

A young child with a nasal cannula and a woman looking at each other. The child is wearing an orange hoodie with the text "LOOK ON THE BRIGHT SIDE" and a lightbulb icon. The woman is wearing a grey shirt with a blue lanyard that says "PARENTS".

# RAINBOW TRUST

SUPPORTING FAMILIES  
WITH A SERIOUSLY ILL CHILD

## **HIDDEN SAVINGS – AN UPDATE:**

How Rainbow Trust continues to save money for the health and social care system and helps them to meet their targets

## EXECUTIVE SUMMARY

Hearing that your child has a life-threatening or terminal illness is one of the most stressful and traumatic experiences that a parent can have. The nature of these conditions in children means that the mental health of parents can be under severe strain for many months or years. It is likely that many will experience feelings of anxiety, distress, depression or even trauma.

**This report highlights the considerable value that Rainbow Trust Children's Charity provides to families with a terminally ill child as well as to the public purse. It illustrates some of the significant expenditure the public sector would incur if Rainbow Trust did not intervene. The practical and emotional support provided by Rainbow Trust Family Support Workers prevents families falling into avoidable crisis situations and helps relieve pressure on the health and social care system, both now and into the future.**

This is at a time when the NHS is understaffed, underfunded, and struggling to meet the sheer demand for its services. The charitable sector plays a vital role in maintaining this essential service, directly helping families, reducing demand on lengthy waiting lists, enabling smooth and early discharge home, collaborating with local authorities, all to help the NHS meet its statutory obligations to provide children's palliative care services.

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## REPORT OVERVIEW

**This report seeks to highlight the considerable value that Rainbow Trust provides to families with a terminally ill child as well as the public purse. It illustrates some of the expenditure which the public sector would incur if Rainbow Trust did not intervene.**

The emotional and practical support provided by our Family Support Workers not only helps to prevent families falling into avoidable crisis situations, but also helps to relieve pressure from the health and social care system, both now and longer term, at a time of protracted strain.

## KEY FINDINGS:

1. Our estimate is that between June 2021 and July 2022 alone, Rainbow Trust Children's Charity saved the health and social care system approximately **£6,064,630**, the equivalent to the salaries of over 200 newly qualified social workers. This is a 200% increase from £1,977,850 reported in our 2016/17 report.
2. Rainbow Trust provides substantial savings to the public purse through numerous practical and emotional support interventions including: help with transport so families can attend appointments they might otherwise miss; providing educational support to help siblings keep up with homework and lessen the need for external educational support; enabling children to be discharged from hospital sooner, families to stay in or return to work and providing targeted bereavement support helping to prevent avoidable crisis situations. Over 70% of families felt our support was vital.
3. The report highlights the most recent data which suggests that there are an estimated 86,625 children in England with life-limiting or life-threatening conditions, of which 25,000 may require respite and palliative care in any year. This is set to increase by 11% to 92,275 by 2030 as medical advances enable more children to live longer into young adulthood making our services in the future just as necessary as they are today.

As we continue to recover from the pandemic and the cost-of-living crisis worsens we predict that referrals will continue to increase as families seek our support more than ever. Our data already reflects this as in 2020/21, 590 new families were referred to Rainbow Trust, 60% more than in 2016/2017. Families with a seriously ill child are already disproportionately impacted by the cost-of-living crisis due to the unavoidably high costs associated with caring for a disabled or seriously ill child such as electricity to power life-saving equipment, higher food costs due to hunger inducing steroids, or extra washing due to incontinence issues. In addition, studies show us that families with a seriously ill child are also more likely to come from an area of high deprivation and the additional financial burden will push more families beyond the poverty line into deprivation.

4. The direct cost per hour for tailored, in-depth social palliative care from Rainbow Trust in 2021/22 is £26. This cost is significantly lower than the variable cost that Local Authorities would incur if Rainbow Trust did not intervene. And yet there remains a large gap in funding accessible to charities who provide niche services such as Rainbow Trust. In fact, last year only 2% of Rainbow Trust's income came from statutory sources, half of which was a one-off pandemic related payment, the rest being from small local statutory grants. These small local grants and statutory funding contracts have successfully demonstrated that we are able to help the NHS and Local Authorities meet their targets and statutory obligations and save the health and social care system money. However, we continue to face significant barriers in accessing sustainable statutory financial support including being unable to access the Government's Children's Hospice Grant.
5. Despite the charitable sector helping the NHS and Local Authorities to meet their targets and statutory obligations, which provides substantial savings to the health and social care system, the pandemic has impacted charities. The 2022 survey by Nottingham Trent University found that 41% of charities felt that the pandemic had significantly weakened charities and they were yet to fully recover and reach pre-pandemic income levels and yet referrals were increasing and services resuming, placing a greater strain on budgets.

## RECOMMENDATIONS

**At a point when the NHS is understaffed, underfunded, and struggling to meet the sheer demand for its services, we urge the Government to recognise the important role Rainbow Trust plays in supporting seriously ill children and their families and to take up our recommendations below.**



### **Recommendation 1)**

Prioritise funding for the charitable sector to ensure that we can continue to provide vital services at a time when demand upon the sector is set to increase as we attempt to recover from the pandemic and the country moves further into the cost-of-living crisis. Charities are having to foot increasing bills to continue providing vital services, at a time when voluntary donations and access to volunteers are reducing.



### **Recommendation 2)**

As a result of the Health and Care Act, Integrated Care Systems are now taking on greater statutory responsibilities. This is a welcome step towards achieving better coordination of services and improved outcomes for the health of the local population.

Rainbow Trust is urging to Government to ensure that there are enough opportunities for the voluntary sector to contribute its expertise in this area, work in partnership on health and care provision and help shape policies that will impact the families we support.



### **Recommendation 3)**

Urgently provide emergency support for families struggling to cope with the rising cost of living. The Government must recognise that the cost-of-living crisis has a disproportionate impact on families with a disabled or seriously ill child. The Government must act now to ensure that families are not forced to make a choice between powering lifesaving equipment or heating their homes.



*Reuel, aged 5, with older brother Moses, aged 7*

## INTRODUCTION

**The health and social care system has been facing an unprecedented amount of pressure with demand far outstripping its capacity to supply its vital services to the general public. This has led to major backlogs in care for over 6 million people<sup>4</sup> as at June 2022, who are at the same time facing a significant cost-of-living crisis.**

Rainbow Trust Family Support Workers have been working tirelessly to fill the gaps and alleviate pressure on the NHS by providing emotional and practical support to families with a terminally ill child. The vital, and often invisible emotional and practical services provided by our Family Support Workers have enabled many families to cope better during a period of protracted strain on the NHS.

Rainbow Trust has supported children with life-threatening and terminal conditions and their families at home and in their local community for over thirty-five years. With innovation and flexibility, Rainbow Trust Family Support Workers relieve pressure on the NHS and social care sector by continuing to work with parents and children, at the very time many other services and sources are overstretched.

Between June 2020 and July 2021, as a result of national and regional restrictions Rainbow Trust experienced a 40% drop in referrals compared to the previous year but was committed to continue providing support for 1,075 families across England, including establishing an online support team. Between July 2021 and June 2022 this number steadily increased to 1,126 and we predict a sustained year on year increase going forward as Covid-19 cases decrease and services resume to pre-pandemic levels.

Rainbow Trust also anticipates a further increase in referrals as a direct result of the cost-of-living crisis as families with a terminally ill child already face an immense amount of pressure coming to terms with their child's illness, coping with grief or managing their altered routines. This is being further exacerbated by additional financial pressures; as many families in this situation have little or no room to make domestic cutbacks due to having to power life-preserving equipment; facing expensive transport costs to and from medical appointments as well as managing the significant increase in the price of basic goods and services.

A recent survey carried out by Family Fund in 2021 found that 85% of families with an ill or disabled child had £500 or less in the bank and 7 in 10 reported having no savings to fall back on whatsoever<sup>5</sup>. Furthermore, a survey conducted by Contact found that 33 percent of families already have extra disability and care related costs in excess of £300 per month. 56% of respondents said disability payments only partly cover these extra costs<sup>6</sup> leaving a significant financial gap that families need to regularly fill through their own means.

These findings are especially concerning once we also consider the fact that more children than expected with a life limiting condition live in areas of higher deprivation (13% most deprived versus 8% in least deprived)<sup>7</sup>. Rainbow Trust is very concerned that this increased financial burden will push more families beyond the poverty line and into deprivation where they can find themselves unable to cover the cost of running vital equipment which would have catastrophic consequences for the sick child. As a result, families in this predicament may find themselves in crisis situations with their mental health impacting their ability to cope with an already challenging circumstance. These consequences will inevitably have a trickle-down effect on demand and costs for the NHS, social services and the voluntary sector.

**“Our energy usage is higher overnight because of the amount of equipment we use.”**

**“You are the only ‘childcare’ we have, and you have been really really helpful. Thank you”**

**“Restrictions lifting makes no difference in our home. We are still shielding as much as possible to protect the vulnerable two in our home.”**



Anna greeting her Family Support Worker Charlotte

## **RAINBOW TRUST'S SAVINGS TO THE NHS AND SOCIAL CARE SYSTEM**

Rainbow Trust helps to plug the widening gap between demand and access to services by pairing families who have a life threatened child with a dedicated Family Support Worker who provides expert emotional and practical support tailored to each family's needs.

Rainbow Trust estimates that through our ongoing support for families, we saved over £6million for the Health and Social Care system between June 2021 and July 2022, a dramatic increase from the circa £3.2 million we identified in 2019-20. We still consider this to be a conservative calculation and have provided examples of potential additional costs, not previously included, later in this report.

This increase is the result of a year-on-year rise in families seeking our support. More than 590 new families were referred to Rainbow Trust for support from a Family Support Worker in 2021-22, compared with 370 in 2016-17. These were additional to families that we were already supporting. We expect this figure to continue increasing as a consequence of the fallout from the pandemic and the knock-on effect of the cost-of-living crisis on families.

## **RAINBOW TRUST IS SUPPORTING THE NHS TO MEET ITS STATUTORY OBLIGATIONS**

Under the general principles of the NICE Guidance and Quality Standards for End-of-Life Care for Infants, Children and Young People, NHS commissioners need to provide children's palliative care services which meet the criteria set out below:

### **NICE GUIDELINES**

- 1) The child and their family should play an active role in discussions about their care.
- 2) Where possible, the child should receive palliative care, including end of life care, in the place they choose.
- 3) Children, young people and parents should be given ample opportunity to contribute to decisions, working collaboratively with the multidisciplinary team.
- 4) If possible, avoid frequent changes to the healthcare professionals caring for them.
- 5) Siblings will also require support to cope with the condition or death of a brother or sister as well as the associated experience of having a grieving parent or caregiver.
- 6) Due consideration given to other family members such as grandparents or close friends.
- 7) Use parallel planning to consider the unpredictability of certain conditions when developing plans for the child's care.



**NICE CALCULATES THAT BY INVESTING £12.7MILLION IN IMPLEMENTING THE GUIDANCE, NON-CASH SAVINGS WORTH £34.7MILLION WOULD BE RELEASED BACK INTO THE NHS IN ENGLAND.**

### **RAINBOW TRUST'S ROLE IN HELPING THE NHS MEET THESE STANDARDS**

- 1) Providing expert advice and information to the whole family enabling them to actively contribute and make well informed decisions about their child's care.
- 2) As a member of the specialist paediatric palliative care team, we are able to help families to access the care they require, in the place they see fit, working hand in hand with community nursing teams to support families with their preferred place for their child's end of life care.
- 3) Our expert Family Support Workers tailor their support to families to ensure that they are provided with information and support from diagnosis through to treatment, are able to discuss any concerns and ask questions which will contribute to decisions about their child's care. We also work collaboratively as part of the multidisciplinary team throughout the child's medical journey.
- 4) Rainbow Trust facilitates continuity of care as our support workers are specifically paired with families and only in exceptional circumstances do these arrangements change. The support is bespoke and consistent and, where necessary, bereavement support is therefore given by someone who knew their child.
- 5) Rainbow Trust understands that when a family is caring for a child with a serious illness or the family experiences the death of a child, siblings are also deeply affected often experiencing feelings of grief, guilt and isolation. Our Family Support Workers help siblings cope through one-to-one support, sibling groups, family workshops and through our Youth Resilience Groups.
- 6) Rainbow Trust recognises the immense contribution made by grandparents and the wider family to support and care for a seriously ill child. We extend our services to the whole family network and ensure that they can access this support for as long as they require. Our support was particularly pertinent during lockdown when families were not able to mix. As frontline key workers, our Family Support Workers were able to continue to provide much needed support when others were not there.
- 7) Providing an adaptable approach to care, one that is tailored to meet the needs of the child and family, regularly reviewing care plans to ensure they are beneficial and effective.

## LIMITED AND SHORT-TERM SUPPORT FROM STATUTORY FUNDING SOURCES

Despite the vital support Rainbow Trust provides and the regular positive feedback we receive from families, we continue to face significant barriers in accessing statutory financial support. The niche and extremely tailored service Family Support Workers provide means that only a very small percentage of Rainbow Trust's income is sourced from statutory funding and there is no secure, steady income stream.

Rainbow Trust continues to work towards rebuilding a stable income stream following the Covid-19 pandemic. Whilst we were one of the first charities to launch an emergency appeal which provided short term financial support against income lost as a direct result of the pandemic, this funding was an exception. Rainbow Trust is unable to access the Government's Children's Hospice Grant and many other forms of statutory funding. In fact, just four out of 333 Local Authorities in England funded our services in 2021-22. Where grants were awarded, they were typically short-term, Covid-related or specific to a particular aspect of our support.

Rainbow Trust continues to rely on the support of charitable trusts and foundations, companies, many benevolent individuals and volunteers to maintain its essential work and meet the increasing post-lockdown demand.

Our experience of ad-hoc funding through various income streams demonstrates that, where our services are known and understood, there is a keen interest to continue making it accessible. More and more families benefit from Rainbow Trust's emotional and practical support, which in turn helps the NHS and Local Authorities to meet their targets and statutory obligations as well as saving money for the health and social care system. It should be noted that because we work predominantly in local community settings and homes, our largest running cost is our staff, rather than buildings like hospices.

## NEW OPPORTUNITIES FOR RAINBOW TRUST TO HELP THE NHS MEET NICE GUIDELINES AND QUALITY STANDARDS

We have some recent examples of partnership working funded by Clinical Commissioning Groups:

- In **North West London**, one Rainbow Trust Family Support Worker was part-funded by Clinical Commissioning Groups to work in partnership with Shooting Star Chase Children's Hospice and provide joined up support for families in this area. More than 30 families are set to benefit from this project, which seeks to reach more families with a seriously ill child, and ensure an integrated approach to their care, minimising duplication.
- **Morecambe Bay** Clinical Commissioning Group provided funding for Rainbow Trust's Dads' Group and Parents Group in 2020-21, and an additional small grant from spring 2021 funded emotional and psychological support for children and families.
- **Tees Valley** Clinical Commissioning Group agreed in Autumn 2021 to fund a part-time Family Support Worker post for three years to help meet targets and long-term Plan ambitions. Rainbow Trust aims to fundraise for enough income to make the post a full-time equivalent. Aims for the role are to ensure:
  - Children with a life-limiting condition and their parents or carers are given information about emotional and psychological support, including how to access it
  - Children with a life-limiting condition are cared for by a multidisciplinary team that includes members of the specialist paediatric palliative care team
  - Parents or carers of children approaching the end of life are offered support for grief and loss when their child is nearing the end of their life and after their death

## HOW MANY CHILDREN AND YOUNG PEOPLE ARE AFFECTED?

Academic data on prevalence in England suggests that there were 86,625 children and young people with a life-limiting or life-threatening illness in 2017-18 and of these an estimated 25,000 may require respite care and palliative care within any year<sup>8</sup>.

Prevalence of such conditions has risen significantly in recent years, partly as a result of more seriously ill babies surviving birth, and in part as a result of medical advances enabling more children to live longer into young adulthood. The most recent prediction suggests that the number of children with life-limiting conditions will have increased by a further 11% by 2030.

There has also been a sustained rise in the number of children with a life-limiting condition who have a hospital admission longer than 28 days each year, rising from 2,482 children in 2001/2 to 3,538 in 2017/18. Using previous trends and patterns, Together for Short Lives estimates that the future prevalence of children aged 0-18 years with a life-limiting condition will rise to 96,275 by 2030, a marked increase from 87,572 in 2017.<sup>9</sup>

These figures demonstrate that demand for Rainbow Trust's services will continue to increase and in order to fund these vital services both now and in the longer term Rainbow Trust will continue to require a steady stream of funding and support.



*Erhun, aged one with his mum, Rosemary*

## **SAVINGS TO THE HEALTH AND SOCIAL CARE SECTOR ENABLED BY RAINBOW TRUST:**

It is not entirely possible to quantify how a family might cope in the absence of receiving vital emotional and practical support from Rainbow Trust, but our most recent survey found that over 70% of families who do receive our care believe that support in the family home was crucial to them. We are confident that the savings enabled by Rainbow Trust's support have been significant for families and the public purse. These include:

- 1) Immediate and specific savings for public services which can be estimated with some confidence, such as enabling families to attend appointments they may otherwise miss through our transport provision - in total, missed hospital appointments cost the NHS over £1billion per year<sup>10</sup>.
- 2) Lack of access and longer waiting times for services such as mental health provision can lead families towards avoidable crisis situations - Rainbow Trust's emotional support including bereavement care and sibling support can provide families with a viable outlet, easing additional pressure on the NHS.
- 3) Prevention has been a key driver of many NHS Long Term Plans. Following much research, findings have shown that there are many benefits to preventative care including enabling families to cope with challenging circumstances early on, leading to better mental and physical health in future. Our support has enabled families to stay in, or return to, employment, supported children to stay in education and reduced referrals to CAMHS. It has contributed to family stability, wellbeing and long-term savings for the public purse.
- 4) The tailored support provided by Rainbow Trust means that many families are not solely dependent on the support of specialist health care workers. This takes the pressure off the NHS, helps to reduce waiting times and goes towards balancing supply with demand.

## EXAMPLES OF SUPPORT

Providing emotional support can help parents to avoid crisis situations such as family breakdown or lasting mental health problems as a result of the extremely stressful situation they are in. This can reduce the need for future social care interventions and the need for professional mental health support. Rainbow Trust Family Support Workers keep in touch through home visits, arranging outings, phone calls, video calls and text messages. A Dads' Group, which switched to meeting online during the pandemic, now meets regularly face-to-face, enabling fathers to keep in touch and share their experiences.

Supporting seriously ill children and their siblings can provide the children with an outlet to share any difficult feelings, as well as a chance to have some fun and do new activities, promoting positive mental health.

- Family Support Workers offer activities such as crafts, quizzes, story time and play sessions with children and their siblings. Rainbow Trust has also provided virtual sibling groups where necessary. Parents are able to have some time to themselves and the comfort of knowing that their children are engaging in fun, safe activities in a way their circumstances may not usually allow.
- Rainbow Trust provides a Youth Resilience Group for 11 to 16 year old siblings of seriously ill children helping them to become experts in their own resilience, come to terms with their experiences and, to help children and young people develop a positive lifestyle and coping strategies.
- Rainbow Trust also helps local authorities meet legal obligations, for example, to provide short breaks for those children with disabilities who have life-limiting or life-threatening illnesses.

A referral was made to Rainbow Trust for sibling support for a young boy when his sister was diagnosed with a very rare inherited metabolic condition, which devastated both parents. The Family Support Worker began to regularly attend and dedicate her time to discussing the sibling's feelings and provide tools to cope with the demands of his sister's condition. His parents said that not only did this provide much needed support for the young sibling, but it also alleviated some of the guilt they were facing because of their shifting priorities.

A referral was made to Rainbow Trust for neonatal support when a mother gave birth to a baby at 25 weeks. The baby remained in intensive care and at one point needed to be resuscitated, which caused great distress to both parents. The Family Support Worker provided an opportunity for parents to discuss their feelings whilst also acting as a companion during the remainder of their time in the neonatal unit. Support was given during difficult conversations with doctors and upon discharge our Family Support Workers continued to provide support so the mother could feel confident to care for her baby at home.

Our support allows parents to have a much-needed break, giving them the opportunity to do general household tasks or outdoor activities which restore an element of normality back to the family dynamic. Importantly, this support also gives the opportunity for a parent to shift attention to a sibling who may at times miss out on some attention due to competing demands of their seriously ill sibling.

Supporting families visiting seriously ill neonates is a vital service. We provide transport to and from appointments, emotional support during hospital stays and visits, care for siblings and a wide range of practical support to alleviate pressure on parents.

- Rainbow Trust Family Support Workers act as a support system for parents who may be attending hospital regularly or getting to grips with their child's diagnosis. They provide expert support and advice to aid parents navigating the complexities associated with certain conditions.
- Previous research<sup>11</sup> has found that one of the barriers preventing parents from being closely involved in their babies' care in neonatal units is lack of support with transport and parking costs. Rainbow Trust's support provides the breathing space for families to be more involved in their children's care and not be obstructed by such barriers.
- Treatment can often be at a specialist hospital located far from home, transport can be expensive, and journeys can become stressful for families to arrange, especially if they have more than one child within their care. Rainbow Trust Family Support Workers alleviate this pressure by taking on the transport duty at no cost to the parents giving them the opportunity to make sure that time with their children remains as meaningful as possible.

We can enable seriously ill children to be discharged from hospital sooner because families are supported to cope better with the demands of caring for them at home. This directly reduces pressure on and costs to the NHS. According to the NHS National Cost Collection, the average cost per night for a child on a ward for children and young people is £2,014<sup>12</sup>, our intervention provides this immediate saving for the NHS whilst giving ongoing support to families during this challenging period.

- Families are able to leave hospital with a sense of reassurance that they will be supported by an expert Family Support Worker who will assist the whole family including parents, carers, the unwell child, brothers, sisters and grandparents.
- Having the support of a Rainbow Trust Family Support Worker also enables the family to adapt to their altered home routine whilst ensuring that the health needs of the child are facilitated and easily incorporated into the home environment. This fosters stability for the parents, siblings and child creating long-term benefits.
- Families have often spoken of the fear and loneliness associated with being discharged from hospital. Anxieties linked to previous traumatic medical experiences are eased by having a knowledgeable Family Support Worker who stimulates conversation and explains associated challenges and expectations.



*Reggie aged 6 months old with his Family Support Worker*

## **SAVINGS AND SUPPORT FOR LOCAL AUTHORITIES**

The Children Act 1989, Section 17, provides a general duty for every local authority to safeguard and promote the welfare of children within their area who are in need. The families that Rainbow Trust supports often meet this legal test and would therefore, require significant support from local authorities. Rainbow Trust helps to ease this pressure through several avenues:

### **MONETARY SAVINGS**

Local authorities provide monetary payments to assist with meeting a child or young person's needs, known as Direct Payments. Surveys on Direct Payments found that there are more people with physical disability or sensory impairment with direct payments than is the case for all other groups<sup>13</sup>. Rainbow Trust recognises these are in very high demand and seeks to ease the burden by providing vital services such as emotional, practical and specialist bereavement support for free that families would otherwise need to fund through Direct Payments.

### **SPECIALIST CARE**

Our expert Family Support Workers specialist care helps to fill the gaps in care, ensuring that parents and children are well supported throughout their child's complex medical journey. Whilst beneficial to parents, this also supports the services provided by local authorities, which have been increasingly stretched within the last decade, by reducing demand and easing the pressure on lengthy waiting lists. Our tailored support helps to reduce the burden on local provision and bolster any existing support families may be receiving

### **COLLABORATION**

Research by Nottingham University and partners found that during the Covid-19 pandemic, there was a high degree of collaboration between charities and local authorities, with survey results finding that 71% of charities worked together with their local authority - an increase of over 36% from previous years. In some instances, the voluntary, community and social enterprise sector was specifically contracted to provide essential services on behalf of the local authority during this time<sup>14</sup>. This element of collaboration ensures that the needs of local residents do not go unmet and helps to avoid the likelihood of people finding themselves facing additional hardship. Such hardship will have a knock-on effect on local authorities with increased demand on social services and for financial support, such as discretionary payments or hardship grants. Charities such as Rainbow Trust bolster any support being received from the local authority and help to fill the gaps in services, ensuring that families with a seriously ill child are well supported throughout their child's medical journey.



## OUR CALCULATIONS

Our calculations look specifically at three scenarios experienced by families that Rainbow Trust supports, to create a picture of likely savings enabled by the provision of this support.

### 1) INTENSIVE SUPPORT FOR FAMILIES

Most families who are referred to Rainbow Trust will have a phase of intensive support at some point. Such input from a Family Support Worker could enable savings for the health and social care system in the following ways:

- Preventing the need for a social worker when a family is struggling to cope with their situation and there are concerns about the welfare of the sick child or their healthy siblings.
- Enabling a seriously ill baby or child to be discharged earlier than planned because Rainbow Trust support has helped a parent to feel more confident to cope with their child's needs.
- Reducing the need for a parent to require a GP appointment and prescription of anti-depressant medication.
- Enabling the sibling of a seriously ill child to cope better with their feelings about their brother or sister's illness and the impact this has had on their family, avoiding the need for professional psychological support or a referral to CAMHS.



#### Calculations:

Average GP consultation + prescription cost = **£70.13**

Transport cost (3 trips) = **£114**

3 months support from a social worker (5 hours per month) = **£690**

National average cost on a transitional care ward = **£969**

Average cost of counselling intervention = **£1,217**

Cost of a child's safeguarding assessment & case management (6 month period) = **£2,777**

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**Total estimated savings by providing three months of intensive support for one family (sum of figures above): £5,837.13**

970 families received support for over 3 months between July 2021 and June 2022. Taking the view that each of these families did require intensive support, as we might expect, we calculate: 970 families x £ 5,837 = £5,661,890

Total **saved** through our intensive support over three months = **£5,661,890 per year.**

## 2) SUPPORT FOR A FAMILY WHERE A CHILD IS RECEIVING CANCER TREATMENT

Cancer is the most common diagnosis for the children we support, affecting 30% of the families on Rainbow Trust's caseload. During the pandemic, some children with cancer had been identified as Clinically Extremely Vulnerable because of their compromised immune systems and for many this continues to shape their daily lives despite the easing of restrictions. Children's cancer treatment has continued but infection control measures have meant that families have experienced additional anxiety.

A Family Support Worker could enable savings in the following ways:

- Providing transport to and from some of the child's appointments for intensive treatment, preventing the need for patient transport services, taxis or petrol.
- Support which prevents families from missing appointments if parents are overwhelmed by the practical and logistical demands of their situation alongside ongoing work commitments and the care of healthy siblings.
- Our service can free up nursing time when a Family Support Worker visits a child as an in-patient and keeps them company while their parent has a break.



### Calculations:

Average cost for NHS non-emergency transport (6 journeys) = **£228**

Cost of two missed paediatric consultant-led outpatient appointments = **£224**

Average nursing costs = **£264**

Average cost of taxi to collect nutrition = **£38**

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**Total estimated savings (sum of figures above): £754 per family while the child is in treatment.**

Between 2021-22 Rainbow Trust supported 165 families where a child has cancer, we therefore calculate:  $165 \times £754 = £124,410$

**Total saved through support while the child is receiving treatment = £124,410 per year.**

### 3) SUPPORT FOR A FAMILY THROUGH BEREAVEMENT

Although more children are living longer with their life-threatening conditions, some children will die each year. Support from a Rainbow Trust Family Support Worker continues through bereavement and provides the consistency of support which many families value because we knew their child. At the time of death many other services just stop.

Savings for the health and social care system can include:

- Preventing the need for counselling or psychological support sessions for a parent and bereaved sibling.
- Preventing the cost of GP appointments used to discuss how they are coping and the possibility of referral for professional support.
- Providing aftercare support to families upon discharge in the event they are receiving professional support, enabling them to leave hospital earlier whilst promoting healthier recovery.



#### Calculations:

Average cost of counselling intervention (assuming the median of 12 hours per case) = **£1,217**

Average cost of GP consultation & prescription cost (two appointments) = **£140.26**

IAPT mental health assessment + 6 sessions = **£547**

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**Total estimated savings for the health and social care system: £1,904.26 per family.**

Between June 2021 and July 2022, Rainbow Trust worked with 65 families who have been bereaved. We can therefore calculate 65 families x £ 1,904 = £123,760.

Total **saved** through provision of bereavement support = **£123,760 saved per year.**



#### GRAND TOTAL OF SAVINGS TO THE NATIONAL HEALTH SYSTEM:

£5,661,890 saving as a result of the intensive support Rainbow Trust provided to 970 families

£124,410 saving due to supporting 165 families where a child has cancer

£123,760 saving due to providing bereavement support to 65 families

**Total Savings: £6,064,630**

## What is not included

Our estimates are conservative and do not include wider implications to the public purse beyond health and social care. Examples are:

- Additional savings for the educational system, reducing the need for one-to-one school-based 'catch-up' support. Examples include: providing transport for a healthy sibling to attend school or nursery when parents need to take their seriously ill child to essential appointments or treatment; and supporting healthy siblings to complete homework.
- Our sibling support may in turn help children achieve their academic potential and prevent mental health difficulties, later in their education and employment. It is difficult to measure the potential impact on health services, welfare and taxable income into adulthood.
- The benefit for the Exchequer and the UK economy when a bereaved parent is enabled to return to work following support from a Family Support Worker or when practical support helps a parent maintain employment during the illness.
- The benefit to society and the Exchequer when parents are supported to find ways to cope better with their situation and family breakdown is avoided, plus the associated long-term impact on mental and physical health.

## The impact of price inflation on charities:

The cost-of-living crisis also presents significant challenges to the charitable sector alongside the families it supports and the wider public. Rainbow Trust anticipates increased demand for our services, whilst at the same time facing the prospect of:

- Increased fuel costs, as care staff provide transport to essential hospital visits, school pick-ups and transport to activities.
- Possible reduced income due to the shifting priorities or lack of funds from individual donors.
- Increased energy running costs.
- Possible reduced reserves impacting our future sustainability and growth.
- Reduced access to volunteers as a continued result of the pandemic as well as the burden of the worsening cost of living crisis. Individuals may find themselves having to prioritise their time towards paid employment rather than voluntary work, having a knock-on effect on service provision but also fundraising abilities. This places greater pressure on the workload of current staff members and the organisation as a whole in the longer-term at a point when demand is set to increase.

Research by Pro Bono Economics predicted that a £20 donation in 2021 will be worth £17.60 in 2024, whilst a grant of £100,000 in 2021 will be worth £88,100 by 2024<sup>15</sup>. This presents a worrying picture alongside the significant anticipated financial challenges that charities such as Rainbow Trust will face in the near future.

## KEY FINDINGS

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1. Our estimate is that between June 2021 and July 2022 alone, Rainbow Trust Children's Charity saved the health and social care system approximately **£6,064,630**, the equivalent to the salaries of over 200 newly qualified social workers. This is a 200% increase from £1,977,850 reported in our 2016/17 report.
2. Rainbow Trust provides substantial savings to the public purse through numerous practical and emotional support interventions including: help with transport so families can attend appointments they might otherwise miss; providing educational support to help siblings keep up with homework and lessen the need for external educational support; enabling children to be discharged from hospital sooner, families to stay in or return to work and providing targeted bereavement support helping to prevent avoidable crisis situations. Over 70% of families felt our support was vital.
3. The report highlights the most recent data which suggests that there are an estimated 86,625 children in England with life-limiting or life-threatening conditions, of which 25,000 may require respite and palliative care in any year. This is set to increase by 11% to 92,275 by 2030 as medical advances enable more children to live longer into young adulthood making our services in the future just as necessary as they are today.

As we continue to recover from the pandemic and the cost-of-living crisis worsens we predict that referrals will continue to increase as families seek our support more than ever. Our data already reflects this as in 2020/21, 590 new families were referred to Rainbow Trust, 60% more than in 2016/2017. Families with a seriously ill child are already disproportionately impacted by the cost-of-living crisis due to the unavoidably high costs associated with caring for a disabled or seriously ill child such as electricity to power life-saving equipment, higher food costs due to hunger inducing steroids, or extra washing due to incontinence issues. In addition, studies show us that families with a seriously ill child are also more likely to come from an area of high deprivation and the additional financial burden will push more families beyond the poverty line into deprivation.

4. The direct cost per hour for tailored, in-depth social palliative care from Rainbow Trust in 2021/22 is £26. This cost is significantly lower than the variable cost that Local Authorities would incur if Rainbow Trust did not intervene. And yet there remains a large gap in funding accessible to charities who provide niche services such as Rainbow Trust. In fact, last year only 2% of Rainbow Trust's income came from statutory sources, half of which was a one-off pandemic related payment, the rest being from small local statutory grants. These small local grants and statutory funding contracts have successfully demonstrated that we are able to help the NHS and Local Authorities meet their targets and statutory obligations and save the health and social care system money. However, we continue to face significant barriers in accessing sustainable statutory financial support including being unable to access the Government's Children's Hospice Grant.
5. Despite the charitable sector helping the NHS and Local Authorities to meet their targets and statutory obligations, which provides substantial savings to the health and social care system, the pandemic has impacted charities. The 2022 survey by Nottingham Trent University found that 41% of charities felt that the pandemic had significantly weakened charities and they were yet to fully recover and reach pre-pandemic income levels and yet referrals were increasing and services resuming, placing a greater strain on budgets.

## CONCLUSION

Our updated estimate is that Rainbow Trust Children's Charity saved just over **£6,064,630** for the health and social care system in between June 2021 and July 2022 alone. However, figures are predicted to be much higher once additional expenses are included.

The essential services we provide make a true difference to families and help to ease the burden on the health and social care sector in many areas. The number of families seeking our support will continue to increase as outlined in this report and Rainbow Trust is ambitiously planning ahead to ensure that families can access our services whenever and wherever needed.

**Despite evidence of these savings and the role Rainbow Trust has in helping the NHS to meet NICE and other statutory standards, the charity does not have access to a sustainable source of statutory funding.**

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## RECOMMENDATIONS

**At a point when the NHS is understaffed, underfunded, and struggling to meet the sheer demand for its services, we urge the Government to recognise the important role Rainbow Trust plays in supporting seriously ill children and their families and to take up our recommendations below.**



### **Recommendation 1)**

Prioritise funding for the charitable sector to ensure that we can continue to provide vital services at a time when demand upon the sector is set to increase as we attempt to recover from the pandemic and the country moves further into the cost-of-living crisis. Charities are having to foot increasing bills to continue providing vital services, at a time when voluntary donations and access to volunteers are reducing.



### **Recommendation 2)**

As a result of the Health and Care Act, Integrated Care Systems are now taking on greater statutory responsibilities. This is a welcome step towards achieving better coordination of services and improved outcomes for the health of the local population.

Rainbow Trust is urging to Government to ensure that there are enough opportunities for the voluntary sector to contribute its expertise in this area, work in partnership on health and care provision and help shape policies that will impact the families we support.



### **Recommendation 3)**

Urgently provide emergency support for families struggling to cope with the rising cost of living. The Government must recognise that the cost-of-living crisis has a disproportionate impact on families with a disabled or seriously ill child. The Government must act now to ensure that families are not forced to make a choice between powering lifesaving equipment or heating their homes.

If your commissioning organisation is interested in talking to us about what we could achieve together, please contact Anne Harris, Director of Care, [e: anne.harris@rainbowtrust.org.uk](mailto:anne.harris@rainbowtrust.org.uk) **t:** 01372 363438.

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**“ You made such a difference to me this summer during our meet-ups in the park, lifting my spirits and listening to me as I've talked about my daughter I always left feeling brighter. I know it's hard as you haven't been able to see my son due to COVID but you've always still been there, offering Zoom chats and WhatsApp. ”**

**“ The biggest thing that I have been impressed with is how my Family Support Worker has adapted to our needs during the lockdown and continued to support my son throughout with sensory games. ”**

**“ As a family we couldn't be without the support you provide us, from when our little boy was still with us, looking after them [my son and daughter] and making sure I had 5 minutes to myself to have a bath or pop to the shops... The emotional support has been amazing, especially now as our little boy died last November and you have been with us every step. ”**



*Jack aged one with his Dad, Matthew*

Front cover:  
Jayden, aged 6 with his Family Support Worker, Monika



SUPPORTING FAMILIES  
WITH A SERIOUSLY ILL CHILD

**“Rainbow Trust has made a massive difference to our family. My daughter cannot wait to see or talk to our Family Support Worker as she is very cut off from people a lot of the time, mentally she is a different person afterwards... I do not have any family and it can be lonely and hard to keep talking to friends about problems they cannot understand. When our Family Support Worker comes we all feel so much better afterwards.”**

#### **HIDDEN SAVINGS - AN UPDATE:**

How Rainbow Trust continues to save money for the health and social care system and helps them to meet their targets

September 2022

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#HiddenSavings



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