care Trust
*Dr Finella Craig – Palliative Care Consultant, Great Ormond Street Hospital for Children NHS Trust
Dr Richard Hain – LATCH Senior Lecturer and Honorary Consultant in Paediatric Palliative Medicine
Dr Simon Lenton – Consultant Paediatrician and Vice-President of the Royal College of Paediatrics
Elaine Edgar – DH
Fiona Smith – Adviser in Paediatric Nursing, Royal College of Nursing
*Francine Bates – Contact a Family
Ginny Storey – Commission for Social Care Inspection
Heather Wood – Chief Executive, Rainbow Trust
Helen McIndon – Children’s Commissioner, Plymouth Teaching Primary Care Trust
*Hilary Samson-Barry – DH
Hugh Cochrane – Analyst, DH
Ian Dodge – DH
Ivan Lewis – Minister for Care Services
Jacky Williams – Warwick Medical School, University of Warwick
*Jane Appleby – Vulnerable Children’s Lead, East Midlands SHA
Janet Spallen – Nurse Consultant Oncology Outreach and Palliative Care, Royal Liverpool Children’s NHS Trust, Alder Hey
Janet Vickers – Nurse Consultant Oncology Outreach and Palliative Care, Royal Liverpool Children’s NHS Trust, Alder Hey
John Copps – New Philanthropy Capital
We are extremely grateful for all the help we have received. We could not have delivered this review without the support and commitment of all those noted above along with everyone who attended our consultation events, meetings and discussion groups.

We apologise to anyone we have inadvertently missed off this list.
Hospitals
Bristol Children’s Hospital
Evelina Children’s Hospital, Guy’s and St Thomas’s NHS Foundation Trust
Gloucestershire Royal Hospital
Great Ormond Street Hospital for Children, London
Great Western Hospital, Swindon
Leicester Royal Infirmary
Ninewells NHS Hospital, Tayside
Nottingham University Hospital
Royal Belfast Hospital for Sick Children
Royal London Hospital, Whitechapel
Royal Marsden Hospital, Surrey
Sunderland Royal Hospital
University Hospital Coventry
Wolverhampton New Cross Hospital
Worcestershire Royal Hospital – BLF-Funded Orchard Service
Wrexham Maelor Hospital – North East Wales NHS Trust

Strategic Health Authorities (SHAs) and NHS Foundation, Acute and Primary Care Trusts (PCTs)
Bexley PCT, Kent
Birmingham Children’s Hospital NHS Trust
Bolton PCT
Bracknell Forest and Berkshire East PCT
Bradford and Airedale Teaching PCT
Brighton and Sussex University Hospitals Trust
Bristol PCT, Commissioners and Community Care – Joint Response
Chesterfield and North Derbyshire Royal Hospitals Foundation Trust
County Durham PCT
Croydon PCT
Cumbria PCT
Darlington PCT
Derby City PCT
Derby Hospital NHS Foundation Trust
Gateshead PCT, Children’s Trust, NHS Foundation Trust, Council and Barnardo’s Joint Response
Hull and East Yorkshire Hospitals NHS Trust
Kensington and Chelsea PCT, Kaleidoscope Palliative Care Team
Leeds PCT
Mid Cheshire NHS Trust
Middlesbrough PCT
Milton Keynes PCT
Newham PCT
Norfolk PCT
North Tyneside PCT
Northumberland PCT
Nottinghamshire County PCT
Oxford Radcliffe NHS Hospital Trust
Oxford Radcliffe NHS Hospital Trust, Helen and Douglas House Hospices
Pembrokeshire and Darwen NHS Trust
Peterborough PCT
Plymouth NHS Hospital Trust
Plymouth NHS Hospital Trust Community Nursing Service
Queen Mary’s Sidcup NHS Trust
Richmond and Twickenham PCT
Robert Jones and Agnes Hunt District Hospitals NHS Trust
Rotherham PCT
Royal Devon and Exeter NHS Foundation Trust
Royal Liverpool Children’s NHS Trust, Alder Hey
Sandwell and West Birmingham NHS Hospitals Trust
Sheffield Childrens NHS Trust
Somerset PCT
South Birmingham PCT
South Birmingham PCT, BLF-Funded Footprints Community Service
South East Essex PCT
South Gloucestershire PCT
South Tyneside PCT
Southampton City PCT and South West Hampshire Community Nursing Services
Suffolk Mental Health Partnerships NHS Trust
Surrey PCT
Sutton and Merton PCT
Swindon PCT
Telford and Wrekin PCT, Borough of Telford
Telford and Wrekin PCT Services for Children and Young People
Trafford NHS Healthcare Trust
United Bristol NHS Trust
Wakefield District PCT

Walsall Teaching PCT
Warwickshire PCT
West Sussex PCT
Western Cheshire PCT
Westminster PCT
Winchester and Eastleigh Healthcare NHS Trust
Yorkshire and Humber SHA

Hospices
Bluebell Wood Children’s Hospice, Doncaster
Brian House Children’s Hospice, Blackpool
CHASE Hospice Care for Children, Surrey
Children’s Hospice Association Scotland (CHAS)
Children’s Hospice South West
Demelza House, Kent
Derian House Children’s Hospice, Lancashire
Donna’s Dream House and Snowdrop Centre, Blackpool
East Anglia’s Children’s Hospices
Eden Valley Hospice, Carlisle
Ellenor Shining Lights Hospice at Home, Kent
Francis House Children’s Hospice, Manchester
Helen and Douglas House Hospices, Oxford
Hope House Children’s Hospices, Shropshire
Hospice Care, Isle of Man
Iain Rennie Hospice at Home, Hertfordshire
Julia’s House, Dorset
Keech Cottage Children’s Hospice, Luton
Little Haven’s Children’s Hospice, Essex
Naomi House, Wessex Children’s Trust
Rainbow Trust Children’s Charity, Surrey
Rainbows Children’s Hospice, Loughborough
Richard House Children’s Hospice, London
St Andrew’s Hospice, Grimsby
St Barnabas Hospices, West Sussex
St Martin’s House, West Yorkshire
St Oswald’s Children’s Service, Newcastle upon Tyne
Zoe’s Place Baby Hospice, Liverpool

Community teams/projects/specialist agencies
Anne Fearn – Specialist Health Visitor
Cambridge Specialist Community Children’s Nursing Teams
Children’s Home Care Team – Mid Cheshire NHS Trust
COMPASS, Somerset
Diana Children’s Community Service and Rainbows Children’s Hospice, Loughborough
Dorset Disabled Children’s Services
EPIC Children’s Respite Service, Essex
Harrow Community Nursing Service
Horizon’s Team, Gloucestershire
IQUOLS Children’s Palliative Care Team
Jigsaw Service, Eastern Wakefield PCT
Lifeforce, London
Palliative Care Subgroup of the South West Regional Paediatric Oncology Service
Star Project – Manchester PCT and Francis House Hospice
Suffolk County Wide Children’s Palliative Care Steering Group
The Lifetime Service, Bristol
The Maypole Project, South London

Universities and educational establishments
Hexham Primary School
Queen’s University Belfast
University of Exeter
University of Nottingham
University of the West of England, Bristol

Social services
Croydon Council
East Berkshire Macmillan Palliative Care Team
London Borough of Barnet
South Tyneside Council
Stockton on Tees Borough Council

Other respondents
Association for Children’s Hospices (ACH)
Association for Children’s Palliative Care (ACT)
Batten Disease Family Association
Big Lottery Fund Palliative Care Initiative
CLIC Sargent Nurses
Fair Play for Children’s Hospices Campaign
Pasque Charity
Rachel Ferris – Specialist Commissioner South West – Northern Somerset PCT
Royal College of Nursing
Society for Mucopolysaccharide Diseases
S.O.F.T. UK
The British Society of Paediatric Palliative Medicine
The Children’s Trust
ANNEX
BIBLIOGRAPHY


