

**HIDDEN SAVINGS:  
HOW RAINBOW TRUST CHILDREN'S CHARITY SAVES  
MONEY FOR THE HEALTH AND SOCIAL CARE SYSTEM**

**This report introduces Rainbow Trust Children's Charity and its support for families whose child is diagnosed with a life threatening or terminal illness. It shows how Rainbow Trust saves money for the health and social care system. This 'social palliative care' is defined as the essential support that a family needs, and may not recognise, alongside medical care, to face each day as it comes.**

## **ABOUT RAINBOW TRUST CHILDREN'S CHARITY**

Rainbow Trust Children's Charity's mission is to ensure that every family who has a child with a life threatening or terminal illness has the support they need. We believe that families with a seriously ill child should be fully supported in the way that suits them, from the moment their child is diagnosed, during treatment, and if needed, through bereavement.

Rainbow Trust provides essential emotional and practical support to families, filling in the gaps between hospital and hospice. We link services together. More than 30 years experience uniquely qualifies us to provide community-based support which, no matter what a family's background or circumstances, puts the family first and looks after every family member.

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This report should be read with the source data on money saved which can be downloaded from [rainbowtrust.org.uk/hidden-savings](https://rainbowtrust.org.uk/hidden-savings)

## EXECUTIVE SUMMARY

Being told that your child is so seriously ill that they might die is something no parent ever wishes to hear. Nobody knows how they would react or how they would cope. You are thrown into a world in which you never expected to be. In the next moment you are coping with the worry and grief of your child's illness, trying to keep life normal for brothers or sisters, getting to and from a hospital for treatment, a hospital that you may never have been to before and could be more than 100 miles away, and negotiating a health system of which you have no experience. Throughout this, family life has to go on: housework, washing, shopping, cooking. Some families really struggle to cope.

Rainbow Trust Children's Charity provides emotional and practical support to families whose child has a life threatening or terminal illness. It provides 'social palliative care', defined by the charity as the essential support that a family needs, and may not recognise, alongside medical care, to face each day as it comes.

Tailored support from a dedicated Family Support Worker enables a family with a life threatened or terminally ill baby or child to cope more effectively with their situation. Families themselves select the areas in which they would most like to have support.

*“ When you are told that your child has a condition that means they might die before you, you join a club that you didn't know existed. What you need is someone that has a map, has walked the route before and will walk with you until you don't need them any longer. That is what Rainbow Trust did for us. ”*

### **A parent supported by Rainbow Trust**

Rainbow Trust has nine teams of Family Support Workers across the country all supporting families in this way. Rainbow Trust is the only national organisation to provide community-based support direct to families wherever, whenever, and however they need it, from diagnosis, through treatment, and for some, through bereavement.

## REPORT OVERVIEW

This report highlights the scale of need and the importance of the social palliative care which Rainbow Trust provides. It considers some of the expenditure which the public sector would be forced to incur if Rainbow Trust did not intervene.

It shows that by providing such support, not only are families able to cope more effectively, but significant sums of money are being saved for the health and social care system.

## KEY FINDINGS:

1. The most recent data suggests that at least 40,000 families in England have a child with a life-limiting or life threatening illness.<sup>1</sup> This is likely to be a conservative figure in light of the expected growth in prevalence of such illnesses and medical advances that enable more children to live longer.
2. We don't know how many of these families will be unable to cope, but we do know that many will struggle to do so and will need the kind of support Rainbow Trust provides.
3. A pilot project to monitor how families assess their ability to cope in five areas of family life found that 100 per cent of families reported that their ability to cope improved, in one or more areas, during six months of support from a Family Support Worker. The five areas monitored were: Quality of life, Quality time, Stability and confidence, Managing stress, and Economic wellbeing.
4. The direct cost per hour for tailored social palliative care from Rainbow Trust in 2016-17 is £22.64. This is a comparable cost to social care interventions from local authority social care services, and also offers the advantage of being a bespoke service, responsive to the needs of the individual family.
5. Rainbow Trust is confident that it saves money for public services in two ways:
  - Immediate and specific savings for public services; which can be estimated with some confidence, such as enabling families to attend appointments they might otherwise miss
  - Potential longer term savings for public services; such as support which contributes to families avoiding crisis situations with repercussions for their mental health, family stability and security of household income.

Our conservative calculations are that our services can save around £2 million per year for the health and social care system.

## RECOMMENDATIONS

**Calls for a sustainable solution to the adult social care funding crisis have been gathering momentum across the political spectrum. However, the urgent need to ensure adequate funding of social care services for seriously ill children and their families has not received the same level of attention.**

Rainbow Trust's social palliative care services fall outside the current NHS England Grant to Children's Hospices, which is limited to clinical care providers. Rainbow Trust services also frequently do not meet the locally determined criteria for Short Breaks' services, for disabled children and their families, which local authorities have a statutory duty to provide. Addressing these obstacles to accessing statutory funds would enable Rainbow Trust to support more families in more parts of the country.

Currently the state funding received by Rainbow Trust only amounts to the cost of 11 days support in each year.

### **Recommendation 1:**

Clinical Commissioning Groups (CCGs) and local authority commissioners should ensure that children's social palliative care providers are eligible for local statutory funding streams, and that local criteria do not have the unintended consequence of excluding services which are by their nature bespoke and varied in their offering.

### **Recommendation 2:**

The Department of Health, working with NHS England, the Department for Communities and Local Government, and the Department for Education, should create a clear policy framework for a system where all elements of children's palliative care - including the non-clinical social care aspects and bereavement care - are recognised as deserving ring-fenced statutory funding.

### **Recommendation 3:**

Rainbow Trust welcomes the additional £2 billion in funding provided to adult social care in the 2017 Spring Budget. However the Government should now prioritise providing additional targeted new funding for child social care to ensure that children with life threatening and terminal illnesses, and their families, also receive the essential support that they need.

## INTRODUCTION

Rainbow Trust Children’s Charity provides emotional and practical support to families where a child has a life threatening or terminal illness. We provide ‘social palliative care’, which we define as the essential support that a family needs, and may not recognise, alongside medical care, to face each day as it comes.

Rainbow Trust provides Family Support Workers to families who have a child with a life threatening or terminal illness to help them cope in an extreme and uncertain time. The Family Support Workers do whatever a family needs. They will help families at home, with transport to and from hospital appointments, and attend important appointments with doctors or consultants. They will play with the sick child, look after siblings, take children to and from school, talk to brothers and sisters who struggle to understand what is happening, help a family make memories, and support families to plan for end of life and funerals. Rainbow Trust Family Support Workers fill in the gaps between the hospital and hospice and help link services together.

Developing this report was prompted by a need to review an earlier report in 2012, which explored the economic impact of our work, using data from 2009-10. Another driver was to highlight the analysis of the outcomes that the service achieves for families in light of current policy discussions about the funding of palliative care for babies and children.

### RAINBOW TRUST’S APPROACH

#### **Section 1: An overview of the scale of need and local funding context.**

This section summarises the most recent quantitative data on prevalence in England of children with a life limiting or life threatening illness. It sets out who is responsible for providing services for these families, and considers the context of financial pressures on local authorities.

#### **Section 2: Rainbow Trust’s model of social palliative care.**

This section describes the services available to families from a Rainbow Trust Family Support Worker, and the findings from a pilot project monitoring how families assess their own ability to cope over a period of six months of Rainbow Trust’s support.

#### **Section 3: How Rainbow Trust services save money for the health and social care system.**

This section shows the cost per hour of Rainbow Trust’s support in 2016-17. It then considers the expenditure which the public sector may be forced to incur if Rainbow Trust interventions did not take place. The unit cost for one hour of Rainbow Trust support in 2016-17 can be calculated with confidence, but it is hard to know what might have happened to a family without Rainbow Trust’s support, and whether or not the state would step in or leave the family to cope alone. It was therefore necessary to work with experienced Family Support Managers to identify common scenarios and their expected outcomes.

Drawing on these learnings, the report estimates where cost savings may exist by considering some of the expenditure which the public sector could be forced to incur if Rainbow Trust did not intervene. This was done for a set of common scenarios using illustrative case studies. These savings may be felt by providers of statutory health and social care services, and by the wider economy.



## **SECTION 1: AN OVERVIEW OF THE SCALE OF NEED AND LOCAL FUNDING CONTEXT**

### **THE SCALE OF NEED IN ENGLAND**

Up to date information on the exact number of children with life threatening and terminal conditions does not exist. The best estimates from academic research were that more than 40,000 children (0-19 years) in England, were living with a life-limiting or life threatening condition in 2009-2010.<sup>i</sup>

The research showed a rise in overall prevalence during the decade from 1999-2000 of 25 per 10,000 population to 32 per 10,000 population in 2009-10. The growth is linked to medical advances which enable more premature babies to survive with complex medical conditions, and improved treatment and support which enables more children to live longer with their conditions.

Recent estimates from Scotland, published in 2015, suggest that the rise in prevalence is continuing.<sup>ii</sup> There is therefore good reason to assume that the 2009-10 estimate of 40,000 children (0-19) with life limiting and life threatening conditions in England is a conservative figure.

### **THE IMPACT ON FAMILIES**

None of us can know how our own family would cope if we had a child who became seriously ill. Studies suggest that families experience high stress levels and face many emotional, practical and financial challenges. Each family has a differing capacity to respond to these challenges.<sup>iii</sup>

Some of the estimated 40,000 families in England whose child has a life-limiting or life threatening condition, may not need Rainbow Trust's tailored support for various reasons, including their child being in a stable phase of illness, existing family support networks, or because they have disease-specific support.

However it is likely that there are families across England today who may not have access to social palliative care support. This could be because of where they live, or because Rainbow Trust operates in their area but lacks the resources to serve all families.

### **WHO IS RESPONSIBLE FOR PROVIDING SERVICES FOR THESE FAMILIES?**

Children's palliative care must cover the spectrum of a child's needs, including health, social care and education. NHS England is responsible for commissioning specialist healthcare elements of child palliative care. Non-specialist child palliative care needs to be commissioned from statutory and voluntary sector providers using 'collaborative commissioning' involving Clinical Commissioning Groups (CCGs) and local authorities.<sup>iv</sup> This makes the funding system more complex.

Another major challenge is that the relatively small number of affected children makes it difficult for CCGs and local authorities to plan effectively from year to year.

The 2009-10 estimates suggest that a small local authority could have as few as 12 affected children to plan for, while a metropolitan borough may have several hundred affected children. Many will be in a stable condition but some will need intensive support if their condition deteriorates.

With prevalence rising it is vital that robust data is collected to support effective planning. Analysis of existing national data on children with complex needs or life-limiting conditions has noted gaps, anomalies and inconsistencies in what is currently collected and shared.<sup>v</sup>

**40,000**  
**CHILDREN (0-19 YEARS) IN**  
**ENGLAND WERE LIVING WITH A**  
**LIFE-LIMITING OR**  
**LIFE THREATENING**  
**CONDITION IN 2009-2010**



## FINANCIAL PRESSURES ON LOCAL AUTHORITIES

Local authority funding is under serious pressure. Calls for a sustainable solution to the adult social care funding crisis have been gathering momentum across the political spectrum. However, the funding of child social care has not received the same level of attention, despite warnings that children's services are under strain.<sup>vi</sup>

What attention there is on child social care is largely focussed on safeguarding children from neglect and abuse, as recently noted by the House of Commons Public Accounts Committee.<sup>vii</sup>

*“There is a risk that local authorities seek to protect children at the expense of helping them, particularly children with a disability. This could mean children with disabilities do not meet the threshold for help.”*

Looking specifically at child palliative care, Freedom of Information requests by Together for Short Lives in 2016, found that four out of five (81 per cent) local authorities are failing to plan and fund care for children and young people who need palliative care.<sup>viii</sup> A separate survey by Together for Short Lives, found that local authority funding for children's palliative care charities has fallen significantly, down by 61 per cent over 2015-2016 - contributing only one per cent of the costs incurred by the providers in their survey.<sup>ix</sup>

Clearly a comprehensive long-term solution to the social care funding crisis is beyond the scope of this report. However, as demonstrated in Section 2, investing in social care providers such as Rainbow Trust could, over time, deliver significant savings for the health and social care system.

In light of these savings, and mindful of the expected growth in prevalence of life threatening and terminal conditions among children, it is logical that providers of social palliative care such as Rainbow Trust should be able to access fair and sustainable statutory funding. Underpinning this should be a joined-up policy framework from government, to ensure all elements of child palliative care are recognised as deserving of funding.

This report's recommendations therefore include a call for local commissioners to ensure that all children's social palliative care providers are eligible for local statutory funding streams. It also calls for commissioners to ensure that local criteria for funds do not have the unintended consequence of excluding services which are by their nature bespoke and varied in their offering. Addressing these obstacles to accessing statutory funds would enable Rainbow Trust to support more families in more parts of the country.

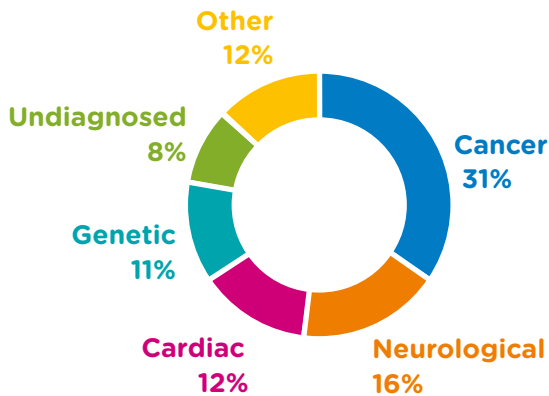
**81%**  
**OF LOCAL**  
**AUTHORITIES ARE**  
**FAILING TO PLAN AND**  
**FUND CHILDREN'S**  
**PALLIATIVE CARE.**

## SECTION 2: RAINBOW TRUST'S MODEL OF SOCIAL PALLIATIVE CARE

### RAINBOW TRUST'S MODEL

Since 1986, Rainbow Trust Children's Charity has provided emotional and practical support to families where a child has a life threatening or terminal illness. Many children and their families are able to cope, or are not in a crisis situation. However, thousands of families have to face the very real possibility that their child may die, and these families struggle to cope on a day-to-day basis.

Diagnoses of children referred to Rainbow Trust 2015-16



Rainbow Trust is a community-based service working in families' homes and local communities. There are nine teams of Family Support Workers, across England who support the whole family, in a place of the family's choice. A Rainbow Trust Family Support Worker is allocated to each family to provide a bespoke service according to the family's needs.

Most Family Support Workers are generalists, however, in recent years Rainbow Trust has introduced a specialist Cardiac Support Worker, two dedicated Neonatal Support Workers and two Sibling Support Workers, in recognition of the specific needs of particular groups.

Neonatal support is a growing feature in light of the rising number of babies with palliative care needs. This rise can be attributed to several factors:

- Rapid developments in medical science which mean that many more babies born prematurely and/or with complex medical conditions now survive birth
- Increasing maternal age at delivery as older mothers can be at greater risk of complications at birth
- The rise in use of fertility treatment is leading to higher numbers of twins and triplets, and multiple pregnancies are more likely to result in premature birth.

Increased partnership working is also enabling Rainbow Trust to pilot new services and to stimulate additional volunteer support to empower families within their communities.

Support varies from face-to-face contact for family members several times a week during a period of crisis, to more occasional contact to check in with a family who has established the mechanisms it needs to cope and whose child is in a stable condition. This might include phone calls, texts or emails. Support is more intense if a child's condition dips, if there is an event which places the family under further strain, or if the child appears to be entering an end of life phase. Support is not limited to the immediate family and can extend to wider family members.

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## THE PROOPS FAMILY

Iris Proops was six months old when she was diagnosed with a tumor on her liver. Despite surgery and a gruelling regime of chemotherapy, Iris died aged two and a half.

Adam, Iris' father, shares his story.

*“The routine of hospital, chemotherapy, home, blood tests, transfusions, infections and hospitalisation becomes worryingly normal. Initially, we did not own a car, so I signed up to a car club. We couldn't take a child with a compromised immune system on the train. Life was tough and financially it hit us hard. Kate, Iris's mum, hadn't been home for a month. Thankfully, we were introduced to Rainbow Trust.*

*[Rainbow Trust Family Support Workers] Mary and Mandy became an indispensable part of our lives. I did not have to worry about getting Iris to hospital any more. Most importantly, Iris loved them. When the very worst was confirmed, and we were told our little girl was going to die, Mary and Mandy were astonishing in their care, compassion and hard work.*

*Rainbow Trust played such an important part in our lives - they gave us time. We had more time to enjoy our daughter as we did not have to sweat the small stuff. Mary and Mandy were totally reliable, always available to talk, and enabled us to focus on what was truly important.”*



Iris Proops

## RAINBOW TRUST FAMILY SUPPORT IS TAILORED TO EACH FAMILY AND MAY INCLUDE ANY OF THE FOLLOWING:



### Advocacy

Family Support Workers can attend appointments with parents and help them understand the medical information they receive. They can direct families to other sources of help and are valued for being independent of statutory services.



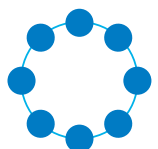
### Bereavement support

Following a child's death, people react and grieve in different ways. Rainbow Trust's service offers bespoke support for the whole family underpinned by a 'public health approach'.<sup>x</sup> Some families decide they would benefit from additional support beyond their family and friends. Family Support Workers can help families discuss options for end of life care, make funeral plans, and can be there for them through bereavement.



### Emotional support

Family Support Workers are available to listen to the concerns or anxieties which the ill child or other family members experience, and provide reassurance and emotional support at a distressing time. This support is often given alongside practical support in the home, while travelling, or while in hospital.



### Groups

Rainbow Trust runs a variety of groups offering sibling support, bereavement support and particular activities such as youth, swimming or art groups.



### Home support

This might involve playing with the sick child or their siblings, or helping with housework, and the practical tasks that can accompany caring for a seriously ill child.



### Hospital support

Many families spend whole days in hospital attending a series of appointments, or may find their child is an inpatient for long periods. Family Support Workers can play with the sick child or their siblings, and can give parents a break from sitting at a child's bedside.



### Sibling support

Emotional support can ensure siblings have a safe outlet for their hopes and fears when a family is coming to terms with a child's serious illness. Practical support can mean a sibling does not need to miss school when parents are attending appointments or visiting a child who is an inpatient. It may also contribute to reducing the impact of a stressful situation on a sibling's educational attainment by ensuring homework continues to be completed.



### Transport

Many families rely on Rainbow Trust for transport to and from hospital, as well as school runs, and family outings. During these journeys, many parents seek and gain emotional support. Transporting equipment, travelling long distances in heavy traffic and finding parking spaces are all made easier with additional support.

## HOW RAINBOW TRUST'S SUPPORT HELPS FAMILIES TO COPE MORE EFFECTIVELY

Bespoke family support, when and where families need it, comprising:



- Emotional support to parents/carers
- Emotional support to sick child
- Emotional support to siblings
- Transport to and from hospital
- Support for sick child in hospital
- Practical support provided to parents/carers
- Family outings/sibling outings
- Attendance at groups
- Information provided about condition/illness
- Signposting to other organisations

LEADING TO



IMPROVED

INCREASED

- |                                     |                          |
|-------------------------------------|--------------------------|
| Ability to manage stress            | Quality of life          |
| Ability to cope with grief and loss | Quality time with family |
| Economic wellbeing                  | Stability and confidence |

LEADING TO



Family able to cope more effectively.

## MONITORING CHANGES IN FAMILIES' ABILITY TO COPE

Rainbow Trust's support is one of several factors which contributes to a family's ability to cope. In 2016, of 136 families surveyed 100 per cent reported that their ability to cope had improved in several areas of family life during a six-month period of support from a Family Support Worker.

Families were asked to score themselves from 0-10, in five outcome areas, examples of which are shown below:

- **Quality of life:** being able to plan family activities at home, or to have time outside the home together
- **Quality time:** enjoying time together as a family, and communicating well together
- **Stability and confidence:** not feeling overwhelmed by conversations with medical professionals, or by practical demands such as daily chores
- **Managing stress:** frequently feeling highly emotional because of the situation
- **Economic wellbeing:** the ability to pay bills, and cope with the costs incurred in travelling to appointments.

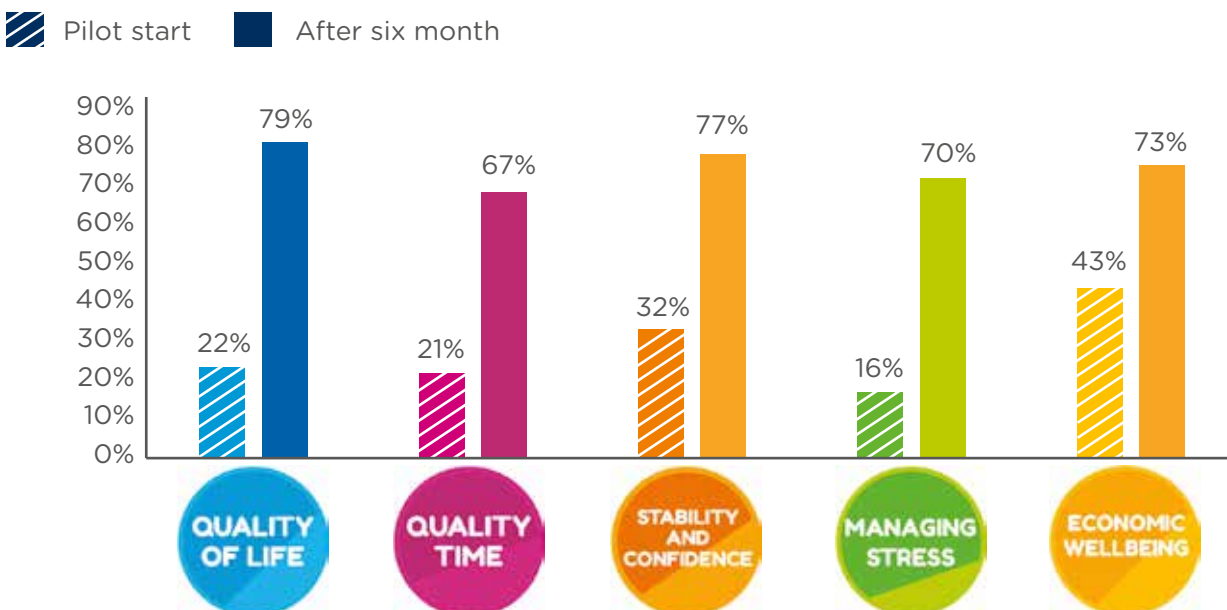
A self-assessed ranking of 1 indicated that the family was struggling, and a ranking of 10 suggested that the family was coping well.

The chart below shows the percentage of families which ranked themselves between 6 and 10 in the five areas, at the start of the pilot, and then after six months of receiving support.

➔ The highest area of need for all families was Managing stress, in which families rated their ability to remain calm and manage their emotions, even when their situation was difficult.

As a result of this pilot, Rainbow Trust is confident that its services are contributing to families feeling able to cope more effectively with their situation. This data collection is ongoing to provide a clearer picture of how families assess their ability to cope over a longer period of Rainbow Trust support.

### PERCENTAGE OF FAMILIES WHICH CONSIDERED THEMSELVES ABLE TO COPE 'WELL' OR 'FAIRLY WELL' IN FIVE AREAS DURING STUDY





## SECTION 3:

# HOW RAINBOW TRUST SERVICES SAVE MONEY FOR THE HEALTH AND SOCIAL CARE SYSTEM

### THE COST OF RAINBOW TRUST SERVICES

The average hourly direct cost of a Rainbow Trust Family Support Worker in 2016-17 is £22.64.

This includes total salary costs (including pension and National Insurance), all transport related costs (a core part of the service), training, external supervision, office costs, and a proportion of their team management costs.

#### How Rainbow Trust is funded

Only three per cent of Rainbow Trust's income came from statutory sources in 2015-16. That's enough to provide our services for just 11 days a year. The remaining 97 per cent was raised from voluntary donations.

Rainbow Trust's social palliative care services fall outside the current NHS England children's hospice funding programme, which covers only clinical health care. At the same time the services frequently do not meet the criteria for Short Breaks' services for disabled children and their families, which local authorities have a statutory duty to provide.

A recent survey of both adult and children's hospices, by Together for Short Lives and Hospice UK, showed that the average children's palliative care service received 22 per cent of their income from statutory sources in 2015-16.<sup>ix</sup>

As previously mentioned, it is likely that there are families across England today who may not have access to social palliative care support, for various reasons. Our aim is to support more families by funding more Family Support Workers and in new areas.

### ILLUSTRATIONS

Rainbow Trust Family Support Workers provide more bespoke care than is routinely available from either public sector or voluntary sector providers. In some parts of England, there are few or no alternative services available to provide high quality support in the community, tailored to the whole family's needs.

It is hard to know how a family might cope in the absence of receiving social palliative care support, and whether or not the state would step in or leave the family to cope alone, which makes it difficult to work out how much money Rainbow Trust saves. However, the following illustrations describe common scenarios encountered by many Rainbow Trust Family Support Workers. The projected costs for interventions which a family may have needed from public services if Rainbow Trust's support was not available are then itemised, to illustrate conservative estimates of money saved.

Rainbow Trust is confident that these examples show that it is saving money for public services. The savings can be divided into two types:

- 1) Immediate and specific savings for public services; which can be estimated with some confidence, such as enabling families to attend appointments they might otherwise miss
- 2) Potential longer term savings for public services; such as support which contributes to families avoiding crisis situations with repercussions for their mental health, family stability and security of household income.



Source data on money saved can be downloaded from [rainbowtrust.org.uk/hidden-savings](http://rainbowtrust.org.uk/hidden-savings)

## ILLUSTRATION ONE

**A newborn baby girl was unable to leave hospital after her birth because of a serious inflammation of the bowel. Her family lived sixty miles away, and her father had mental health issues which affected his ability to work. Her mother returned to work full-time and was the main income provider. There were two older siblings who attended nursery. The family lived in a privately rented flat and because of the father's mental health difficulties they were estranged from their extended family network.**

The mother found it hard to balance work and be a parent to a seriously ill child. Working commitments and a lack of money to pay for petrol and parking meant the parents were unable to visit their baby regularly. When they did visit, they found it easier to take the siblings with them than to fit in nursery drops and pick-ups as well. They were embarrassed by their situation and often felt judged by questions from staff when they were able to visit the hospital. Both felt exhausted.



Hospital staff became increasingly concerned by the apparent lack of attachment of the parents with their baby daughter. Their visits were irregular and became less frequent. They were not present for long enough to learn the routines and interventions that their baby needed to be able to go home. This increased the likelihood of a prolonged stay in hospital. Staff began raising safeguarding concerns based on the parents' apparent unwillingness to look after their child.

A social care professional then spoke with the family and made a referral to Rainbow Trust for support. A Family Support Worker listened to the parents' concerns. The family initially asked for support to collect their children from nursery, and transport support for visiting the hospital as these were causing them the most difficulty. The Family Support Worker gained the trust of the family and as a result communication improved with the hospital and social care staff.

The interventions reduced the financial burden of travel to the hospital for the parents, while some transport to and from nursery from the Family Support Worker meant that the siblings' attendance at nursery was no longer interrupted. At the same time, some of the childcare provided by the Family Support Worker enabled the mother to attend a series of counselling sessions. As a result, the mother began to feel more effectively able to manage her emotions and anxiety.

The Family Support Worker assisted the family to put in an application for social housing, and both the social care agency and hospital wrote supporting letters for their application. The baby was then discharged to the new family home. Her parents are now confident to care for her with the support of their Rainbow Trust Support Worker and another care agency.

Conservative estimate of money saved for health and social care through intensive support of one family over six months:  
**£9,820.**



## POTENTIAL SAVINGS FOR PUBLIC SERVICES\*



### No need for involvement of a local authority social worker because the parents were more involved in their child's care

Money saved for the local authority: £40-£55 per hour of client-related work for a local authority social worker.



### Additional days as an inpatient avoided

Money saved for the CCG: specialist paediatric inpatient care per neonatal cot per day is £424 for the highest level of care.



### Cost of a child's case being taken to a child safeguarding meeting avoided

Rainbow Trust support helped parents visit their daughter more often, which alleviated safeguarding concerns, and enabled an improved relationship between the family and the staff.

Money saved for the local authority: £1,151 for overall cost of child protection core assessment, plus £1,626 for average total cost of case management processes for a 'child in need' over a six month period.

In a more serious scenario, money saved to both health and social care services could be around £5,924 to support a Family in Crisis over a six-month period, including weekly visits by a Mental Health Support Worker, a Mental Health Social Worker, and weekly 1 to 1 family support provided by social services. Note this is a conservative estimate given that these costings are for a child without additional needs.

The cost of preventing a case being taken to a child safeguarding meeting is not easy to establish, since a number of cases would be discussed in one meeting. However, such a meeting requires input from a range of professionals, so each case could be estimated to cost many hundreds of pounds to prepare and discuss.



### Additional mental health support for father avoided

Money saved for the CCG because emotional and practical support from a Family Support Worker contributed to father's mental health remaining stable: £44-65 for cost of GP consultation; £46 prescription costs per consultation, £284 mental health care clusters (initial assessment), £105 per patient contact with Improving Access to Psychological Therapies (IAPT) service, or £125 per week for one to one support from Mental Health Social Worker.



### Spending on educational or CAMHS support for siblings avoided

Money saved for both local authority and the CCG. The emotional and practical support provided by a Family Support Worker or Sibling Support Worker could enable a sibling to maintain routine, including: keeping up with their homework, helping them to manage their complex feelings, and feel more stable. This is likely to reduce demand on education support services.

Timely interventions which enable siblings to avoid poor psychological health could save money for the CCGs. For example, £811 for six months of weekly Child & Adolescent Mental Health Service (CAMHS) sessions.



### Use of Patient Transport Service avoided

Transport support from Rainbow Trust can mean that a low-income family does not need to use a local Patient Transport Service (PTS), or to claim transport costs through the NHS Low Income Scheme.

Money saved for the CCG: an estimated minimum of £31 per journey using PTS service.



Source data on money saved can be downloaded from [rainbowtrust.org.uk/hidden-savings](http://rainbowtrust.org.uk/hidden-savings)

## ILLUSTRATION TWO

**Rainbow Trust received a referral for a family with a single mother and a son aged five. The child had a rare facial tumour and was undergoing chemotherapy as an outpatient. At referral the child was due to have an intensive six-week period of daily radiotherapy.**

English was not the family's first language and communication was mainly through the child. A Rainbow Trust Family Support Worker supported the family for more than three years. As the relationship developed and the mother's English improved, the Family Support Worker was able to act as an advocate in meetings with medical professionals, and helped to communicate the mother's wishes. The Family Support Worker was also able to provide a recap on the medical information given to the mother to maintain her understanding of the treatment of her child.

Rainbow Trust could offer transport to outpatient appointments when the child was immune-suppressed, which removed the need to use NHS patient transport, and prevented missed appointments. The Family Support Worker also provided extensive ward support, while the child was an inpatient, visiting twice a week. This improved the emotional health of the child who felt less isolated, and it also enabled the mother to have a break from the ward without feeling guilty.

On one occasion, the hospital was unable to provide the correct feed for the child because they were out of stock. An error occurred where the necessary nutrition was delivered to their home address whilst the family was at the hospital. The Family Support Worker was able to go to the family home to collect nutrition for the child.



### POTENTIAL SAVINGS FOR PUBLIC SERVICES\*



#### Use of Patient Transport Service avoided

Transport support from Rainbow Trust can mean that a low-income family does not need to use a local PTS, or to claim transport costs through the NHS Low Income Scheme.

Money saved for the CCG: an estimated minimum of £31 per journey using PTS service.



#### Missed appointments prevented

Rainbow Trust support, including transport, prevented the family from missing appointments.

Cost of missed appointment incurred by the CCG if family did not attend: £208 for a paediatric consultant-led outpatient attendance or £96-£153 unit cost for outpatient palliative care (adult or child), depending on degree of specialist care required.



#### Presence of Family Support Worker improved communication between staff and the parent, and reduced sense of isolation for child as inpatient

It cannot be assumed that, in the absence of Rainbow Trust ward support, a nurse would necessarily have the capacity to sit with a child. However, assuming some nursing time is occasionally freed up on busy wards, the cost saving for the CCG may be in the region of £11.50 to £31.50 for half an hour of nursing staff time, depending on a nurse's grade.



#### Cost of taxi to collect nutrition prevented

Saving for the CCG who would otherwise have needed to organise collection of the child's feed.

Conservative estimate of money saved for health and social care for a family whose child is receiving cancer treatment: **£637.**





A Rainbow Trust  
Family Support  
Worker

### ILLUSTRATION THREE

A five-year-old girl was diagnosed with a cancer of the nerve cells. A referral was made to Rainbow Trust three months later, following her relapse. By this stage of her illness, the girl spent most of her time as an inpatient. Rainbow Trust became involved to provide emotional and practical support to the whole family. After a long series of treatments, it became clear that she was not going to survive. She died nearly three years after diagnosis.

During the child's final weeks, a Family Support Worker provided intensive support, night and day. The Family Support Worker drove her brother to the hospital from school while her parents were in the hospital. The Family Support Worker also took her brother to his swimming lessons to give him a break from the emotionally intense hospital experience. When his sister died, the Family Support Worker was there to answer his questions, and reassure him that Rainbow Trust would continue to support his family. Working alongside the hospital social worker, the Family Support Worker was able to help the parents to plan and arrange the funeral.

The presence of a Family Support Worker during this time allowed the family to feel comfortable sharing their experiences of grief. Their Family Support Worker continues to visit the family to provide bereavement support. They listen to the challenges that the parents and sibling now face, and they have facilitated meaningful family activities, such as creating a memory box. The mother initially found it hard to take her son to school following the bereavement because of the memories that it brought back. For a while this meant he missed school, but the Family Support Worker, Deputy Head, and school counsellor worked together on a plan that meant a rota was drawn up to ensure someone could do the school run for the sibling until the mother felt able to resume. The mother has since discussed her plans to go back to work with the Family Support Worker and talked through her worries. Encouragement has been important because the mother took significant time off work to care for her daughter.



### POTENTIAL SAVINGS FOR PUBLIC SERVICES\*



#### Spending on educational or CAMHS support for sibling avoided

Money saved for both local authority and the CCG. The emotional and practical support provided by a Family Support Worker or Sibling Support Worker could enable a sibling to keep up their homework, as well as helping them to manage their complex feelings, and feel more stable. This is likely to reduce demand on education support services.

Timely interventions which enable siblings to avoid poor psychological health could save money for the CCG. For example, £811 for six months of weekly CAMHS sessions for a child or adolescent.



#### Spending on health and mental health support for parents may be avoided

Grief is a natural process and everyone will respond differently to the death of a child. It is likely that Rainbow Trust's support could help to prevent parents from seeking mental health support in the years after a child's death.

Money saved for the CCG:

- £44-65 for cost of a GP consultation for one family member
- £46 prescription costs per consultation
- £105 per patient contact with Improving Access to Psychological Therapies (IAPT) service.



#### Wider benefit

Exchequer and the UK economy benefits from a parent's return to work, which was enabled by a Family Support Worker.

Conservative estimate of money saved for health and social care when a family is supported through bereavement: **£1,550.**



## EXTRAPOLATIONS FOR TOTAL ESTIMATED MONEY SAVED IN ONE YEAR

The illustrations set out in this report are designed to reflect the range of support that a Rainbow Trust Family Support Worker can provide. In each illustration the total money saved is a conservative estimate to provide an indicative figure of the support needed in a worst case scenario.

We recognise that this degree of support would not apply to every family that Rainbow Trust supports. However, for some this will be the minimum level of support required and the money saved could be an underestimate.

### Illustration 1 suggests that intensive support for a family may save £4,910 for the health and social system during a three month period.

Most families that receive Rainbow Trust support will have a phase of intensive support at some point, although some will not. If we take the figure of approximately 370 new referrals per year (based on 2016-17) as one indication of the need for intensive support over just three months, we might calculate:

370 families x £ 4,910 saved through intensive support over three months  
= **£1.816 million saved per year.**

### Illustration 2 suggests that support for a family where a child is receiving cancer treatment may enable a conservative estimate of savings of £637 per family while the child is in treatment.

Cancer is the most common diagnosis for the children whose families we support. If just 10 families are supported in such a way by each of our nine teams over the course of one year, we might calculate: 90 families x £637 saved through support while child receiving treatment  
= **£57, 330 saved per year.**

Across our nine teams in 2015-16 there were 194 children with cancer whose families were referred to Rainbow Trust, so the likely savings could be much higher.

### Illustration 3 suggests that supporting a family through bereavement might create estimated savings of £1,550 per family.

In 2015-16, Rainbow Trust worked with 67 families whose child died. We might calculate savings of:  
67 families x £ 1,550 saved through provision of bereavement support  
= **£103, 850 saved per year.**

### Combining these savings together, a conservative estimate of the total savings enabled each year would be:

£1,816,000 intensive support  
£57,330 support for families where a child has cancer  
£103,850 bereavement support

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### **£1,977,180 estimated total savings**

enabled each year for the health and social care system.

### TO SUMMARISE:

Rainbow Trust might be conservatively considered to save the health and social care system in the UK around £2 million per annum. Despite this, the charity has no access to the central NHS England Children's Hospice Grant programme which helps to fund children's hospices, and only three per cent of its income currently comes from statutory sources.

We believe there must be more the government can do to enable Rainbow Trust to provide vital services to families in the most difficult of situations.

## CONCLUSION AND RECOMMENDATIONS

Being told that your child is so seriously ill that they might die is something no parent ever wishes to hear. Nobody knows how they would react or how they would cope. For those families who find themselves in this situation, social palliative care can provide the essential support that a family needs, and may not recognise, alongside medical care, to face each day as it comes.

This report shows that by providing such support, not only are families able to cope more effectively, but significant sums of money are being saved for the health and social care system.

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### KEY FINDINGS:

1. The most recent data on prevalence in England suggests that at least 40,000 families have a child with a life-limiting or life threatening illness.<sup>1</sup> This is likely to be a conservative figure in light of the expected growth in prevalence of such illnesses, and medical advances that enable more children to live longer.
2. We don't know how many of these families will be unable to cope, but we do know that many will struggle to do so and will need the kind of support Rainbow Trust provides.
3. A pilot project to monitor how families assess their ability to cope in five areas of family life found that 100 per cent of families reported that their ability to cope improved in one or more areas, during six months of support from a Family Support Worker. The five areas monitored were: Quality of life, Quality time, Stability and confidence, Managing stress, and Economic wellbeing.
4. The direct cost per hour for tailored social palliative care from Rainbow Trust in 2016-17 is £22.64. This is a comparable cost to social care interventions from local authority social care services, however offers the advantage of being a bespoke service, responsive to the needs of the individual family.
5. Rainbow Trust is confident that it saves money for public services in two ways:
  - ➔ Immediate and specific savings for public services, which can be estimated with some confidence, such as enabling families to attend appointments they might otherwise miss
  - ➔ Potential longer term savings for public services, such as support which contributes to families avoiding crisis situations with repercussions for their mental health, family stability and security of household income.

Our conservative calculations are that our services save around £2 million per year for the health and social care system.

## RECOMMENDATIONS

**Calls for a sustainable solution to the adult social care funding crisis have been gathering momentum across the political spectrum. However, the urgent need to ensure adequate funding of social care services for seriously ill children and their families has not received the same level of attention.**

We urge all health and social care commissioners to recognise the significant contribution of these child social palliative care services to the creation of short and long term cost savings for the statutory health and social care system.

In light of these savings, and mindful of the expected growth in prevalence of life threatening and terminal conditions among children, it is logical that providers of social palliative care should be able to access fair and sustainable statutory funding. Underpinning this should be a joined-up policy framework from government, to ensure all elements of child palliative care are recognised as deserving funding.

Rainbow Trust's essential social palliative care services fall outside the current NHS England Grant to Children's Hospices, which is limited to clinical care providers. Rainbow Trust services rarely meet the locally determined criteria for Short Breaks' services for disabled children and their families, which local authorities have a statutory duty to provide. Addressing these obstacles to accessing statutory funds would enable Rainbow Trust to support more families in more parts of the country.

### **Recommendation 1:**

CCGs and local authority commissioners should ensure that children's social palliative care providers are eligible for local statutory funding streams, and that local criteria do not have the unintended consequence of excluding services which are by their nature bespoke and varied in their offering.

### **Recommendation 2:**

The Department of Health, working with NHS England, the Department for Communities and Local Government, and the Department for Education, should create a clear policy framework for a system where all elements of children's palliative care - including the non-clinical social care aspects and bereavement care - are recognised as deserving of ring-fenced statutory funding.

### **Recommendation 3:**

Rainbow Trust welcomes the additional £2 billion in funding provided to adult social care in the 2017 Spring Budget. However, the Government should now prioritise providing additional targeted new funding for child social care to ensure that children with life threatening and terminal illnesses, and their families, also receive the essential support that they need.

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A Rainbow Trust  
Family Support  
Worker



## RAINBOW TRUST HAS NINE CARE TEAMS ACROSS ENGLAND. THEY ARE:

- **Central London** - covering certain central London boroughs
- **Cumbria and North Lancashire** - covering Cumbria and North Lancashire
- **Essex** - covering Essex and NE London
- **North East** - covering Cleveland, Co. Durham, Northumberland, Redcar, Teesside and Tyne & Wear
- **North West** - covering Manchester and the wider Greater Manchester region
- **Southampton** - covering Dorset, Hampshire, West Berkshire, West Sussex and South Wiltshire
- **South West** - covering Bath, Bristol, NE Somerset, South Oxfordshire and North Wiltshire
- **Surrey** - covering Kent, SE/SW London, Surrey and Sussex
- **West London** - covering Bedfordshire, Buckinghamshire, East Berkshire, West and North West London and Hertfordshire.

### Hidden Savings:

How Rainbow Trust Children's Charity saves money for the health and social care system.

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“As a service Rainbow Trust is able to respond effectively to immediate needs. Planned services are unable to react when help is really needed and this often falls outside of their remit. Rainbow Trust always manages to step up to the plate and fill the gap.”

A father supported by Rainbow Trust