



# BETTER CARE: Better Lives

Improving outcomes and experiences for children,  
young people and their families living with  
life-limiting and life-threatening conditions



## DH INFORMATION READER BOX

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## FOREWORD



The Government is determined to ensure that every child gets the best start in life, and the ongoing support they and their families need to allow them to fulfil their potential, irrespective of circumstances.

One of the most difficult things a parent has to face is being told that their child is likely to die before they will. Families bringing up children with life-limiting or life-threatening conditions have such diverse and poorly understood problems that they deserve to be given special attention. For many parents, looking after a disabled child with a complex or rare health condition is a life-long responsibility. Their children will often not grow up and leave home as other children do, and their child's requirement for complex care and support will not reduce over time as the child grows older – for many it increases as they become bigger, heavier, stronger or more challenging, and parents and carers themselves become less physically able to manage. Families that face such huge responsibilities need to be recognised and supported.

These families have most to gain from a holistic, integrated approach to service delivery. There is no longer any legislative barrier to joint working but there is evidence that a coherent, holistic approach to service commissioning often breaks down because of narrow and short-term preoccupations with budget restrictions applying to just one aspect of service need. If we can develop systems that work for these children and their families then these are likely to work equally well for families with less challenging needs.

Adequate funding in inappropriate services can be as bad as inadequate funding, and we must avoid at all costs families breaking down completely – with all the accompanying financial implications – from want of a particular service,

or of significant, regular and reliable short breaks that meet the whole family's needs.

This is why the Government is investing heavily in supporting all families with disabled children, including those who need palliative care services. Putting disabled children at the heart of the Every Child Matters agenda, we want to ensure that we couple this investment in front-line services with reform of the way local services are delivered, so they are more responsive and accountable to the needs of children and their families. Other health policy developments such as the National Institute for Health and Clinical Excellence *Improving Outcomes Guidance for Children and Young People with Cancer* and the Department of Health's *National Service Framework for Long-Term Conditions* will also have a positive impact on services for life-limited children and their families.

The package of investment we have put in place across the NHS and local authorities provides an unprecedented opportunity for local organisations to work in partnership to transform and drive up the capacity, range and quality of services for disabled children with complex health needs.

This investment, together with the recently published *Children's Plan, the NHS Operating Framework* and this first ever national strategy for children's palliative care, sets out a clear framework for all partners to work together to improve the health, wellbeing and experience of services of our young disabled population.

These families deserve our support and the Government looks forward to working with you to provide it.

Alan Johnson MP  
Secretary of State for Health

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

## MINISTERIAL FOREWORD



I am delighted to contribute a few words to this direction-setting document for the future of palliative care services for children and young people.

The recently published report of the Independent Review of Palliative Care Services for Children and Young People in England and the joint Treasury and Department for Education and Skills report into services for disabled children – *Aiming High for Disabled Children* – offer an important opportunity to advance the agenda for these groups of very vulnerable children and their families. These complementary and hard-hitting reports have shown us what we must do to arrive at a point where all children have the opportunity to realise their potential, regardless of their condition or disability.

This document builds, in particular, on the excellent work undertaken by Professor Sir Alan Craft and Sue Killen on the Independent Review of Children's Palliative Care Services. Their report sets out clear expectations for improving choice, access and continuity of care, and seeks to place palliative care at the centre of local children's service provision.

Our aim now is to align this work with the wider activity on improving services for all disabled children. Only in this way will we achieve the step change in overall service provision that is so badly needed.

### Family-focused services

I know from speaking with parents and carers that living with and looking after a child or young person with a life-limiting or life-threatening condition presents significant challenges – not only in physical and emotional terms, but also in

negotiating the intricacies of the health and social care systems in order to secure the services the family needs. These challenges are particularly acute when a child and family are faced with limited life expectancy.

These families in particular want more convenient, more personal, more community-based care. They want different agencies to work together, so they don't have to repeat stories, fill in different forms and have lots of separate assessments or appointments. They also need continuity of care – so their child can be cared for at times of crisis by professionals they know and trust, in an environment of their choice wherever possible.

For these ideals to become a reality, we need services that are designed with full input from the service user as a matter of course. Health and social care commissioners, providers and regulators are crucial here as they have the power to improve services to meet the needs of local people by putting individual and community engagement at the centre of the commissioning and decision-making processes.

These changes can only really happen at local level. It is here we can best break down the barriers between health and social care and bring in the expertise and experience of the voluntary sector in delivering services. The challenge is to achieve true partnership working by focusing commissioning activity on delivering the best outcomes for children and young people and their families.

This document gives examples of the kind of joined-up commissioning that is key to achieving the equitable and sustainable services needed.



## The Government's commitment

In addition to the recently announced funding package for disabled children's services in *Aiming High for Disabled Children* and *The Children's Plan* for the NHS, new growth funding has been included in baseline allocations to enable primary care trusts to work with local authorities to increase significantly the range of services for children and young people. This includes substantial funding for short breaks and to support the service in responding to the needs of children and young people requiring palliative care, focusing on building a sustainable service of palliative care networks and support for community nursing teams. Improving the quality and experience of palliative care services has been identified as a priority in the *NHS Operating Framework for 2008/09*, and we expect significant progress to be made in this area.

Everything is in place for us to start transforming these vital services. There is much to do and we must not fail the families who live with these challenging situations every day of their lives. This is about a service-wide push to drive up quality and standards, which relies on getting everything – personalised services, commissioning frameworks, the right capacity – to work together to achieve the best possible outcomes for parents and children.

For the Government's part, we will continue to monitor progress, for example through:

- the priorities set out in the *NHS Operating Framework* and *The Children's Plan*;
- the disability indicator under the Public Service Agreement;

- improved patient and public involvement;
- an expansion of the current child health service mapping programme; and
- pursuing discussions with the regulatory bodies on future review and inspection mechanisms.

## And finally...

I am extremely grateful to the steering group of key stakeholders that have supported this work (a list is attached at Annex A) as well as all those who contributed their views to the Independent Review. I hope that in producing this document and in the follow-up work, we will do justice to the service and organisation needs you have identified – and I trust that you will continue to play a vital role in its delivery.

I look forward to working closely with you as we set about making real our vision of high-quality children's palliative care services.



Ivan Lewis MP  
Parliamentary Under-Secretary of State  
for Care Services

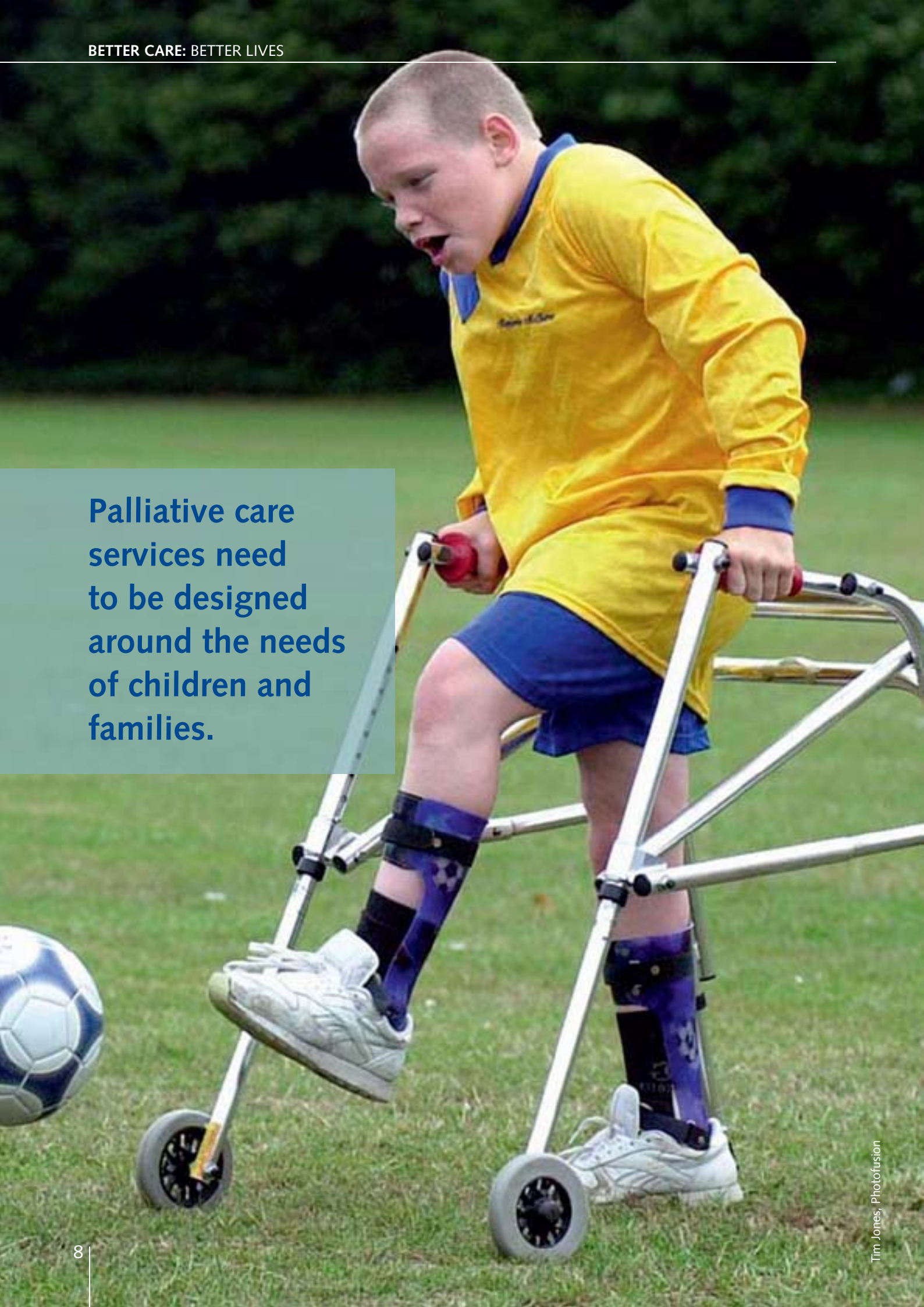


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Palliative care services need to be designed around the needs of children and families.





## MY LIFE WOULD BE EASIER IF...

More people understood what is the matter with me so that I didn't have to keep explaining what is wrong and how to look after me.

I didn't have to wait months for a wheelchair so that I will have grown out of it by the time I get it – or maybe I won't even be alive when it arrives.

I was able to go to school regularly and play with my friends as near to home as possible, with the help I need to help me join in the lessons and look after me while I am there.

I could benefit from the services offered by hospices more.

I had someone to look after me so that my mum and dad could go out for the evening.

I had someone I could talk to when I am sad.

Mummy and daddy could get help at home to look after me as soon as they need it so they didn't have to manage on their own.

There were nurses who could look after me at home rather than having to go into hospital.

There was someone to look after my mum and dad and brothers and sisters when I die so that they aren't sad.

**Services will be commissioned and delivered in line with identified local need and national policy, and driven by best practice.**



## THE VISION

Every child and young person with a life-limiting or life-threatening condition will have equitable access to high-quality, family-centred, sustainable care and support, with services provided in a setting of choice, according to the child and family's wishes.

Services will be:

- responsive to and respectful of the diverse needs of children, their families and carers; and
- built around a philosophy of 'children first' – i.e. adopting a needs-led, problem-solving approach rather than relying on diagnostic labels, enabling families to pursue ordinary lives and see their children achieve their full potential.

To achieve this, the commissioning and delivery of services will be planned strategically and developed in close partnership between:

- healthcare;
- education;
- children's services; and
- voluntary sector organisations.

Services will be commissioned and delivered in line with identified local need and national policy, and driven by best practice. There will be full integration of services with a seamless transition of care between primary, secondary and tertiary healthcare settings, and close partnership working between healthcare, education, social services and voluntary sector organisations.

Services will be configured and organised to enable access to the following key components:

- an early, inclusive, joint (health and social care) assessment of need;
- an identified key worker/lead professional with responsibility and authority for negotiating and co-ordinating packages of care;
- care that is planned and delivered in full consultation and partnership between the child and family, and service providers;
- clear, comprehensive information and support regarding the child's condition, including sources of further support;
- practical assistance and timely provision of equipment and adaptations;
- universal provision of emotional, psychological, spiritual and bereavement support for the family (including siblings), carers and wider community;
- education and learning appropriate to the age and stage of development of the child or young person;
- play and recreational opportunities;
- specialist short breaks with appropriate healthcare, nursing and medical input;
- access to responsive care and support from staff skilled in children's palliative care management; and
- better advanced and emergency care planning to enable the child to die in their preferred place of care.

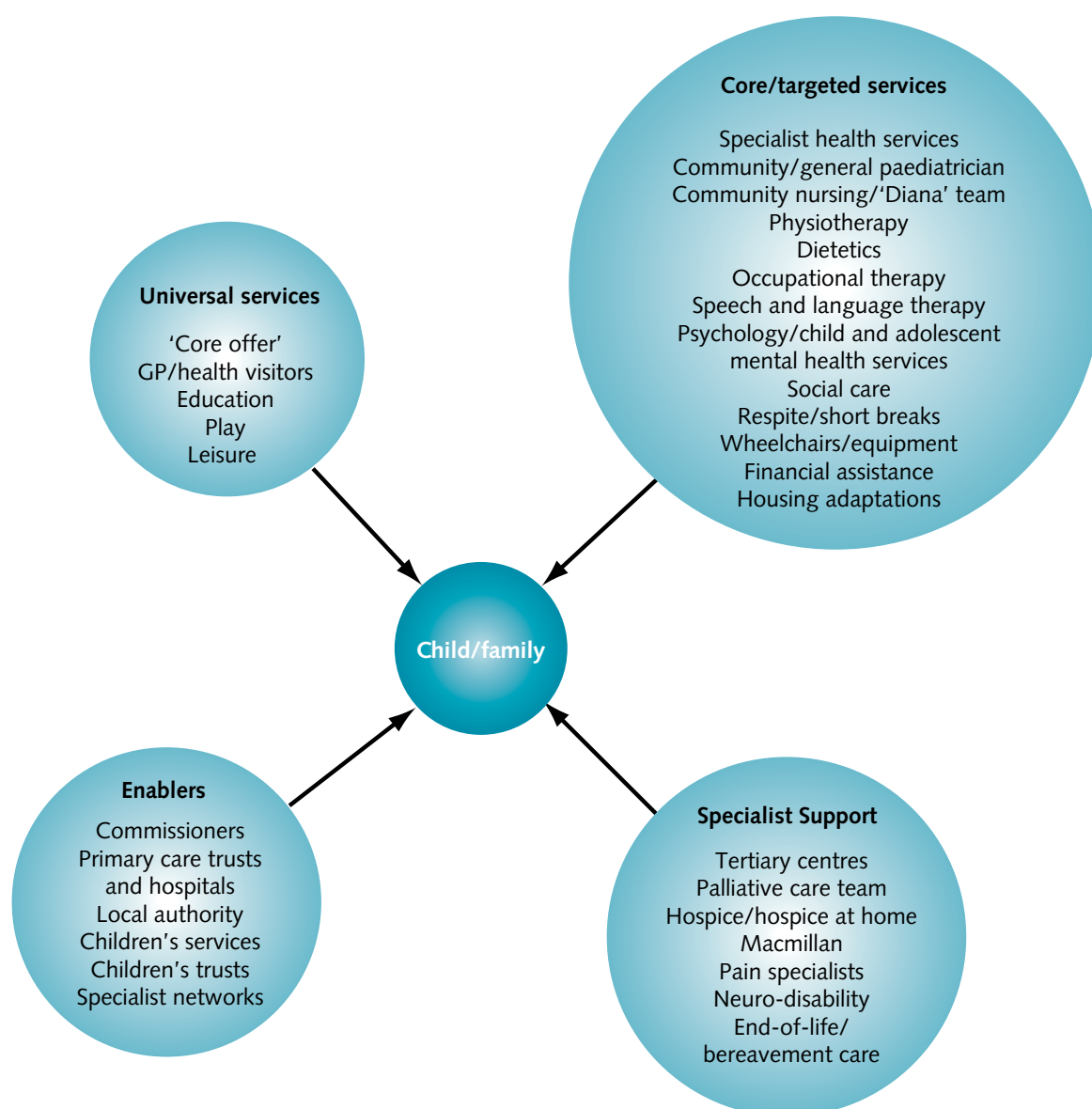


## Delivering the vision

We are at a turning point in improving outcomes and experiences for all children and young people with life-limiting and life-threatening conditions, including those with a disability. The findings of the Independent Review of Children's Palliative Care Services and the cross-government programme Aiming High for Disabled Children are backed by a significant financial commitment. This will help deliver the step change in service provision that is needed for these children, young people and their families, all of whom wish to pursue ordinary lives, achieve their full potential and make a contribution to society.

To achieve this vision we need a fully integrated approach among key delivery partners from the statutory and voluntary sectors. Only in this way can we ensure that a choice/range of services is available when needed to enable the child or young person to live as full a life as possible, as well as providing the necessary support to their family.

Above all, services need to be designed around the needs of children and families rather than the criteria of different agencies or organisations – or professional boundaries. Key service elements are mapped in the diagram below.





**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.**

## INTRODUCTION

'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 enhancements of the 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.'

(Association for Children's Palliative Care/Royal College of Paediatrics and Child Health Guide, 2003)

This document sets out future directions for children's palliative care services and the systems in which these sit. It builds on the *Palliative Care Services for Children and Young People in England*, published in May 2007. Part of the review was a wide-ranging consultation involving:

- key sector stakeholders;
- health and social care professionals;
- children, young people and their families;
- the voluntary sector; and
- key academics and researchers.

The Government accepted and endorsed the recommendations contained in the report. This document is the next step in the process of change.

### Aims of this document

This document is intended to:

- highlight the key aspects of the Independent Review of Children's Palliative Care Services, which reported in May 2007;
- challenge and inspire local commissioners to champion the needs of this patient group and devise local strategies to meet them; and
- act as a framework for future service delivery for local commissioners and service planners/providers, with information on the services that should be available and guidance on how they should be delivered.

### Context: palliative care for children and young people

Palliative care for children starts at diagnosis and is about making life experiences better for children and young people who are diagnosed with life-limiting and life-threatening conditions. The range of illnesses, many of which are rare, and symptoms, many of which are common, makes it hard to define and predict care needs.



The time span of many children's illnesses may mean that palliative care extends over many years. Moreover, children may continue to develop physically, emotionally and cognitively throughout the course of their condition, and this affects both their health and social needs, as well as their understanding of disease and death. Healthy children and young people mainly live in families and are encouraged to be part of a wider community such as school, and religious and recreational groups. The effect of a child or young person having a life-limiting or life-threatening condition impacts not only on the child themselves but also on the whole family and the wider communities in which they live. This impact should not be underestimated.

As the Independent Review noted, the needs of children and young people with life-limiting and life-threatening conditions are, on a day-to-day basis, often the same as those who have disabilities or other complex health needs. They require high-quality, accessible, responsive services, matched to individual need, focused on improving their life experience. Inevitably, however, there will be times when an acute illness or incident, a deterioration in the underlying condition or rapid symptom changes will progress very quickly and there will be a need for crisis support and end-of-life care.

Children's palliative care is often seen as a specialist 'niche' medical service. This is only partly true. What is often lacking is a much wider assessment of what an individual child or young person requires in terms of general, day-

to-day services, many of which are provided by or in partnership with local authorities and the voluntary sector.

Palliative care for children is about providing a continuum of care – from the provision of universal services for children (e.g. education, social care, transport, home help, short breaks etc.) through acute care and the management of the individual child and family, to very specialist support such as that provided by tertiary centres and specialist bereavement services.

It is imperative that access to the specialist and non-specialist elements of the system are joined together to enable better choice, experiences and outcomes.

## Challenges for commissioners and service providers

In order to deliver the vision of children's palliative care services, we must face up to the challenges that currently make it difficult to provide the most effective support for families. These include:

- the change in the profile of children with life-limiting or life-threatening conditions over the last 20 years due to technological advances and increased survival rates of low-birthweight babies;
- poor co-ordination of public services across the statutory and voluntary sectors, particularly transition between children's and adult services, to address the wider family's needs;

- little acknowledgement of the need for earlier interventions and assessments;
- insufficient investment in local prevention strategies or timely referral to specialist services;
- high thresholds/eligibility criteria for accessing existing palliative care services;
- insufficient prioritisation for children with life-limiting or life-threatening conditions, and short-term funding;
- lack of transparency/agreement between budget holders on who will fund which aspect of care and support;
- lack of capability, capacity and equity within universal services to meet many of the needs of these children (and related workforce issues, including a shortage of specialist staff);
- lack of information, consultation and empowerment for children with life-limiting or life-threatening conditions and their families; and
- the need for a range of specialist short breaks which would include breaks in the home, in children's hospices and with other voluntary sector providers, as well as better co-ordinated specialist support.


## Costs and cost-effectiveness

It is clear from current service provision that children with life-limiting and life-threatening conditions present a range of complex and potentially expensive challenges to children's services.

There are likely to be considerable advantages to joint commissioning and planning between neighbouring primary care trusts and local authorities for specialised services. This reduces the burden on families and ensures that local services are better placed to take a comprehensive approach to meeting needs.

In order to plan sustainable services for the future, commissioners will need to adopt a joint approach, involving key partners and stakeholders in designing and delivering services.

This document provides a framework from which local areas can build their own delivery strategies. This framework is underpinned with new funding to ensure better outcomes for children and families. Children's trusts commissioners and service providers will be ultimately responsible for ensuring that services are accessible to all who need them.

A young girl with a mustache is using a metal walker in a school hallway. She is wearing a blue knitted sweater and green pants. In the background, a boy with a mustache is walking towards the camera, wearing a black sweater with 'SKI' written on it. The hallway has a wooden floor and a white wall with a 'WINTER' sign and a green Christmas tree decoration.

The Government believes that disabled children [including those with life-limiting or life-threatening conditions] should be considered both a local and a national priority.



## MAKING CHANGE HAPPEN

The Government is committed to working with key partners in the voluntary and statutory sectors to set what is now a shared agenda to achieve real and lasting change, particularly in improving experiences and outcomes for children with life-limiting and life-threatening conditions, including those who have disabilities or complex health needs.

**Partnership working is crucial.** It is a core principle running through a number of key policies and priorities – the *Every Child Matters: Change for Children*<sup>1</sup> agenda, the *National Service Framework for Children, Young People and Maternity Services*,<sup>2</sup> *Making it Better for Children and Young People*,<sup>3</sup> *Aiming High for Disabled Children*<sup>4</sup> and *The Children's Plan*.<sup>5</sup>

These complementary partnership visions across the NHS and local government help embed the aims set out in the *Commissioning Framework for Health and Well-being*<sup>6</sup> and in *The Children's Plan*, which confirmed the Government's commitment to improving health outcomes for children and young people and announced a child health strategy to be published in spring 2008.

The Government believes that disabled children, including those with life-limiting or life-threatening conditions, should be considered both a local and a national priority. Much has been achieved under Every Child Matters and the Children's National Service Framework, but there is a need to do much more.

To ensure that children's palliative care services are given sufficient priority, are planned effectively and are fit for purpose, the following eight strategic service development goals have been identified:

1. Improved data.
2. Equality of access to universal services.
3. Responsible and accountable leadership.
4. Choice in preferred place of care and expansion of community services.
5. Better end-of-life care.
6. Stronger commissioning and value for money.
7. Successful transition between children's and adult services.
8. Planning and developing an effective and responsive workforce.

These goals should be central to the care and management of all children with a range of long-term conditions, including those who are disabled

1 Department for Education and Skills/Department of Health, 2004

2 Department for Education and Skills/Department of Health, 2004

3 Department of Health, 2007

4 HM Treasury/Department for Education and Skills, 2007

5 Department for Children, Schools and Families, 2007

6 Department of Health, 2007

and those with other complex health needs. Palliative care should form a thread through the lives of these children, and this strategy seeks to place palliative care firmly on the agenda of those responsible and accountable for local provision of children's services.

The Independent Review of Children's Palliative Care Services and *Aiming High for Disabled Children* have given a renewed focus on the needs of these children, as well as informing the 2007 Comprehensive Spending Review (CSR). It is now a crucial time in the debate as key stakeholders and the Government come together to discuss ways to improve services for all disabled children and their families, including those with palliative care needs.

## Funding and future service development

The Government has identified significant funding for both the NHS and local government through the 2007 CSR. This is in addition to the funding already announced to support the cross-government *Aiming High for Disabled Children* programme. This new investment is designed to boost the provision of vital services for disabled children as well as giving them and their families a real choice as to how they are delivered.

Substantial additional growth funding is being directed to primary care trust (PCT) baseline allocations so that they can:

- increase the level and range of specialist short breaks for children with disabilities, including those with life-limiting and life-threatening conditions;
- support improvements in the overall provision and availability of palliative care services, in particular 24-hour crisis support;
- support capacity building, including building palliative care networks.

**We are working to help ensure that children and young people with life-threatening and life-limiting conditions benefit substantially from this investment.**

## Funding priorities: children's palliative care

The Independent Review identified three key funding priorities to improve the quality and experience of children's palliative care services. Commissioners will want to take these into account when allocating the new CSR funding.

### Children's community nursing teams

As noted by the Independent Review, children's community nursing teams are the bedrock of local service provision for children and young people with palliative care needs. Additional capacity is provided in many areas by palliative care teams set up with Big Lottery Fund monies and by the 'Diana' nursing teams established as a permanent memorial to the late Princess of Wales. The extra Government funding announced through the CSR allows for local areas to support these teams and to explore how best to move towards a multidisciplinary approach and a more holistic care package in a location of the child and family's choice. Commissioners will need to consider how this new funding can enable the development of children's community nursing services capable of providing an all-round care package, including end-of-life care, 24 hours a day, seven days a week in the location that the child and family prefer.

The Department of Health, through its mapping of children's services, will check progress on the development and sustainability of these teams, and on the building of capacity in children's palliative care services generally.

### Short breaks

The Independent Review also identified a lack of short breaks as a key issue for families. The new money being made available to the health service and local government through *Aiming High for Disabled Children* is intended to ensure that all children with life-limiting or life-threatening conditions and their families can access the specialist short breaks they need, whether at

home, in a children's hospice or other voluntary sector provider, or in the community.

### Children's palliative care networks

Networks have the potential to ensure that the right people work together, sharing best practice and planning services effectively. They also offer the potential for feeding in the voices of service users at a more strategic level. In some areas, palliative care networks are working well. Where this is the case, they are beginning to join services together more effectively, and are providing a route through which the voluntary sector – including children's hospices – engages more effectively, as well as providing a focal point for more strategic planning within regions.

The range of services involved and the overlap between health and social care points to the value of developing palliative care networks and devising a planning/strategy framework that includes PCTs, local authorities and children's trusts. Given the need to strengthen delivery, local areas should develop networks which require some funding to increase their capacity.

### Public Service Agreements

Since their introduction in the 1988 CSR, Public Service Agreements (PSAs) have played a pivotal role in focusing public service delivery and driving improvements in outcomes. To build on this success, over the past two years the Government has been working with front-line professionals, the public and experts to renew the performance management framework for the next generation.

New PSAs set out the key priority outcomes the Government wants to achieve in the next Spending Review period. Each PSA is



underpinned by a single Delivery Agreement shared across all contributing departments and developed in consultation with delivery partners. The PSAs also describe the small basket of national outcome-focused performance indicators that will be used to measure progress towards each PSA.

Within the Delivery Agreement for PSA 12 ('Improve the health and wellbeing of children and young people') is indicator 5, aimed specifically at children with disabilities, including those with life-limiting or life-threatening conditions requiring palliative care.

#### **Indicator 5: Improving services for disabled children**

This is a new indicator, which will be based on parents' experience of services and the 'core offer' principles made in *Aiming High for Disabled Children*, which are:

- clear information;
- transparent eligibility criteria and process for accessing services;
- multi-agency assessment;
- participation in shaping local services; and
- clear and meaningful feedback to complaints.

The measure will cover the families of all children with disabilities, including those with palliative care needs, and will ask about all services provided by their local authority and PCT. By 2011, disabled young people and their parents should be able to report a more favourable experience of these services.

### **Monitoring**

Indicators underpinning the PSA form part of the local government National Indicator Set (NIS). Performance against these indicators will form part of each local area's discussions about Local Area Agreement (LAA) priorities. Where local performance against one of the indicators is poor and improvement is considered a local priority, the local authority and its partners will agree a specific local improvement target with the Government as part of the LAA process.

The LAA arrangements are consistent with the unified performance framework the Department of Health is developing for health and social care. The framework is based on a move away from centrally driven targets towards a 'self-improving system' whereby patients/service users and local commissioners decide how services are developed and used locally. The new framework is supported by NHS metrics, which covers the full range of health and adult social care services and maps across to the NIS.

It is vital that all children are able to access the full range of universal services, including education, childcare and GPs.



## SERVICE DEVELOPMENT: STRATEGIC GOALS

### 1. Improved data

**Goal:** Better data collection to enable evidence-based decision making and commissioning at a local level.

#### Background

One of the biggest challenges facing children's palliative care commissioners, providers and service users is a lack of uniform, regular and accurate information about the nature of life-limiting conditions and the services available to support them. This means that it is difficult to effectively plan, commission and deliver services to children and families where they are most needed. Equally, without this source of information, it is impossible to predict need, track prevalence or spot trends.

To enable improvements in future service provision, it is necessary for primary care trusts (PCTs), children's trusts and local authorities to be well informed about the needs of children who require palliative care within their local population, and to have systems in place to monitor the services they are providing and to assess their overall effectiveness, quality and efficiency. Local assessments should identify:

- the number of children with life-limiting and life-threatening conditions including those with disabilities and continuing complex health needs (including trend information to enable projections of numbers for the next 5–10 years);

- mapping of existing services to identify service overlaps and gaps;
- uptake of existing services and user satisfaction;
- service costs and value for money; and
- workforce numbers, skills and competencies.

#### Data sources and techniques

Possible data sources include:

- local public health data;
- the Child Health Mapping Project;
- the Children in Need census;
- disabled children's registers;
- special educational needs partnership information;
- mortality and prevalence data (national and local);
- Association for Children's Palliative Care/ Association of Children's Hospices Mapping Programme (see box on following page); and
- the National Service Framework (NSF) Standard 8 Audit Tool.

Population needs and current or potential service gaps may be assessed by a process of benchmarking existing statutory and voluntary sector services against current service standards (i.e. NSF standards, joint strategic needs assessments and the choices and experiences of service users). Local health equity audits and equality impact assessments are also helpful.



### **Case study – Children's palliative care minimum dataset and services mapping initiative**

The national implementation of a children's palliative care minimum dataset (MDS) is being facilitated by partnership working between the Association of Children's Palliative Care (ACT), the Association of Children's Hospices and the NHS. The MDS has been designed to specifically enable accurate collection of data on life-limited and life-threatened children who require palliative care. The MDS is accompanied by a series of questionnaires to capture information about the type and level of services available in the statutory and voluntary sector in each region.

The MDS and services information is collected locally, through provider organisations within networks, and collated to provide each network with accurate local information for commissioning and quality assurance. A secure national database will be established to collate data from each region and provide

national comparison of numbers of children with life-limiting and life-threatening conditions and the services available to them. Services information will also be available via an online national service directory.

The standardisation of data collection and service mapping will enable a joined-up picture to be produced of the numbers of children with life-limiting and life-threatening conditions, as well as a comprehensive map of the national provision of services.

The MDS and services questionnaires have been developed and piloted in Merseyside and Cheshire by a team from the Merseyside and Cheshire Children and Young People's Palliative Care Clinical Network, led by Dr Lynda Brook.

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Tracking the experience of users can provide useful information for refining services and is a crucial element of the 'core offer' to parents, which is being introduced as part of the *Aiming High for Disabled Children* programme.

To help the spread of best practice in local authorities and PCTs for supporting disabled children, two expert groups (an Improving Data Group and a Disability Definition Group) will be formed to take forward this commitment to ensure services can be effectively planned and tailored to meet local needs. These groups will advise on the methodology of data collection and move towards a common agreed terminology and criteria for assessing disabled children and at what level.

### Moving forward

*Aiming High for Disabled Children* made a commitment to:

*better local level data on disabled children and regular monitoring of the progress made on improving outcomes for disabled children, with much greater use of comparisons across the country to judge how different local areas are performing.*

### Roles and responsibilities

Key roles	Responsibilities
Commissioners	<ul style="list-style-type: none"> <li>• Data collection and analysis</li> <li>• Service standards, specification and contract monitoring</li> <li>• Collaboration with service providers</li> </ul>
Service providers	<ul style="list-style-type: none"> <li>• Develop and provide services reflecting service specification</li> <li>• Collect user satisfaction information</li> <li>• Inform commissioners on trends</li> <li>• Working with commissioners to ensure that services are continually reviewed and fit for purpose</li> </ul>
Regulators	<ul style="list-style-type: none"> <li>• Develop and implement systems for monitoring standards of service delivery</li> </ul>

## 2. Equality of access to universal services

**Goal:** All children will have equal access to universal/generic services, regardless of their condition.

### Background

Irrespective of their condition, all children need to experience life as a child. This means being able to achieve the outcomes as described in *Every Child Matters*, and in particular staying safe, being healthy, and enjoying and achieving. In essence, this means being able to grow, learn, develop and achieve their potential, within the constraints of their illness or condition.

It is vital that all children – including those with life-limiting and life-threatening conditions and those who are disabled or who have complex health needs – are able to access the full range of universal services. These span mainstream children's services, such as:

- education (in both mainstream or special schools);
- childcare and play therapists; and
- GPs;

to more generic support such as:

- transport;
- housing adaptations;
- home help;
- wheelchairs and community equipment;
- information; and
- short breaks services.

### Information and service provision

All children with life-limiting or life-threatening conditions are likely to be known to universal services, such as their GP, health visitors and education services. These services should be able to inform children and their families about what services they can offer, and work in partnership to ensure that support is timely, accessible and effective. Earlier assessments will ensure more responsive and appropriate referrals to specialist services.

Where children and young people need extra support to enable them to access education, playgroups, etc., these services need to be flexible in approach and delivery to meet the needs of the child and family.

### Moving forward: joined-up services

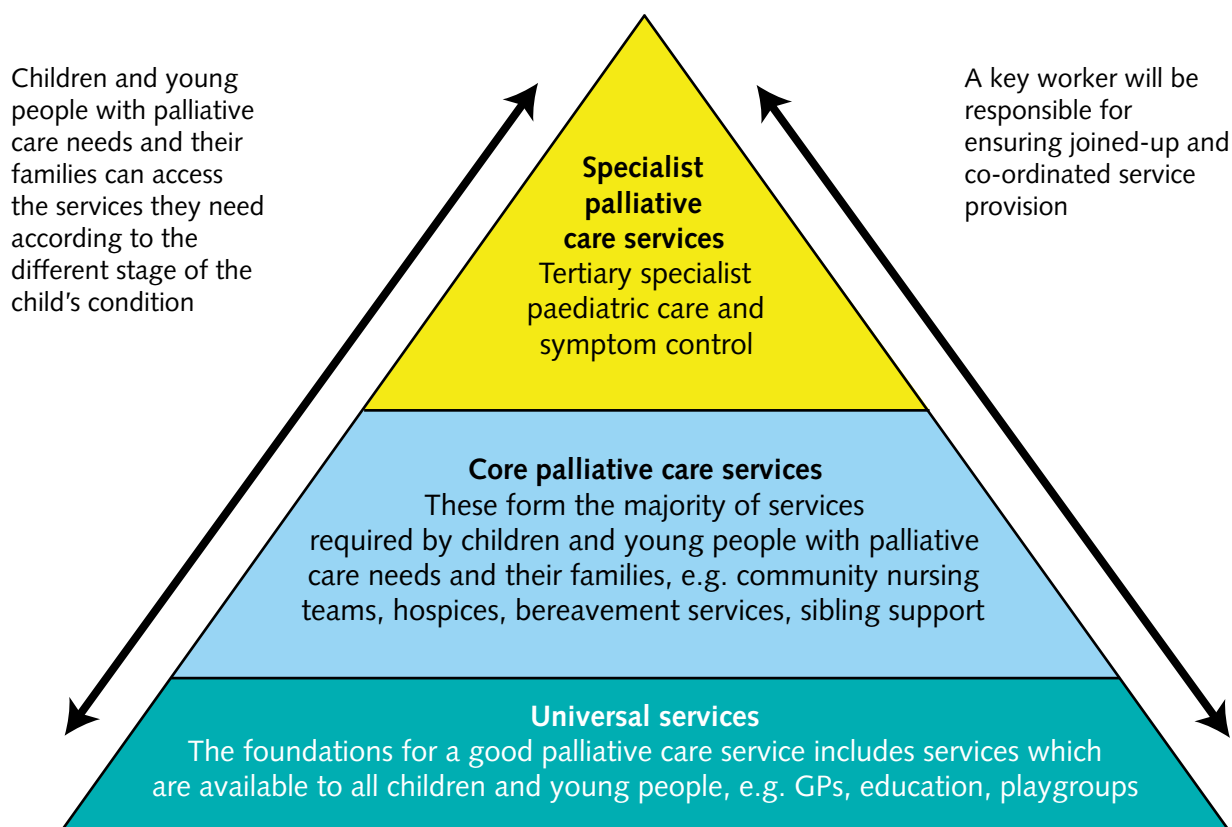
Local partners need to work together to identify the services best placed to meet the needs of the child and where these services are best delivered. Traditional methods of service delivery may need to be reviewed so that children and their families are able to access services in places and at times that are convenient. In some cases, this may mean taking the services to the child.

It is important that children and families with additional needs, such as those with life-limiting or life-threatening conditions or disabilities are equally able to access universal services. This will depend, crucially, on PCTs, children's trusts and local authorities developing a co-ordinated approach.

Mechanisms to achieve this will need to include:

- joint assessment of need and care planning between organisations using the Common Assessment Framework – and incorporating more specialist assessments, as appropriate;
- joint funding or aligned budgets; and
- an agreed decision-making formula – e.g. the Decision Support Tool currently in development for the National Framework for the Assessment of Children's Continuing Care.





### Roles and responsibilities

Key roles	Responsibilities
Commissioners	<ul style="list-style-type: none"> <li>• Data collection and analysis</li> <li>• Service standards, specification and contract monitoring</li> <li>• Demographic knowledge and understanding</li> <li>• Develop ability to commission responsibly from a variety of providers</li> </ul>
Service providers	<ul style="list-style-type: none"> <li>• Plan, develop and implement provision of equitable and accessible services, including culturally sensitive services</li> <li>• Development of culturally aware staff</li> <li>• Evidence of ability to respond rapidly to differing and changing needs</li> </ul>
Regulators	<ul style="list-style-type: none"> <li>• Performance review of service provision</li> </ul>

### 3. Responsible and accountable leadership

**Goal:** Strong and visible leadership, across the whole sector, with key people responsible and accountable for effective and efficient service design and delivery.

#### Background

All too often, responsibility and accountability for children's services, particularly in respect of disabled children and those needing palliative care has taken the form of a single line in a job description, often as an add-on to a broader role and without specifying the knowledge, experience or understanding that should go with that responsibility. This needs to change.

It is vital that there is high-level leadership accountability for the development of sustainable services for children with life-limiting and life-threatening conditions. This role demands a sound knowledge of the complexity of the issues around children's policy and service development, and of the diverse needs of children and their families.

#### The approach

Strong local and regional partnerships need to be established and maintained, based on a common understanding of the issues affecting children with life-limiting and life-threatening conditions, as well as those with disabilities and complex health needs, to lead and manage multi-agency and multidisciplinary teams in children's services.

This could be achieved by identifying a senior clinician with specialist skills, knowledge of and expertise in working with children and families with palliative care needs to provide strategic leadership for future service development. Given the relatively low numbers of children with life-limiting and life-threatening conditions, it is likely that this role would be most effective working across a cluster of PCTs or a regional or other geographical area. Some areas may also consider developing local champions to take this work forward.

#### Moving forward: the role of networks

In order to improve and enhance the understanding and awareness of the needs of children with life-limiting and life-threatening conditions, local networks, jointly developed with local authorities and children's trusts, can be an effective model of service provision. Regional networks are needed at strategic health authority/ Government Office level, in order to be operationally relevant and efficient.

These multi-professional, multi-organisational networks could sit alongside the adult palliative care networks. This would promote and enable joint working across the issue of transition from children's to adult services.

Opportunities may also exist to link new networks into existing networks – e.g. cancer, neonatal, etc. The advantage is that these networks are already established and operational, with senior organisational commitment.

The structure of the new networks and the way in which they relate and integrate with other existing networks (e.g. PCT-cluster networks or cancer networks) should, however, be flexible in order to maximise their impact locally.

The networks will provide the forum in which:

- better integrated and more effective commissioning models can be developed and shared;
- statutory and voluntary agencies will work together to provide an agreed and comprehensive range of services;
- local needs can be assessed, through mapping of affected children and young people and available services (this would be via children's trust arrangements);
- skills, knowledge and expertise can be exchanged;
- local service users can be involved and included in service development;

- care pathways can be implemented;
- more equitable services can be developed;
- training and development opportunities for staff can be developed at a more strategic level across all agencies; and
- development of a recruitment and retention strategy can be pursued.

The Department of Health will provide some additional support – over and above the growth monies announced via the Comprehensive Spending Review 2007 – to develop the networks.

### Roles and responsibilities

Key roles	Responsibilities
Strategic health authorities	<ul style="list-style-type: none"> <li>• Development of networks – ensure they are established and functional</li> <li>• Ensure that there is co-ordination/cohesion of service provision across the area</li> </ul>
PCTs/children's trusts	<ul style="list-style-type: none"> <li>• Demographic knowledge and understanding</li> <li>• Ensure that there is one person who is not only accountable for the monitoring of the services commissioned and provided, but also able to demonstrate appropriate knowledge and understanding of the needs of children and their families</li> </ul>



#### 4. Choice in preferred place of care and expansion of community services

**Goal:** To ensure that all children have a choice on location of care, 24-hour access to multidisciplinary community teams and, when needed, specialist palliative care advice and services.

##### Background

The Government is committed to offering service users more choice as to where they receive care. Evidence from the Independent Review tells us that families want more care provided in the community setting – preferably at or close to home, or in a home-from-home setting such as a children's hospice – so that, as far as possible, they are able to continue family life with minimal disruption.

of York<sup>7</sup> – to demonstrate an increased financial cost associated with repeated and prolonged admissions to hospital, while at the same time identifying cost savings and benefits to the quality of patient care by having more care provided in the community. There are sound financial arguments in favour of delivering care outside traditional hospital settings where appropriate.

The York study confirmed that, due to a general lack of community-based support, there are many unnecessary admissions to hospital in the evenings, overnight and at weekends, and that too many children attend outpatient clinics on a regular basis for simple tasks, such as blood tests, which could be undertaken in the home. This inflation of hospital-based activity puts enormous strain on the system, is expensive to manage and is not in the best interests of the child and family.

Successful provision and delivery of the best possible palliative care services, including choice as to where and by whom these services are delivered, will demand full engagement of all service providers in the statutory and voluntary sector, commissioners and partner organisations.

##### Over-reliance on hospital-based care

The Independent Review offered compelling evidence – via analytical work undertaken by the Health Economics Consortium at the University

The challenge is for PCTs, local authorities and voluntary agencies, through their children's trust arrangements, to work in close collaboration to ensure the development of multi-agency community teams with the skills and competence to provide the full range of planned and co-ordinated health, education and social care. Effective discharge planning is also required, to avoid unnecessarily long admissions and delayed discharges.

<sup>7</sup> Independent Review of Palliative Care Services for Children and Young People: Economic Study, Lowson et al., May 2007

### Moving forward: multidisciplinary children's community teams

For families, continuity is paramount and particularly so in time of crisis. Families would not suddenly want to have a new team of professionals at the end of their child's life as they will have developed relationships with their existing team, who understand the child and will listen to them as parents. Accordingly, there should also be 24-hour access to advice and support, including for specialised end-of-life care. Within this, there is a need to make the distinction between 24-hour access to advice and tertiary centres to support professionals and the need for 24-hour access to advice and support for families from professionals that they know and trust. Both are needed.

Most areas have a children's community nursing (CCN) team. Some may also have Big Lottery Funded or 'Diana' teams offering additional, targeted resource and specialist expertise. Although the size, sustainability and skill mix of these teams varies (and some receive only the bare minimum of support), they provide a sound base from which to develop more comprehensive service provision for children and families at a local level. It is essential that these teams are protected and expanded. There should be children's palliative care expertise available, either within the team or across areas where cluster arrangements are developed. 'Diana' teams provide an effective model from which to build palliative care expertise within teams. 'Diana'

teams also provide an effective model which could be developed in many parts of the country.

Multi-professional, multi-agency staffing of teams should ideally include representatives of the following groups:

- core community children's nurses;
- providers of specialist medical support;
- carers;
- psychologists/bereavement specialists;
- education providers;
- health visitors;
- school nurses;
- allied healthcare professionals (occupational therapists, speech and language therapists, dieticians, physiotherapists, etc.); and
- social workers.

### Moving forward: short breaks

In supporting the *Aiming High for Disabled Children* programme, the Government has made a very substantial financial commitment to increasing the provision of respite care and short breaks and has identified significantly increasing the range of short breaks as a priority in the *NHS Operating Framework for 2008/09*. The expectation is that by 2011 children, young people and their families will be offered a choice of short break services in keeping with a Full Service Offer (FSO) to be set out by the Government in guidance.<sup>8</sup> This will include specialist short breaks when needed, close to

<sup>8</sup> Available from [www.everychildmatters.gov.uk/socialcare/disabledchildren/aiminghigh/progress](http://www.everychildmatters.gov.uk/socialcare/disabledchildren/aiminghigh/progress) from Spring 2008

home, via the extension of existing services, and/or the development of new ones. PCTs and local authorities will need to work together during the 2008–11 period to meet the FSO and will be aided in doing so through dedicated national support arrangements.

Children's hospices and a range of other voluntary sector providers play an important role in providing specialist short breaks for life-limited children or for family-centred short breaks. The new funding presents clear opportunities for the voluntary sector to expand existing services and/or develop new provision.

### Examples of short break provision

**Hospice/hospice at home** – help families achieve a break together or time to themselves in a home-from-home environment, or in the family's own home.

**Sitting services** – people who regularly visit the child in his or her own home, enabling parents to spend time with their other children, have an evening out or even to do the shopping.

**Befrienders/activity services** – people who take the child out into the community, for example to the cinema, swimming, parks, shopping, and a wide variety of other activities.

**Short break fostering** – people who look after the child in the carer's own home, perhaps for one night, a weekend or longer, depending on the child's needs.

**Community houses** – where children and young people can have the opportunity to be creative with arts, crafts, cooking, baking and going out for activities within the community.

**Domiciliary care** – care provided at home which gives help with personal care and domestic tasks.

### Roles and responsibilities

Key roles	Responsibilities
PCT/local authority/ children's trust commissioners	<ul style="list-style-type: none"> <li>• Develop a vision of a local palliative care provision to inform future commissioning</li> <li>• Service specifications based on needs assessments and accurate data</li> <li>• Monitoring of contracts and outcomes</li> <li>• Market stimulation and development</li> </ul>
Service providers	<ul style="list-style-type: none"> <li>• Provision of service as outlined in specification</li> <li>• Evidence of and demonstration of ability to act/react in a timely and appropriate manner</li> <li>• Evidence of safe recruitment of appropriately skilled and experienced staff</li> </ul>
Regulators	<ul style="list-style-type: none"> <li>• Work with commissioners and other agencies – e.g. Department of Health; ACT to develop a comprehensive monitoring tool</li> <li>• Conduct thematic reviews using the agreed monitoring tools</li> </ul>



## 5. Better end-of-life care

**Goal:** Access to specialist end-of-life care and 24-hour support and advice should be available.

### Background

Well-managed and well-supported end-of-life care is a key component of palliative care services. It is impossible to overestimate the extent to which the level and type of care provided can affect the family's experience of the loss of a child.

Some children and young people will become ill and die very suddenly – often in a matter of days – while for other children with palliative care needs, this process may happen over a period of many years.

End-of-life care focuses on preparing for an anticipated death and managing the end stage of a terminal condition from the point of recognition that the end of life is approaching. This includes care during and around the time of death – and for the family immediately afterwards. It enables the supportive and palliative care needs of both child and family to be identified and met throughout the last phase of life and into bereavement.

### The challenges

Many children die in hospital because parents, quite understandably, feel unable to cope with the final stages without access to the clinical support and advice that they need and can trust. It is vital that all agencies are able to respond

in a swift, timely and compassionate manner. Care needs should be assessed (or in many cases continually reviewed), and a plan of care with all relevant agencies put in place. Continuity of care, teamwork and advanced planning (including out-of-hours cover) are absolutely key.

Families need access to the multidisciplinary community team working seven days a week as well as to 24-hour specialist support and advice. Models of service provision will need to be developed when determining this level of access to reflect the needs of the local population, the number of children with palliative care needs and the geographical location, be it rural or urban.

Some of these issues, as they relate to adult services, are being addressed through the Department of Health-funded *End-of-Life Care Programme*. A key element of the programme is the dissemination of a number of tools to support improvements in care provision. Some of the key elements within these tools are relevant and transferable to children's services. They include:

- the Liverpool care pathway for the dying patient;
- the Gold Standards Framework;<sup>9</sup>
- preferred place of care; and
- advance care planning.

In addition, there is a need for access to:

- specialist palliative care support from recognised specialist professionals as and when needed; and
- specialist psychological, emotional and spiritual care, and bereavement support.

### Bereavement and family support

Bereavement and grief are natural processes and the majority of people find their own way through their loss. Nevertheless, some people will experience difficulty in adapting and may benefit from the support of others outside of their extended family and friends. A small minority may benefit from professional assistance to help them cope. Provision of bereavement care can take different forms, occur in varied contexts and be offered by a range of professionals through to volunteers. Within the context of palliative care, the care of bereaved individuals and families is an essential consideration in the end-of-life process and should be built into local end-of-life care strategies.

### Moving forward: bringing in voluntary sector expertise

In recognition of the specialist skills and expertise of the voluntary sector, particularly children's hospices, in palliative care and, more specifically, end-of-life care and bereavement support, local partners should work with them to identify the most appropriate ways to provide and deliver this support for children and their families. This may be based around the hospice or delivered in the community.

### Case study – Great Ormond Street Hospital: A parent's last request

Sahima had been in hospital ever since she was born with multiple life-threatening congenital anomalies. She had never been outside. Sahima deteriorated and the doctors had told her parents she would not survive more than a few days. Sahima's parents asked if they could be helped to take their daughter home at least once before she died.

Great Ormond Street Hospital operates a 'rapid discharge policy', which enables children to go home in less than 24 hours if necessary. The following process is involved:

1. Discussion with parents about choices on location of care (home, hospice, hospital, anywhere else they would like – e.g. holiday home, grandparents' house etc.) and the support available at each of these locations.
2. Rationalise medications – to give only those that will be of benefit and that are minimally invasive.
3. Contact the local CCN team to see what services can be provided locally e.g. can they offer 24-hour cover?
4. Contact the GP and make arrangements to ensure that the out-of-hours GP service is aware of the child and the situation, including any 'not for resuscitation' agreements.

5. Refer to the local hospice, even if the family does not wish to use it (some are able to offer an outreach service).
  6. Speak to the local paediatrician to ensure that they are aware of the child and the situation. Discuss and agree the role of the hospital. Some families may still want to attend hospital or have visits from the local paediatrician.
  7. Where appropriate, liaise with education, social services etc.
  8. Organise equipment for home with the CCN team and GP.
  9. If the family needs 24-hour nursing in the home, this can be organised through the CCN team and/or hospice, depending on area and availability. CCN teams will often involve social services to look at what additional services can be provided.
  10. Ensure that a written symptom management plan is given to the parents, GP, out-of-hours service, CCN team, hospice and local hospital.
  11. Ensure that parents have a list of contact numbers and know who they can contact for advice/support at different times of the day or night. Ensure that all professionals know who will be contacted and who they can contact in turn if they need further advice.
- Once discharged:
12. The palliative care team will see the family at home as soon as possible after discharge. Ideally, this will be a joint visit with the CCN team and GP.
  13. The palliative care team will be available for telephone support round the clock.
  14. The palliative care team can continue home visits as needed and at the request of parents/local services.
- After Sahima died, her parents said:  
**‘One day at home is worth more than three weeks in hospital.’**  
 (Names in this case study have been changed.)

### Roles and responsibilities

Key roles	Responsibilities
Commissioners	<ul style="list-style-type: none"> <li>Service specification and monitoring of provision according to identified needs assessment</li> </ul>
Service providers	<ul style="list-style-type: none"> <li>Develop choice of provision according to identified needs</li> <li>Evidence of and demonstration of ability to act/react in timely and appropriate manner</li> </ul>
Regulators	<ul style="list-style-type: none"> <li>Monitor access, safety and governance</li> </ul>

## 6. Stronger commissioning and value for money

**Goal:** To drive improvements in understanding of need and to better inform comprehensive service commissioning.

### Background: commissioning children's palliative care

The process of commissioning plays a vital role in identifying local palliative care needs and models of effective delivery. It also enables transparency and agreements on levels of investment to meet those needs.

Standard 8 of the *National Service Framework for Children, Young People and Maternity Services* recommends that 'a range of flexible, sensitive services should be put in place to take account of the physical, emotional and practical needs of the child with a life-limiting illness and their family.'

Collaborative commissioning arrangements are vital to bringing this about. *Commissioning children and young people's palliative care services: A practical guide for the NHS Commissioners*,<sup>10</sup> issued under the Children's NSF, aims to support commissioners in their role, increasingly through children's trust arrangements, joint commissioning and the use of pooled budgets, to work with partners to develop children's palliative care services.

<sup>10</sup> Department of Health, 2005

<sup>11</sup> *Integrated multi-agency care pathways for children with life-threatening and life-limiting conditions*, Association for Children's Palliative Care, 2004

A best value approach to commissioning palliative care services is necessary. Specialist external or 'spot' purchasing arrangements are often very expensive. For specialist services, there are likely to be considerable advantages to joint commissioning with neighbouring PCTs and local authorities. It is more cost-effective, as well as being preferable for children and their families, if these services are provided locally. This reduces the burden on families and ensures that local services are better placed to meet health, education and social care needs.

### Towards an integrated care pathway

The ACT Care Pathway<sup>11</sup> is an example of a comprehensive care pathway for children with palliative care needs. It is designed to facilitate commissioning of the full range of services, and to be used according to the individual needs of the child or young person. A national framework for assessing the continuing care needs of children with complex healthcare needs, including palliative care, is under development. This will require a whole-system approach that reflects an integrated care pathway. In effect, this means that:

- primary, secondary and/or tertiary care are co-ordinated;
- there is referral to or input from specialist assessment as a matter of course; and
- the need to refer to education or social care is identified in every case.



Children with a rapidly deteriorating condition and short-term life expectancy (days or weeks) will be fast tracked through the assessment process so that they are immediately able to receive continuing care.

### **Moving forward: the future for commissioning**

*The Commissioning Framework for Health and Well-being*<sup>12</sup> has a strong focus on addressing inequalities in access to health services and advocates the increased co-location of appropriate services. The framework has been developed to ensure that commissioners are fully equipped to commission services in the most effective way, for the best outcomes. This means:

- understanding the local community;
- having clear and accurate data;
- involving service users and key partners such as the voluntary sector; and
- creating a transparent procurement process.

It also recommends setting and agreeing clear standards for service providers, who can then be performance managed on this basis.

### **Moving forward: World Class Commissioning**

World Class Commissioning<sup>13</sup> will drive the required improvements in the capacity and ability of commissioners to meet local needs more effectively. This involves a shift towards a longer-term and more strategic approach to commissioning services. The aim is to deliver improved outcomes and provide a proactive, rather than a reactive service. It focuses on the importance of assessing and prioritising population needs with the emphasis on strategic outcomes, procuring services and managing providers to deliver the required outcomes. Central to successful commissioning will be an ability to work in close partnership with all local community partners.

Commissioners will require outstanding knowledge management and analytical skills in order to develop a long-term view of community needs. They will also need to build on their position within the local community, developing closer relationships with key partners and playing a more proactive role in shaping and defining local services. Key to success will be a PCT's ability to both listen and communicate back to its community partners.

<sup>12</sup> Department of Health, 2007

<sup>13</sup> Department of Health, 2007

### Moving forward: the voluntary sector – an under-used resource

PCTs and local authorities will need to engage with service providers from all sectors to commission local services to support population needs. There is a particular need to develop a much more sophisticated and partnership-based relationship with the voluntary sector – including children's hospices and hospice at home services – both as a key service delivery partner and to augment local statutory provision.

Only when this happens at every level of planning and delivery will commissioners be able fully to capitalise on the specialist knowledge and expertise that exists, including the innovative approaches developed in the field of children's palliative care and the children's hospice movement over the years. Children's hospices have much to contribute to the wider service provision for this small yet very vulnerable group of children.

The voluntary sector brings a unique dimension to the provision of children's palliative care and usefully complements statutory provision. For example, the voluntary sector is able to engage creatively with local communities, and has the flexibility to develop innovative services and to create beacons of excellence. It also plays an important advocacy role for life-limited children at local and national levels and is well placed to identify gaps in services (such as the transition from children's to adult services) and to work with the statutory sector to address those gaps. The best outcomes for children are

achieved where voluntary and statutory services work together and this is a real opportunity to make progress.

#### Case study – Voluntary and statutory sector working in partnership: St Oswald's Children's Service, Newcastle upon Tyne

The core service of St Oswald's Children's Service is the provision of specialist short breaks for children who have a shortened life expectancy in the North East. The service opened in 2003 and is provided by a regional charity that now works to a tried and tested partnership model with seven local authority and PCT areas.

In the run-up to opening the new service, partners were all driven by the desire to develop assessment and referral pathways that would be as equitable and transparent as possible, so that children and families accessing the service are not solely 'those who shout the loudest' or winners in a 'postcode lottery'.

St Oswald's worked with health and social care to co-design and develop the pathways that are underpinned by the same principles in all seven areas.

- They identify 'entry points' in each local area for all enquiries.
- Then, social care and health work together to ensure a holistic assessment of the needs of the child and family, building on existing statutory sector assessment processes.

- The local joint planning meeting matches the needs of the child and family to the range of services. Should the child need a specialist service in their package of care, a referral is made by the statutory sector, sharing all the assessment information and child's plan with St Oswald's.
- Every child becomes part of the looked-after children system. This works well with a 'team around the child approach' and, at the review, all aspects of the child's care are discussed, including the level of need for the service.

One of the keys to the successful implementation of the model is the role of 'pathway co-ordinators' in each area. Pathway co-ordinators provide leadership and a knowledge base about the service and work closely with St Oswald's. They also develop an understanding of the likely demand for the

service in their area and this assists with the business planning processes for all the partners.

### **Commissioning arrangements and a regional contract**

The service is commissioned by the local authorities and the three-year contract reflects and embodies the partnership model agreed with the seven PCTs. The contract is the same for each area and there is a set joint fee from both the local authority and PCT from the area the individual child comes from. St Oswald's meets the remaining costs for each child. The annual contract meeting with commissioners from local authorities and PCTs as well as the contracting officers agrees the fee for the following year. The annual meeting is also an opportunity to jointly explore with commissioners possible future service developments, whether from St Oswald's or from community services.

## **Roles and responsibilities**

Key roles	Responsibilities
Commissioners	<ul style="list-style-type: none"> <li>• Service specifications according to identified needs assessments</li> <li>• Monitor provision and contracts, ensuring value for money</li> <li>• Demonstrate knowledge and understanding of children's services in their specialist context</li> </ul>
Service providers	<ul style="list-style-type: none"> <li>• Develop choice of provision according to identified needs</li> </ul>
Regulators	<ul style="list-style-type: none"> <li>• Monitor quality of services</li> </ul>

## 7. Successful transition between children's and adult services

**Goal:** To ensure that transition for life-limited young people to adult services is a planned and purposeful process.

### Background

Due to improved outcomes and medical advances, more children and young people with life-limiting and life-threatening conditions are living beyond childhood, which means moving from children's to adult services. These young adults and their families have often developed close relationships with a number of providers, frequently over a number of years, and the move to adult services can be a daunting prospect.

Successful transition involves ensuring that services are properly planned so that the young person can move seamlessly into adult care at a time appropriate to them and their family. The successful transition process will:

- start early;
- be flexible;
- be individually tailored to meet the needs of the young person and family; and
- continue, if necessary, following the transfer to adult care.

Transition is not synonymous with transfer. Transition is an active process rather than a single, unplanned event. The process must begin early, be planned and regularly reviewed, and be age and developmentally appropriate. Successful transition should include education, social services and voluntary agencies as active partners. Service development must also, wherever possible, be undertaken in collaboration with the young people involved, enhancing their sense of control and independence for their future life.

### Moving forward: transition planning

Consideration needs to be given as to where services are best provided and by whom, taking into account the young person's age and level of maturity. There may be occasions when it is in the best interests of the young person that their care continues to be provided by services with which they are already familiar, such as during a health crisis or when the young person appears to be approaching the end of their life. The need for dual planning – planning for the death of the young person alongside planning for the young person's future within adult services – is key to good transitional planning.

Co-ordination of transition care is critical and, if this does not already exist, a transition support worker/named key or lead worker should ideally be identified for each young person to oversee their transition, ensuring links with a counterpart within the receiving adult service. The ACT Transition Care Pathway<sup>14</sup> provides a good

<sup>14</sup> Association for Children's Palliative Care, 2007, [www.act.org.uk](http://www.act.org.uk)



framework for planning transitional care for life-limited young people, ensuring that their needs are central to the process.

### **Moving forward: future service planning challenges**

To ensure that all disabled children and their families can benefit from responsive, flexible services as soon as they need them, and are included in universal services, the Government will make disabled and life-limited children a priority at both local and national level, improve benchmarking of early intervention practices and set up a *Transition Support* programme (under the *Aiming High for Disabled Children* programme) to help children and young people and their families benefit from intensive, co-ordinated support and person-centred planning.

The future challenge is one for both the children's and adult sectors. The number of young people living into adulthood will continue to increase, yet the adult sector and adult physicians may have little experience in 'paediatric' diseases in adult life. Accordingly, few plans exist for their co-ordinated care as adults and there may be very few services suitable for young adults (e.g. a lack of age-appropriate short break facilities, few chances of meaningful employment, few residential places that can take young people with very complex health needs and few specialists with a holistic approach to a young person's care).

The challenge lies in using the existing services and developing principles of best practice and guidance to improve professional practice across both children's and adult services.

### **Case study – Multi-agency working: Ellenor Foundation Hospice at Home Service**

Transition planning started at Deborah's school review, before she left children's services and was accepted into adult services. Multi-agency meetings between children's and adult services were held to discuss both her short- and longer-term needs. Deborah was very unwell at times, however, so parallel planning was essential. The arrangements for transition were made alongside care planning for the possibility that Deborah was reaching the end of her life.

The community paediatrician oversaw Deborah's medical needs, which are now being managed by her GP and palliative care consultant within the Ellenor organisation. Pain is a problem and this is closely monitored by the palliative care team. An end of life plan has recently been introduced and, as Deborah lacked capacity, a best interests meeting was held to discuss this.

Deborah was discharged from the community children's nursing team to a learning disability team, which brought together a range of disciplines including physiotherapy, occupational therapy and nursing. The district nurses visit weekly and care for Deborah's gastrostomy. It was agreed that the family needed additional support and respite. Deborah was accepted at Douglas House (an adult hospice in Oxford).

A joint assessment of her health and social needs granted funding for home respite, and funding from the Independent Living Fund was secured enabling her to attend a day centre with a one-to-one carer.

Throughout the transition process the lead nurse acted as key worker to co-ordinate all aspects of Deborah's care. This was essential.

(Names in this case study have been changed.)

### Roles and responsibilities

Key roles	Responsibilities
Commissioners	<ul style="list-style-type: none"> <li>• Service specifications developed based on local needs assessments/data</li> <li>• Stimulate market place to fill the identified gaps in service provision</li> <li>• Evidence of research-based, best practice services being created and stimulating providers to do the same</li> </ul>
Service providers	<ul style="list-style-type: none"> <li>• Develop effective and appropriate service delivered according to specification</li> <li>• Evidence of collaborative working</li> <li>• Services staffed by appropriately qualified and trained staff</li> </ul>
Regulators	<ul style="list-style-type: none"> <li>• Monitor quality and effectiveness of service</li> </ul>

## 8. Planning and developing an effective and responsive workforce

**Goal:** Children and families are cared for by an appropriately skilled, experienced and confident workforce.

### Background

The workforce is the key vehicle for developing a reliable, responsive and sustainable service, delivering the kind of support that children and families need, where and when they need it. The importance, contribution and value of a fit-for-purpose workforce are critical to achieving the improvements proposed in this document. As well as ensuring the necessary skills are developed within the existing workforce, it is important to consider succession planning to ensure sustainability.

### Universal services

At various stages throughout their lives, children and young people who are disabled or who have life-limiting or life-threatening conditions will require access to professionals with different types and levels of skills, knowledge and expertise.

Some children's trusts have taken a lead role in agreeing and developing a generic core of staff who can provide basic care and support, by helping develop a range of complementary skills. For example, a care/support worker who

can undertake some basic nursing duties, as well as providing social care and educational input. These staff will work with children with a range of conditions, in a range of settings. The worker will follow the child, providing continuity of care and limiting the number of professionals that children and families need to come into contact with.

### Case study – Assistant practitioner foundation degree: a joint initiative between Redbridge Children's Trust and London South Bank University

Families often comment on the number of people that they have contact with on a daily basis in order to support the care of their child, and the frustration they experience when there are conflicting opinions or advice. An example of this is a vulnerable child who will have a carer from the local PCT to look after their health needs, a social worker to support their hygiene and personal needs, and a learning support assistant to support them while at school.

To address this issue, Redbridge Children's Trust identified the need to develop a role that covered all aspects of the child's life. The aim was for one carer to have the skills and competencies to support all of the child and family's needs whereby previously three agencies would have been involved. In collaboration with London South Bank University, the assistant practitioner foundation degree has been developed.

It is the first programme of its kind in that it is open to staff working across health, education and social care. It is a completely service-led programme. The needs of the local population were identified and competencies were drawn up and built across the three areas to enable staff to work wherever the child was cared for or needed support.

While on the course the practitioners remain working within their service areas, with the opportunity to work in other areas in order to develop competencies to complete the course. The practitioners develop varying skills and expertise and are therefore able to offer support on a range of issues such as speech and language, benefits and educational support. It is a two-year, full-time programme leading to a foundation degree.

### Core service provision/targeted services

Most areas of the country have access to children's community nursing teams. Many are based in single PCT areas, but size, skill mix and the capacity to respond effectively are variable – and access to specialised services is often limited. Nevertheless, these teams represent the bedrock of service provision at a local level.

Children and families need more and better services provided on a multidisciplinary and multi-agency basis. There is an acute need to 'grow' existing services to ensure that services can be delivered to children and their families across a range of settings. This growth will ideally include but not be limited to:

- provision of 24-hour access to advice and support;
- making effective use of the specialist multi-professional clinical skills of staff in tertiary centres; and
- fully capitalising on the expertise and insight of voluntary sector partners.

### Moving forward: specialist palliative care

There will be a need for core services to include specialist palliative care knowledge and expertise – particularly for managing children approaching the end-of-life phase, including access to symptom control advice and bereavement support, available 24 hours a day, 7 days a week. This knowledge and expertise will need to be clinically driven and developed in collaboration between commissioners, service providers and the Royal Colleges.



It is likely to be neither practical nor sustainable for individual areas to have their own specialist team. However, teams could be developed to cover clusters of PCTs, arranged through the regional networks, ensuring that every local area has 24-hour access to the specialist support and advice.

### Moving forward: capacity building

A workforce action plan will be published by the Department for Children, Schools and Families in early 2008. This will promote a workforce with the capacity to improve the quality and experience of palliative care services, better access to therapies and which supports effective transition to adult services.

### Roles and responsibilities

Key roles	Responsibilities
Commissioners	<ul style="list-style-type: none"> <li>• Service specifications developed based on local needs assessments/data</li> <li>• Ensure that education and training institutions develop programmes in line with service specifications in order to have a fit-for-purpose workforce capable of delivering high-quality services</li> </ul>
Service providers	<ul style="list-style-type: none"> <li>• Ensure that staffing levels and skill mix are sufficient to deliver service safely and efficiently</li> <li>• Evidence of ongoing training and education to meet altering demands</li> <li>• Evidence of appropriate education commissioning and quality monitoring of contracts</li> </ul>
Regulators	<ul style="list-style-type: none"> <li>• Monitor quality and effectiveness of service</li> </ul>



Everyone with a commitment to delivering better, more responsive and sustainable palliative care services for children should have a role to play in helping deliver the step change that is needed.

## CONCLUSIONS AND NEXT STEPS

### Summary

This document sets the future direction for children's palliative care services. It is a call to action to all those engaged in providing services – commissioners, service providers, voluntary sector partners – to improve the experiences of young people and their families by:

- improving data sources;
- building stronger joint working arrangements;
- developing better needs assessments and support regimes;
- tackling inequalities; and
- encouraging the delivery of care in the most appropriate setting.

This document sits as a framework for future service development. It seeks to highlight the key aspects of the Independent Review and challenge local areas to take this group of children, who need palliative and end-of-life care, more seriously.

At the same time, there is a need for flexibility to allow for local determination and delivery. With a commissioning-led health service, local areas must be allowed to come to their own decisions on local funding priorities and, ultimately, on how services are configured and delivered. Everyone with a commitment to delivering better, more responsive and sustainable palliative care services for children should have a role to play in helping deliver the step change that is needed.

### Building for the future

New opportunities and challenges will continue to arise so there is a need to continue to assess the progress made in transforming services as well as refining approaches to reflect new developments. In order to ensure that we build for the future, the Government will:

- support workforce development and training;
- embed World Class Commissioning;
- continue working in partnership with stakeholders;
- provide national leadership and support; and
- continue to monitor progress, e.g. by expanding the Child Health Mapping Project and pursuing discussions with the regulators on effective review/inspection mechanisms.

To support this future direction, the Government has made a substantial financial commitment across disabled children's services. There is now a clear expectation on key partners to work together to achieve the transformation in services that is needed and deliver value for money.

### Next steps

Phase II of the children's palliative care project will cover the development of support materials and a series of roadshow events around the country. The aim will be to publicise the strategy and support and enable local areas to start to form their own delivery strategies.







## ANNEX A

### National Strategy Steering Group

**Hilary Samson-Barry** – Programme Director for Partnerships for Children, Families and Maternity, Department of Health (**Chair**)

**Jane Appleby** – Vulnerable Children's Lead, East Midlands Strategic Health Authority

**Val Bagnall** – Partnerships and Policy Lead, St Oswald's Children's Service

**Hardip Begol** – Special Educational Needs and Disability, Department for Children, Schools and Families

**Lizzie Chambers** – Chief Executive, Association for Children's Palliative Care

**Rob Dickman** – Team Leader, Children's Disability Policy, Department of Health

**Peter Ellis** – Chief Executive, Richard House Hospice, London

**Barbara Evans** – Health, Care and Additional Needs Policy Committee, Association of Directors of Children's Services

**Rachel Ferris** – South West Specialised Commissioning Group

**Barbara Gelb** – Chief Executive, Association of Children's Hospices

**Dr Richard Hain** – Chair, British Society of Paediatric Palliative Medicine

**Christine Lenehan** – Director, Council for Disabled Children

**Dr Simon Lenton** – Consultant Paediatrician/ Royal College of Paediatrics and Child Health

**Mary Lewis** – Senior Nurse and Clinical Lead, Lifetime Service, Bath

**Helen McLindon** – Children's Commissioner, Plymouth Primary Care Trust

**Katrina McNamara-Goodger** – Head of Policy and Practice, Association for Children's Palliative Care

**Liz Morgan** – Nurse Adviser, Children and Young People's Services, Department of Health

**John Overton** – Executive Chairman of the Quercus Foundation at Acorns

**Toby Price** – Sutton Disability Partnership for Children and Young People, London Borough of Sutton

**Katie Rigg** – Team Leader, Children's Community Nurses, Cumbria

**Fiona Smith** – Adviser in Children and Young People's Nursing, Royal College of Nursing

**Steph Sollosi** – Independent Children's Service and Strategy Consultant

**Janet Vickers** – Nurse Consultant, Oncology Outreach and Palliative Care, Royal Liverpool Children's Hospital, Alder Hey

## ANNEX B

### Descriptions and definitions

#### Children's palliative care

Children's palliative care is an active and total approach to care, embracing physical, emotional, social and spiritual elements. It focuses on enhancements of the quality of life for the child and support for the whole family, and includes the management of distressing symptoms, provision of respite and care from diagnosis through death and bereavement.

#### Symptom management

Symptom management is the control of the physical aspects of symptoms combined with attention to the psychosocial and spiritual aspects of symptoms.

#### Short breaks/respite care

Short breaks/respite care is care where the three main functions are:

- to provide the child or young person with an opportunity to enjoy social interaction and leisure facilities;
- to support the family in the care of their child in home or an alternative community environment such as a children's hospice; and
- to provide opportunities for siblings to have fun and receive support in their own right.

Short breaks/respite care may offer the whole family an opportunity to be together and to be supported in the care of their child, or it may offer care solely for the child or young person.

#### Specialist respite care

Specialist respite care refers to a setting of care, a programme of care or a service that provides additional services. It may take place in the child's home or in a setting outside of the home such as a hospital, long-term care facility or hospice. Specialist respite care provides the support required to meet the child's holistic care needs and enables children and families to access short break services. Specialist respite care will often address some aspects of symptom management.

#### Hospice

This term is often used interchangeably to describe a philosophy, a programme of care or a site of care. The term is commonly used to refer to an organisation or programme of care that provides, arranges, co-ordinates and advises on a wide range of clinical and supportive services for dying patients and those close to them.

#### Children's hospice

A children's hospice is an organisation which provides palliative care for a child or young person with a life-limiting condition and their family, and aims to meet all needs – physical, emotional, social and spiritual – through a range of services including children's palliative care, specialist respite care, terminal and emergency care, 24-hour telephone support, practical help, advice and information and bereavement support for all family members.

### Hospice at home

Hospice at home is an integral component of children's palliative care. Hospice at home is a term commonly used to describe a service which brings skilled, practical children's palliative care into the home environment. Hospice at home works in partnership with parents and families and provides hands-on expert nursing care, on a 24-hour basis, along with other elements of palliative care including:

- emotional, psychological and social support, counselling and spiritual care;
- access to specialist colleagues in other disciplines, such as physiotherapy, as required;
- provision of information, support, education and training where needed to all carers both lay and professional;
- close collaboration and communication with the primary care team, the child's acute hospital specialists if appropriate, and other agencies;
- specialist respite care;
- 24-hour end-of-life care; and
- bereavement support.

### End of life

The 'end-of-life' phase ends in death. Definition of its beginning is variable according to the individual child/young person and professional perspectives. In some cases it may be the child/young person or the family that first recognises

its beginning. In other cases the principal factor may be the judgement of the health/social care professional/team responsible for the care of the patient.

### End-of-life care

End-of-life care is care that helps all those with advanced, progressive, incurable illness to live as well as possible until they die. It focuses on preparing for an anticipated death and managing the end stage of a terminal medical condition; this includes care during and around the time of death and immediately afterwards. It enables the supportive and palliative care needs of both patient and family to be identified and met throughout the last phase of life and into bereavement. It includes management of pain and other symptoms and provision of psychological, social, spiritual and practical support.

### End-of-life care services

End-of-life care services are services to support those with advanced, progressive, incurable illness to live as well as possible until they die. These are services that enable the supportive and end-of-life care needs of both child/young person and family to be identified and met throughout the last phase of life and into bereavement. It includes management of pain and other symptoms and provision of psychological, social, spiritual and practical support. This is not confined to discrete specialist services but includes those services provided as an integral part of the practice of any health or social care professional in any setting.

### Supportive care

Supportive care is an 'umbrella' term for all services, both generalist and specialist, that may be required to support people with life-threatening illness. It is not a response to a particular disease or its stage, but is based on an assumption that people have needs for supportive care from the time that the possibility of a life-threatening condition is raised.

### Care of the dying

Care of the dying is the care of the patient and family in the last hours and days of life. It incorporates four key domains of care, physical, psychological, social and spiritual and supports the family at that time and into bereavement.

### Key working/care co-ordination

Key working/care co-ordination is a service involving two or more agencies, which provides disabled children and young people and their families with a system whereby services from different agencies are co-ordinated. It encompasses individual tailoring of services based on assessment of need, inter-agency collaboration at strategic and practice levels and a named key worker for the child and their family. Families with disabled children should only have a key worker if they want one (Care Co-ordination Network UK (CCNUK), 2006).

### Complex care/continuing care

Continuing care is a bespoke package of care beyond what is available through core and universal health services. It is provided to children with high levels of complexity or intensity of nursing care needs.

### 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.

### Family

Family includes informal carers and all those who matter to the patient.

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## ANNEX C

### Equality Impact Screening

- Policy area: Children's palliative care.
- Aim of the policy: Achieve better outcomes and experiences for children and young people with life-limiting and life-threatening conditions.
- Population groups the policy is intended to benefit and how: Children and young people with life-limiting or life-threatening conditions and their families – by setting the future direction for children's palliative care services.
- Related policy areas: Policy is a distinct part of the children's disability agenda.

#### Screening

The policy is to support children (aged 0–19) with disabilities – specifically, and regardless of gender, those with life-limiting or life-threatening conditions who exhibit the greatest need. Issues relating to race, religion and belief were of particular relevance in developing the policy because services need to take proper account of cultural preferences, e.g. the cultural and familial requirements around where care is provided, and by whom, as well as how a child or young person is supported at the end of life and how the wider family is supported following their death. These issues were the subject of rigorous debate as part of both the Independent Review and in taking forward the Review recommendations (by the Department of Health), and the default position is that all providers must take steps to build cultural preferences into the services they provide to children and families.

The policy represents a framework from which local areas will build their own delivery strategies – as such, it is a direction-setting policy representing best practice. Children's trust commissioners and service providers will ultimately be responsible for ensuring that services are accessible to all who need them, as well as taking account of any specific cultural requirements.

#### Conclusions

This work builds on the Independent Review of Children's Palliative Care Services, which reported in May 2007. As part of the review, a wide-ranging consultation was conducted involving key sector stakeholders, health and social care professionals, children, young people and their families, the voluntary sector, as well as key academics and researchers. The Government has accepted and endorsed the recommendations contained in the Independent Review report and has committed to delivery of a national strategy to meet the expectations of both the Review and of sector stakeholders. As such, the policy direction has been set and cannot be altered – a strategy steering group of key stakeholders from the children's palliative care sector has progressed work on delivery of the strategy, to ensure that the policy is equitable, fit for purpose and non-discriminatory.

Children's palliative care is concerned with the treatment of children with life-limiting or life-threatening conditions. The overall number of children and young people suffering from conditions requiring palliative care is small – this group represents a small and very distinct subcategory of the broader disabled children cohort.

The key aim is to improve the quality of and access to children's palliative care services, as well as improving the outcomes and experiences of children and families. The policy sets out expectations for improving choice, access and continuity of care, and seeks to place palliative care at the centre of local children's service provision. It highlights how commissioners, providers and teams of palliative care professionals can shape the provision of services to meet the needs of children, young people and their families. And it emphasises the roles that each can play in providing child-focused, family-centred services and gives examples of what could be put in place to achieve this.

The policy is directed largely at children's trust commissioners and service providers. The Department of Health role is to articulate the structures of how services should be delivered; at the same time the policy needs to be flexible to allow for local determination and delivery. With a commissioning-led service, local areas must be allowed to come to their own decisions on local funding priorities and, ultimately, on how services are delivered.

The policy sits as a framework for future service development. It seeks to highlight the key aspects of the Independent Review and challenge local areas to take this group of children more seriously. Accordingly, local areas will need to devise their own strategies and spend their money better to deliver more effective and more equitable services.

Based on the information set out above, an equality impact assessment is not necessary.



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