

# Overstretched and underfunded

The state of children's hospice  
funding in 2025



A report by  
**Together for Short Lives**

Images courtesy of Tina Gue and Jessie May

together  
for  
short  
**lives**



## Foreword

Across the UK, children's hospices are a lifeline for thousands of seriously ill babies, children and young people – and for the families who care for them. By providing a broad range of services from end of life care and symptom management to emotional and psychological support, children's hospices are a vital source of help at times of overwhelming need.

Despite their importance, children's hospices are continuing to navigate their way through a deeply uncertain and unsustainable financial landscape. While they may be providing more care than ever before, they are doing so under mounting financial pressure.

Inflation, workforce shortages, and rising demand for care are stretching services to breaking point. At the same time, despite increases in local NHS and council funding, statutory funding is still falling short of what is required, leaving many hospices forced to rely on their reserves and public generosity just to maintain the care families depend on.

This is a crisis in need of urgent action. Families caring for children with life-limiting and life-threatening conditions need reassurance that this support will be there – not just today, but tomorrow and in the years ahead.

With the NHS 10-Year Plan nearing publication and work underway in the devolved nations to update and develop new strategies and service specifications, there are now several opportunities for governments to act.

A sustainable future for children's hospices is possible but only if political leaders seize the moment. That means committing to equitable and fair funding for the long term that reflects the true cost of care. It means holding statutory bodies to account for their role in commissioning high quality children's palliative care. And it means working with the sector to ensure every seriously ill child and their family can access the support they need, when and where they need it.

At Together for Short Lives, we are committed to playing our part in building a stronger future. Step by step, hand in hand, day by day, making sure that no one has to face living through their child's short life – and death – alone.

That includes working to achieve a higher average of funding for children's hospices per child from integrated care boards. It also includes closing the £310 million shortfall in NHS funding for children's palliative care and securing the future of the Children's Hospice Grant.

But we cannot do this alone. We need action from governments across the UK now. Because these children and their families cannot wait.

Together we must work to make sure that every child and young person has access to high quality, sustainable palliative care when and where they need it.

**Nick Carroll**

Chief Executive, Together for Short Lives



# Executive summary

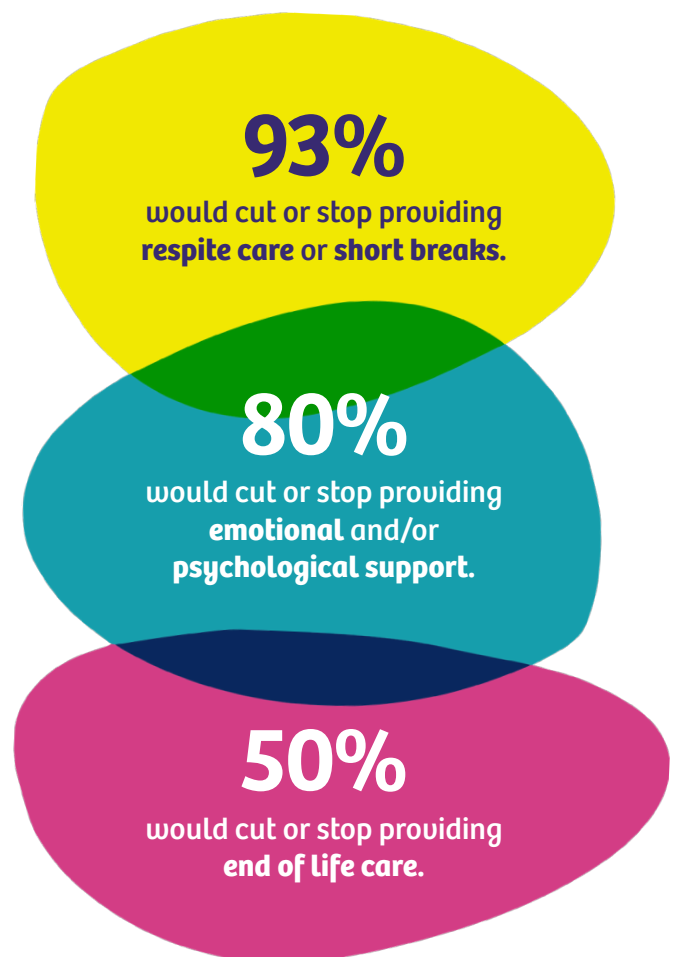
- Across the UK, children's hospices are a lifeline for seriously ill children and their families, delivering more care and support than ever before.
- Despite encouraging signs – including cash terms increases in statutory funding for children's hospices – support from the state still falls short of what is required, forcing hospices to rely even more on the generosity of the public to plug the gap.
- As in recent years, high inflation and growing costs of recruiting and retaining skilled and experienced staff continue to drive children's hospices' costs up.
- With reserves set to dwindle and deficits projected to grow, the future of children's hospice care is becoming increasingly unsustainable.
- Governments across the UK must take urgent action to ensure that seriously ill children and their families can access the crucial hospice and palliative care they need.

## The importance of NHS England funding

The funding that NHS England (NHSE) provides to children's hospices, formerly known as the Children's Hospice Grant, is a crucial and welcome contribution to the cost of providing care to children and their families. While it is encouraging that this funding has increased in cash terms, the proportion of charitable expenditure that it accounts for is continuing to shrink.

In 2023/24, this funding accounted for around 16% of children's hospices' charitable expenditure, while in 2024/25, it covered only 15%.

That said, this funding remains crucial to the sustainability of children's hospices and the services they provide. **Children's hospices have told us that if this funding were not available beyond 2025/26, the impact would be profound:**



## Statutory funding at a local level is continuing to fall in England

Despite some progress over the past year, statutory funding from integrated care boards (ICBs) and local authorities remains well below the levels received by children's hospices just three years ago.

In 2021/22, children's hospices received, on average, £688,830 each from ICBs and their predecessors, clinical commissioning groups, accounting for approximately 19% of hospices' charitable expenditure. Although average funding increased by 18% between 2023/24 and 2024/25 – from £477,677 to £564,126 – it remains 18% lower than in 2021/22.

From freedom of information (FOI) requests, funding from ICBs has also been found to vary significantly across the England. While North East London ICB spent the most with an average of £434 per child or young person, North Central London ICB was scored as spending the least with an average of £23.

While we welcome the higher average funding provided by local authorities to children's hospices in 2024/25, further analysis suggests that it has been driven by an increase in spot purchasing. This does not indicate a shift towards a more consistent and sustainable funding solution but instead underlines the lack of secure and consistent financial support from local authorities.

Overall, the uneven, short-term and unpredictable nature of local statutory funding reinforces the urgent need to maintain NHSE funding – and for it to be ringfenced and increased to reflect inflation and rising costs.

## Children's hospices deliver outstanding value for money

As well as providing vital and compassionate care to seriously ill children and their families, children's hospices also provide exceptional value for every pound invested.

In 2024/25, for every £1 invested by the state, children's hospices in England provided over three times that value in care (£3) – with the majority funded through charitable income. This means the state's investment is being more than tripled by public generosity.

With demand for children's palliative care rising and pressures mounting across the health and care system, it is vital that governments and NHS bodies invest sustainably in children's hospices, recognising not only the human case, but the compelling economic one too.



## Children's hospices are providing more care – but at a greater cost

Across the UK, children's hospices are providing more care than ever before. Since 2019/20, the number of children and young people receiving end of life care has more than doubled, rising by 98%, while caseloads for symptom management support have surged by 108%. In the past year alone, average caseloads have increased by a further 21%.

At the same time, inflation and the cost of recruiting and retaining skilled and experienced staff is continuing to soar.

In 2024/25, children's hospices' average charitable expenditure increased by 15%, rising from £4.6 million in 2023/24 to £5.3 million in 2024/25. When compared to 2021/22, children's hospices in England's average charitable expenditure has increased by 34% from an average of £3.6 million.

Recruiting from the same pool of staff as the NHS and other providers – and under pressure to match NHS pay and conditions – a majority of children's hospices (88%) reported that rising staff costs were a key driver of their increased expenditure.

Meanwhile a significant number of children's hospices (62%) said that their higher expenditure was due to a higher cost of consumables, while over half cited higher energy (50%) prices and increased activity levels (53%) as key factors.

## A deeply concerning impact both now and in the future

As a result of a lack of long-term and sustainable statutory funding coupled with the increasing costs of providing lifeline care, children's hospices are having to utilise their reserves and rely more heavily on their charitable income to maintain essential services.

In 2024/25, nearly two thirds (59%) of hospices that responded to our survey ended the year with a deficit. When extrapolated across all 39 hospices that provided care to seriously ill children in 2024/25, we have estimated a total shortfall of £942,733.

Although this marks an improvement on 2023/24, the outlook is considerably more concerning with 91% forecasting a deficit in 2025/26.

## A similar picture in Northern Ireland, Scotland and Wales

Children's hospices in other parts of the UK are experiencing similar challenges.

While inflationary pressures are continuing to drive the increase in care costs, statutory funding for children's hospices across Northern Ireland, Scotland and Wales has not kept the pace.

## Urgent action is needed

We therefore call for the following action to make sure that children's hospice care in England, Northern Ireland, Scotland and Wales is funded in a way that is equitable and sustainable for the long term:

### England

- We call on the UK Government to commit to protecting and maintaining ringfenced NHS funding for children's hospices, formerly known as the Children's Hospice Grant, beyond 2025/26.
- Ministers should increase this funding annually to make sure it contributes to at least the same proportion of children's hospices' expenditure as it did when NHS England increased the grant to £25 million in 2023/24.
- As a minimum, this would mean that the grant is increased to the following amounts in the years to come:
 

2026/27: £28 million	2028/29: £29 million
2027/28: £28.5 million	2029/30: £30 million
- To make sure the funding is ringfenced for children's hospices – and paid in full and on time – the government should also maintain the safeguards that NHS England (NHSE) has put in place as part of the 2025/26 payment process.
- As part of the NHS 10-Year Plan, the UK Government should commit to reviewing the way in which children's palliative care is planned and funded.
- This should lead to multi-year long-term NHS funding for the health elements of children's palliative care in England that fills the £310 million gap that we have identified to sustain lifeline services, including children's hospices.<sup>1</sup>
- A review should also examine whether children's palliative care would be more effectively commissioned at a national or regional level to create economies of scale.
- The Department of Health and Social Care (DHSC) should conduct its own modelling to determine how much the NHS should spend on the health elements of children's palliative care – and then hold local NHS bodies to account for the extent to which they spend money for this purpose.

## Northern Ireland

- The Northern Ireland Executive should commit to providing additional and sustainable statutory funding to Northern Ireland Children's Hospice for the long term. This funding should be sufficient to cover 50% of the costs incurred in providing lifeline care and support to children and their families.
- The Executive should ensure that any additional and recurrent statutory funding that is awarded is tied to and increases in line with the rising costs caused by inflationary pressures.
- The Northern Ireland Executive should make sure sustainable funding is in place to implement 'Providing High Quality Palliative Care for Our Children: A Strategy for Children's Palliative and End-of-Life care 2016-26' in full.<sup>2</sup>

## Scotland

- The Scottish Government should re-commit to providing additional and sustainable statutory funding to Children's Hospices Across Scotland (CHAS) for the long term.
- This funding should be sufficient to cover 50% of agreed costs in providing lifeline care to children and their families, alongside additional costs associated with rising employer National Insurance Contributions and achieving pay parity with the NHS.
- The Scottish Government should ensure that any additional and recurrent statutory funding that is awarded is tied to and increases in line with the rising costs caused by inflationary pressures.
- The Scottish Government should provide sustainable funding so that its new national strategy for palliative and end of life care can be implemented in full.<sup>3</sup>

## Wales

- We join Tŷ Hafan and Tŷ Gobaith in calling for all Welsh political parties to commit to sustainable, fair funding for both children's hospices. That means committing to 25% of care costs in 2025, rising to 30% by 2030.
- The Welsh Government should ensure that any additional and recurrent statutory funding that is awarded is tied to and increases in line with the rising costs caused by inflationary pressures.

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# Introduction

**Across the UK, the number of children and young people with life-limiting and life-threatening conditions is rising rapidly. As this population grows, the role of children's hospices within the wider health and care system is becoming ever more important.**

Children's hospices are a lifeline for seriously ill children and their families. Providing a broad range of essential services, from end of life care and symptom management to respite care and psychological support, the care provided by children's hospices is of fundamental value to thousands of families navigating the challenges of caring for a seriously ill child.

Not only are children's hospices a lifeline for families, but they also offer excellent value for money. By addressing the holistic needs of children and young people – at home as well as in the hospice – they relieve immense pressure on the NHS and local care services. It is therefore no surprise that the UK Government sees hospices as playing a vital role in shifting care closer to the community.<sup>4</sup>

Yet, despite their importance, children's hospices are continuing to face serious challenges in securing fair and sustainable funding for the long term.

To understand more about the current state of children's hospice funding across the UK, we conducted a survey in April 2025. We asked all 39 hospice organisations that provided care to seriously ill children how they were funded in 2024/25 and the impact this has had on the services they have been able to provide.<sup>i</sup> We also asked how they expect this to change in 2025/26.

In total, 34 children's hospice organisations responded – including providers based in Northern Ireland, Scotland and Wales.

In addition to the survey, we also sought to assess how England's 42 integrated care boards (ICBs) are currently supporting children's hospices. Our previous research has shown wide variation in ICB spending on hospice care for children and young people. To reassess this, we issued a series of freedom of information (FOI) requests to all ICBs, asking them to report:

1. The total amount spent on hospice care for children and young people with life-limiting or life-threatening conditions between 6 April 2024 and 5 April 2025, with a breakdown by hospice organisation.
2. The number of children and young people with life-limiting or life-threatening conditions who accessed hospice care in that period, with a breakdown by hospice organisation.

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<sup>i</sup> At the end of 2024/25, Rennie Grove Hospice Care ceased providing services for children. As such, this report uses a total of 39 children's hospice organisations for the analysis of 2024/25 data. For 2025/26 and beyond, the total number of children's hospice organisations is 38.

3. The number of children and young people in their area who could benefit from children's hospice care.
4. The total amount they plan to spend on children's hospice care between 6 April 2025 and 5 April 2026, with a breakdown by hospice organisation.

This report presents the findings from our survey and FOI requests. It also provides a series of recommendations for governments and health and care systems across the UK, to ensure children's hospices are funded in a way that is equitable and sustainable for the long term.

## Terms used in this report

Where the term children's hospice is used in this report, it means children's hospice organisation. Averages have been calculated as a mean of the total responses to a particular question.

Finally, throughout the report the terms '**charitable expenditure**' and '**care costs**' are used interchangeably to refer to the costs incurred in providing lifeline palliative and end of life care to children and young people with life-limiting and life-threatening conditions and their families.

# Archie's story

**"The truth is, I couldn't live without their support."**

**This is Archie's story, told by his mum, Laura.**

Archie was born extremely prematurely at 23 weeks, severely deprived of oxygen. He suffered brain damage which resulted in multiple complex medical needs including a tracheostomy to help him breathe, and a feeding tube to help him eat.



Images courtesy of Tina Gue and Jessie May

Archie was later diagnosed with Cerebral Palsy, a lifelong condition that affects his movement and co-ordination, and due to the severity of his condition it is unlikely that he will reach adulthood.

Archie spent the first 11 months of his life in Bristol Children's Hospital, where he almost died a number of times. But thankfully, after having two life-saving operations, his family were able to bring him home – just in time for his first birthday: **"It was a day that we never thought would arrive, and then suddenly it was here. We were allowed to take him home, to be a proper family,"** explains Mum, Laura.

However, this was only just the beginning of their journey. The transition from hospital to home for a family with a life-limited or terminally ill child is an incredibly tough one. Archie was still attached to so many wires for monitoring, he was fed via a feeding tube, had a tracheostomy to help him breathe, and was still on oxygen 24/7. They didn't know how they were going to do it with such an unwell child.

Luckily, that's where Jessie May stepped in.

**"Jessie May had been visiting us in hospital since Archie was six months old, so we knew the team and trusted them. They helped us with the transition from hospital to home, and gave us all the information we needed about their services and all of the support they offer. They were a lifeline to us at a really difficult time."**

– Laura, Archie's mum





Jessie May have continued to visit the family, offering respite for his parents: **"They come and look after Archie so I can have a short break. As the years go on, caring for a disabled child is exhausting both physically and mentally. The truth is that I couldn't live without their support."**

The staff at Jessie May allow Laura and her husband to take time to be a couple, to go to the cinema or to the pub. They have also supported the family to take Archie to hydrotherapy: **"They have enabled us to do things that otherwise would have been impossible."**

The hospice also hosts events, for families to meet other parents: **"It can be really difficult to hang out with friends because of all the steps involved in just getting there. But the Jessie May events are different. There are nurses there to help if you need it and other people in your situation too. Sometimes, with a disabled child, it can feel like you are talking another language. But these other parents just understand."**



# Statutory funding for children's hospices in England

For children's hospices in England, statutory funding derived from NHS England (NHSE), integrated care boards (ICBs) and local authorities remains a vital, yet insufficient contribution to the costs incurred in running a children's hospice.

On average, statutory funding in England accounts for approximately one third (30.1%) of children's hospices' charitable expenditure. Despite this, children's hospices provide far more value in care: for every £1 invested by the state, children's hospices provide £3.32 in care and support, largely funded through charitable income.

**The proportions of charitable expenditure that each statutory funding source covers can be broken down as follows:<sup>ii</sup>**



Despite a 14.7% increase in statutory contributions over the past year, inflationary pressures and associated rising costs has led to a 15.1% increase in children's hospices' charitable expenditure. This widening gap is placing significant pressure on hospices to utilise their reserves and increase their reliance on charitable income to maintain lifeline care for seriously ill children and their families.

While positive progress has been made in recent months, namely the decision to maintain NHSE funding for children's hospices (formerly known as the NHSE Children and Young People's Hospice Grant), and increase it to £26 million for 2025/26,<sup>5</sup> there is still an urgent need for a more equitable and sustainable funding solution.<sup>iii</sup>

<sup>ii</sup> In total, 30 children's hospice organisations in England responded to our survey and provided information on the statutory funding they received in 2024/25. However, data from one hospice was omitted from the statutory funding analysis due to concerns about its accuracy. As a result, 29 responses were included in the statutory funding analysis, and charitable expenditure for this section was based on these 29 responses.

<sup>iii</sup> In December 2024, the UK Government also announced that they would provide £100 million in capital funding for all children's and adults' hospices in England across 2024/25 and 2025/26, enabling improvements in facilities, IT systems, and outdoor spaces to enhance palliative and end of life care. Allocations from this capital funding were not included in the funding hospices reported receiving from NHS England, integrated care boards and local authorities.

## NHS England funding for children's hospices

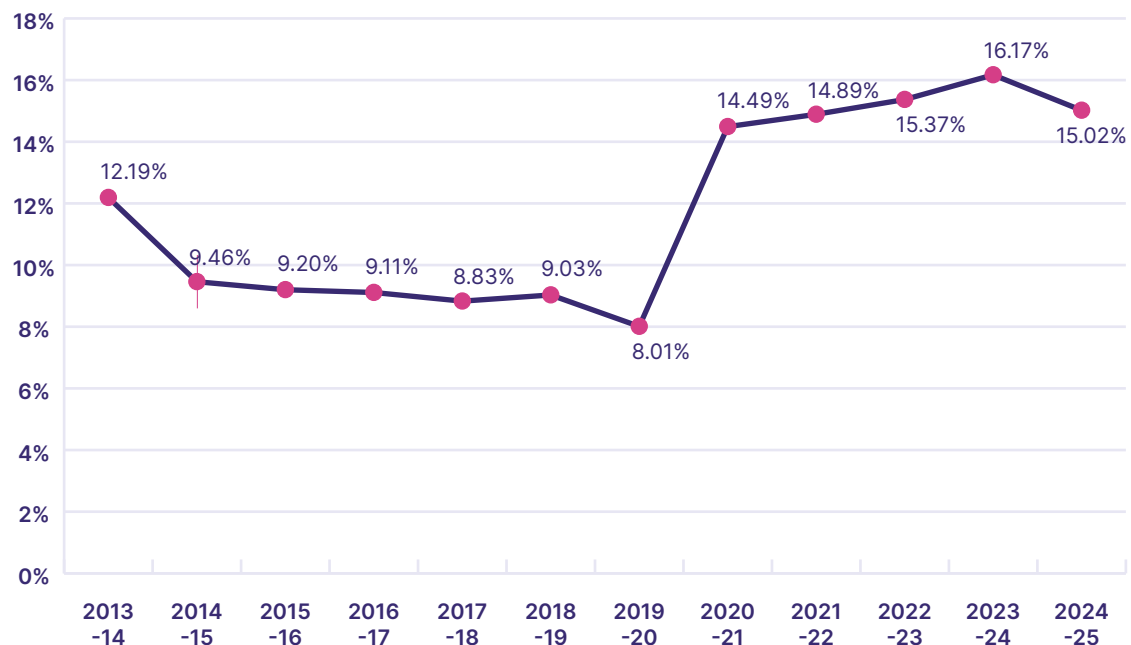
In July 2019, NHSE committed to increasing the Children's Hospice Grant to £25 million by 2023/24, and ringfencing it specifically for children's hospices.

Since then, this funding stream has been a key source of income for children's hospices across England. However, from 2023/24, it has only been confirmed and committed to on a one-year basis. Most recently, in December 2024 when the UK Government announced that £26 million of funding will be available for children's hospices in 2025/26.<sup>6</sup>

In the financial year of 2024/25, the grant was worth approximately £25 million. This equated to an average allocation of £723,885.52 per hospice and represented an increase of 6.9% on the previous year's average of £677,123.59.<sup>7</sup> Despite this rise, and the fact that the grant is set to increase to £26 million in 2025/26, we are concerned that it has not kept pace with the escalating costs of providing children's palliative care.

In 2023/24, this funding accounted for around 16% of children's hospices' charitable expenditure, while in 2024/25, it only covered 15%. As a result, children's hospices have had to find additional funding to provide lifeline care and support. In many cases, this has meant drawing down on financial reserves or increasing their reliance on fundraising and charitable donations.

**Mean contribution to charitable expenditure  
from NHS England children's hospice grant**



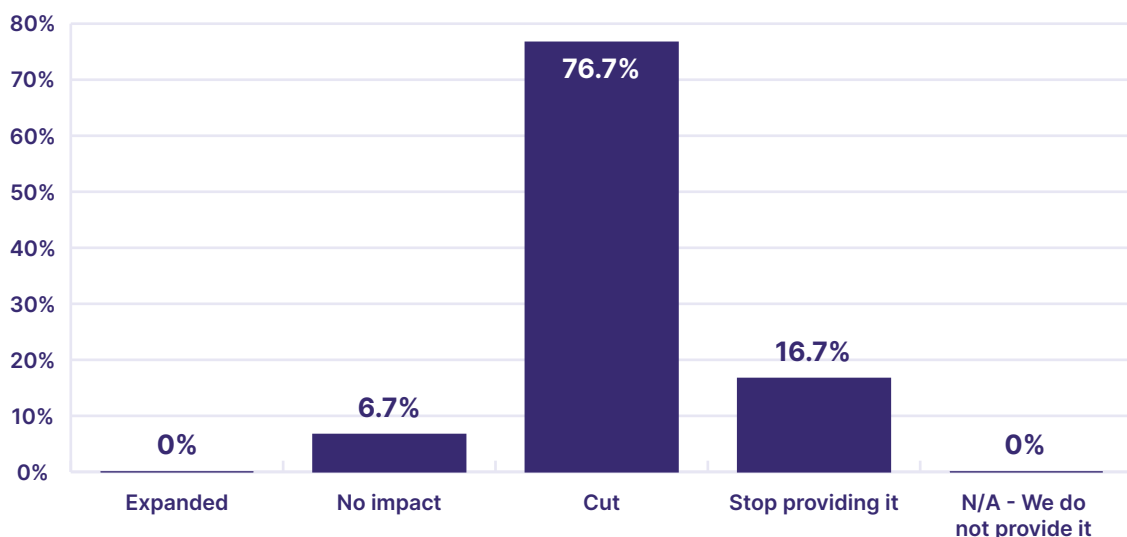
That said, it is clear from our survey that the grant remains crucial to the sustainability of children's hospices and the services they provide. This is particularly evident when considering the services that would be at risk if this funding were not available.

According to children's hospices in England, if this funding were not available beyond 2025/26, the following action would have to be taken:<sup>iv</sup>

- **80%** would cut or stop providing **emotional and/or psychological support**.
- **50%** would cut or stop providing **end of life care**.
- **43%** would cut or stop providing **symptom management support**.
- **50%** would cut or stop providing **hospice at home**.
- **80%** would cut or stop providing **counselling**.

In addition, 77% of children's hospices would reduce the respite or short breaks they offer, while 17% would stop providing it altogether.

### The predicted impact on short breaks for respite if the Children's Hospice Grant was not available from 2026-27 onwards



<sup>iv</sup> Analysis based on survey responses from 30 children's hospices in England. See appendix B for a graph showing all the action that would be taken if the NHSE funding for children's hospices was not maintained for years beyond 2025/26.

Respite care is a lifeline for families of seriously ill children. Evidence shows that regular access to short breaks helps reduce emotional exhaustion and prevents mental health problems among parents and carers.<sup>8</sup> This is especially the case for mothers, who are significantly more likely to experience both physical and mental health challenges because of their caring responsibilities.<sup>9</sup>

The lack of sufficient respite care could therefore further exacerbate these inequities. On that note, it is also deeply concerning that emotional and psychological support services, including counselling, are among those most at risk without this funding. These services are critical for families' wellbeing and are not easily replaced by other forms of support.

It is therefore vital that this funding stream is maintained for years beyond 2025/26. It is also essential that it is increased and committed to for the long term. Not only has the current approach of year-to-year allocations resulted in a significant amount of uncertainty, but it has also hampered children's hospices' ability to plan and develop their services for the long term.

**"Full commissioning of palliative and end of life care with funded contracts is needed for the sector. Continual year on year grants is not sustainable and does not allow for mid or long-term planning."**

– East Anglia's Children's Hospices (EACH)

Overall, while the decision to maintain and increase the NHSE funding stream for children's hospices to £26 million in 2025/26 is incredibly welcome, it still represents a short-term solution and does not fully address the growing cost pressures facing hospices.

To ensure the sustainability of lifeline care for seriously ill children and their families, this funding must be secured on a long-term basis. It must also be increased annually to reflect inflation in the cost of providing children's hospice care, and to make sure that, as a proportion of children's hospices' expenditure, it contributes the same amount as it did when the grant increased to £25 million in 2023/24.

## Local integrated care board funding

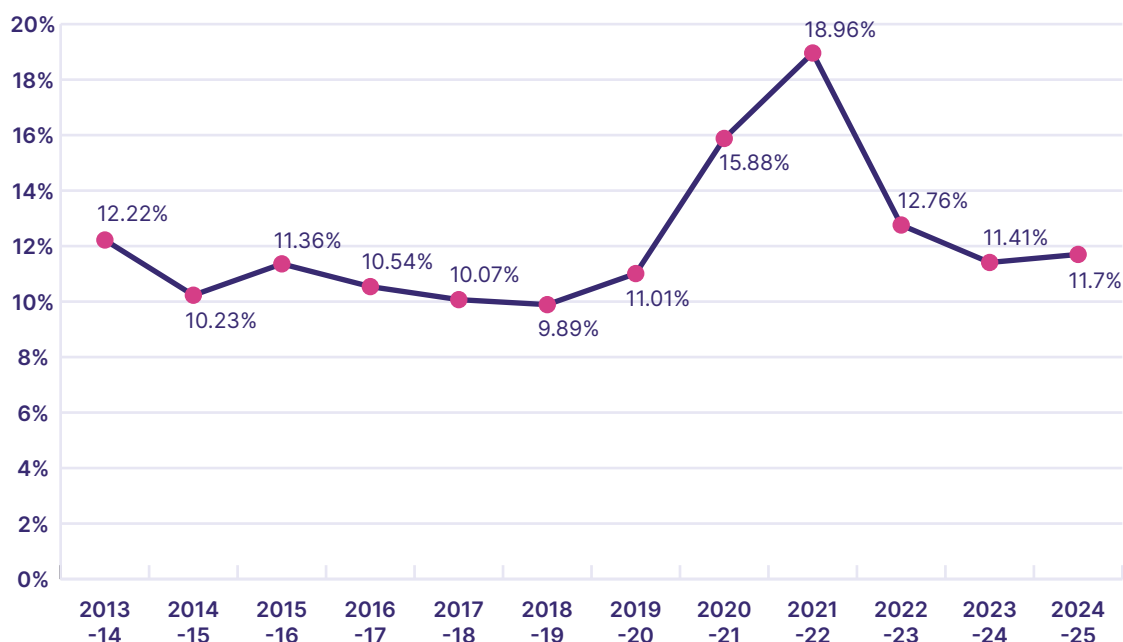
### Continuing to fall

Under the Health and Care Act 2022, integrated care boards (ICBs) have a statutory duty to commission palliative care that meets the reasonable requirement of the people for whom they are responsible.<sup>10</sup> As such, part of children's hospices' statutory funding is also derived from ICBs.

In 2024/25, children's hospices received an average of £564,126.17 from their local ICBs – a rise of 18.1% compared to the average of £477,676.59 received in 2023/24.<sup>11</sup> At the same time, the share of charitable expenditure that ICB funding accounts for has also increased – rising from 11.4% in 2023/24 to 11.7% in 2024/25.



### Mean contribution to charitable expenditure from ICBs/CCGs



While this growth is encouraging, we are still concerned that at an individual hospice level, the proportion of charitable expenditure funded by ICBs continues to vary significantly. Nearly half (48%) of all children's hospices that responded received less than 10% of their charitable expenditure from ICBs. Meanwhile, nearly one third (28%) received less than 5% of their charitable expenditure from ICBs. Only one children's hospice received 30% or more of their charitable expenditure from ICBs.

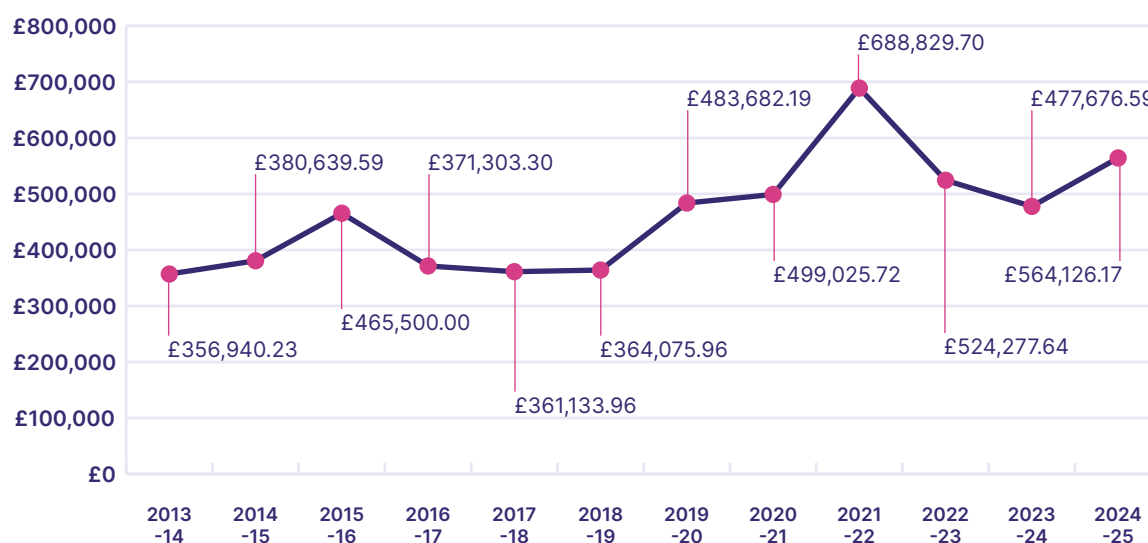
**"Only a small percentage of the babies, children and young people that we support are funded, this does not provide equity and fairness."**

– Noah's Ark Children's Hospice

In addition, despite the recent improvement, ICB funding has still not recovered to the levels seen three years ago. In 2021/22, children's hospices received an average of £688,892.70 from ICBs, and their predecessor clinical commissioning groups (CCGs). When compared to the average funding received in 2024/25, this not only represents a 18% reduction in cash terms, but the share of charitable expenditure covered has also fallen from 19%.

In other words, while ICB/CCG funding previously covered £1 for every £5 spent by hospices, it now accounts for only £1 for every £9 spent supporting seriously ill children and their families – placing even greater pressure on voluntary income to plug the gap.

### Mean contribution from ICBs/CCGs



Looking ahead, we have estimated that this progress will stall in 2025/26 with average ICB funding only expected to rise by 5.5% to £595,003.71. As a result, we have estimated that in 2025/26, ICB funding will account for approximately 11.3% of hospices' care costs – down from the 11.7% witnessed in 2024/25.

At an individual hospice level, less than half (47%) of children's hospices expect any increase at all in their ICB funding while 32% expect their funding to decrease, and 6% anticipate no change.<sup>v</sup>

All of this indicates that unless action is taken to drastically increase funding from ICBs, the downward trajectory is set to continue.

### Variance in ICB funding

In April 2025, we also issued a series of freedom of information (FOI) requests to all 42 ICBs to further examine the extent to which the amounts spent on hospice care varies across England. Similar to the FOIs submitted to ICBs in April 2024, and published in June 2024,<sup>12</sup> we asked ICBs to provide:

1. The amount spent on children's hospice care from 6 April 2024 to 5 April 2025 (including a breakdown of funding per children's hospice organisation).
2. The number of children and young people who accessed children's hospice care during this period.
3. The number of children and young people in their area with a life-limiting or life-threatening condition who could benefit from hospice care.
4. Their projected spend on children's hospice care for 2025/26 (again including a breakdown of funding per children's hospice organisation).

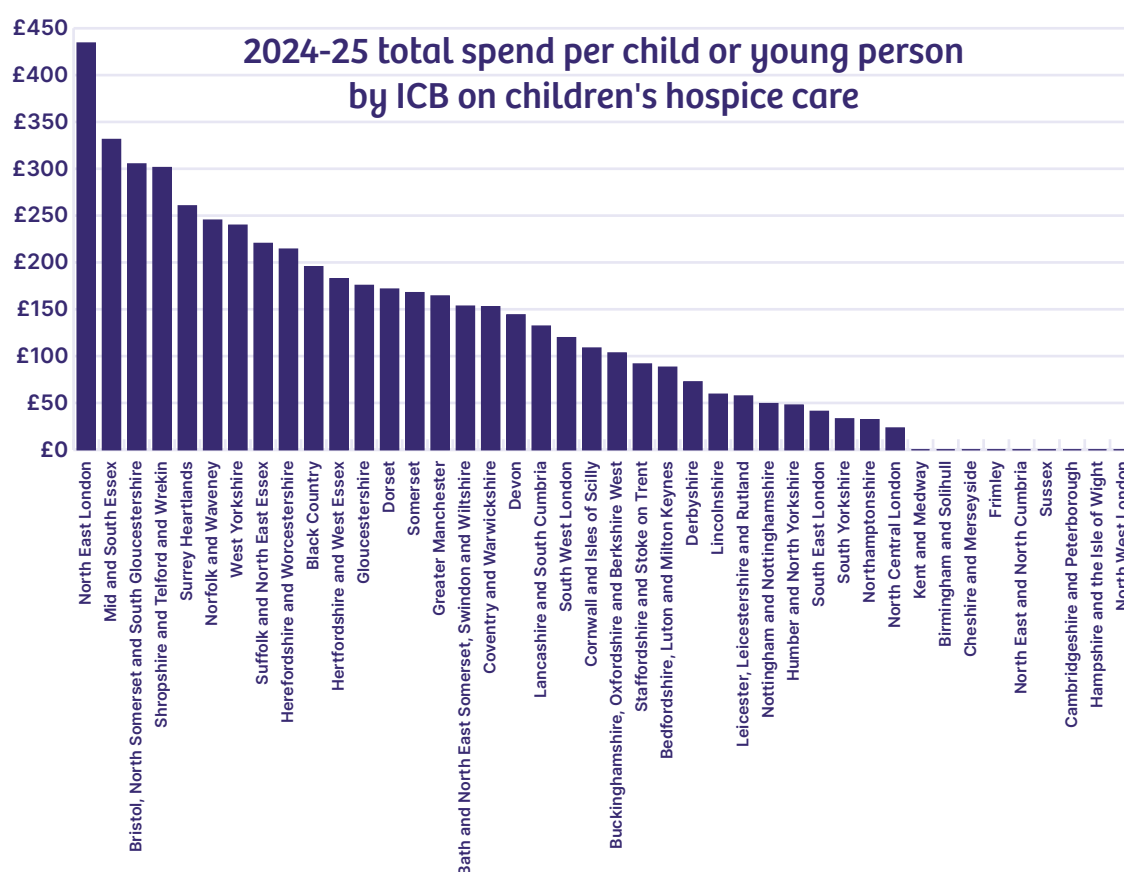
<sup>v</sup> Calculated as a percentage of all hospices expecting to provide care to seriously ill children in 2025/26. Five children's hospices in England did not respond to the survey.

41 ICBs responded to our FOI requests.<sup>vi</sup> Once received, to ensure the figures provided for spending in 2024/25 did not include individual ICB allocations for the £25 million of NHSE funding and could be used to assess local spend, responses were cross-referenced with previous FOI responses published in 2024 and individual ICB allocations themselves.

Overall, 33 ICB responses were confirmed – either directly by the ICB or through our cross-referencing – to exclude the £25 million NHS England funding in their 2024/25 figures. These responses were subsequently included in our analysis.<sup>vii</sup>

As many ICBs told us that their financial year ran from 1 April 2024 to 31 March 2025, we also included responses provided within this timeframe within our analysis.

From these FOI requests, we have found that in 2024/25, the average amount spent by ICBs was £155.12 for every case of a life-limiting or life-threatening condition among children and young people. The average spend per child, or young person has therefore increased by 2.7% from £151.03 in 2023/24.



<sup>vi</sup> Please see appendix H for individual ICB responses to our FOI request.

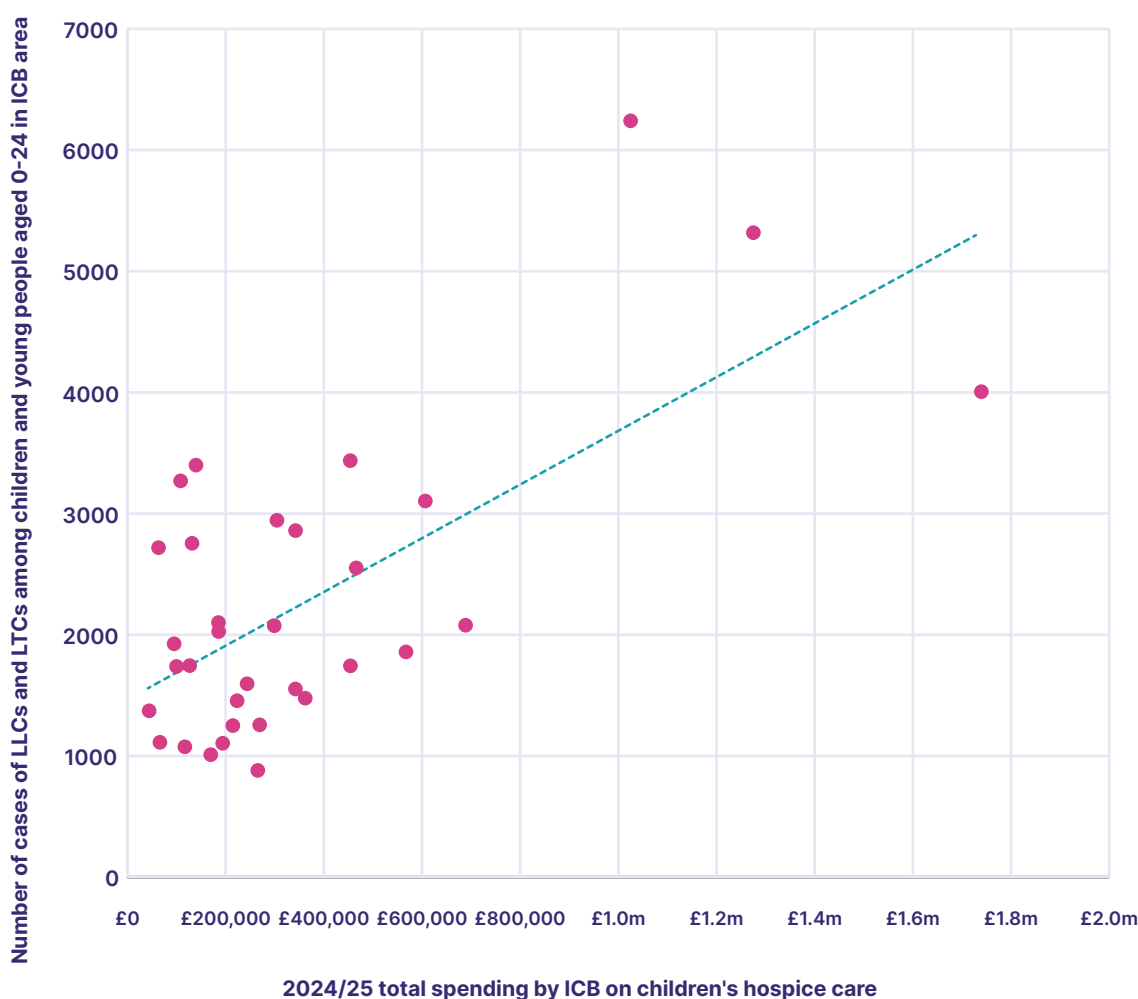
<sup>vii</sup> While Kent and Medway ICB did respond to the FOI request, the figures they provided related only to funding allocated to Demelza. This is because Ellenor, which also provides children's palliative care in the area, receives an all-age grant reflecting its services for both children and adults. As the ICB's response did not fully represent the total amount spent on children's hospice care by the ICB and would've resulted in it being categorised as the fourth lowest spending ICB, it was omitted from our analysis.

Sussex ICB also responded to the FOI request but due to a suspected error in the figures provided, the response was omitted pending further clarification.

Shropshire, Telford and Wrekin ICB also provides funding to adult hospices that provide care to patients aged 18 and over. However, the ICB was unable to breakdown the financial value for patients aged 18-25.

However, as in previous years, we have also found stark disparities, with ICB spending varying by as much as £410.98 per child or young person.

**2024-25 total spending by ICB on children's hospice care per number of cases of life-limiting and life-threatening conditions (LLCs and LTCs) among children and young people aged 0-24 in each ICB area**



While North East London ICB spent the most with an average of £434.26 per child or young person, North Central London ICB was scored as spending the least with an average of £23.28.<sup>viii</sup>

Here it is important to note that while North Central London ICB is recorded as the lowest spending ICB, the ICB also provides funding to a range of NHS trust services that provide palliative care to children with life-limiting and life-threatening conditions. The total spend with Noah's Ark Children's Hospice is therefore not reflective of the total ICB spend on children's palliative care in North Central London.



It is also important to note that, at any one time, many children and young people with life-limiting or life-threatening conditions are relatively stable and will not need active care and support from a children's hospice. The funding that an ICB decides to allocate to a children's hospice will depend on the need for care and support, in addition to how local children's palliative care services are configured across hospital, community and children's hospice settings.

Nonetheless, we do not believe that the extent of the variation can be justified. The significant disparity between ICB spending suggests real inconsistencies in how ICBs are fulfilling their statutory responsibilities to commission palliative care services based on local need.

**"Different ICB's will fund different types of work. Criteria for a funded package varies and there is no clear framework."**

– Noah's Ark Children's Hospice

## Lack of local data held by ICBs

Our FOI requests also revealed a concerning lack of local data held by many ICBs about the children and young people they fund services for.

Of the 41 ICBs that responded, we have found that only 32% (13 ICBs) could provide data on the number of children and young people who accessed hospice care in 2024/25. Where data was available, the average number was 378 children and young people per ICB.<sup>ix</sup>

Similarly, only 10 ICBs (24%) were able to tell us how many children and young people with life-limiting or life-threatening conditions in their area could benefit from palliative care. 76% (31 ICBs) stated that they do not hold this data.

This lack of data is particularly concerning given the legal requirement for ICBs to commission services that meet the "reasonable requirements" of their local populations.<sup>13</sup> Without accurate information on the size and needs of the population, we question how ICBs can plan effectively and make fair funding decisions.

Unfortunately, this appears to be a persistent issue. Last year, our FOIs found that only 40% of ICBs could provide data on the number of children and young people who had accessed hospice care in 2023/24.<sup>14</sup> It is therefore concerning to see little improvement here.

<sup>ix</sup> Bedfordshire, Luton and Milton Keynes ICB and Lincolnshire ICB were both unable to provide data for quarter 4 of 2024/25 at the time of request. Meanwhile Shropshire, Telford and Wrekin ICB only held data for a 6 month period in 2024/25. Nevertheless, all ICBs were scored as holding the relevant data.

## Local authority funding

Under the Children Act 1989, local authorities in England have a statutory duty to provide services to assist family carers of disabled children – specifically by giving them breaks from caring.<sup>15</sup> In line with this duty, many children's hospices receive statutory funding from local authorities to help deliver respite care and other vital services.

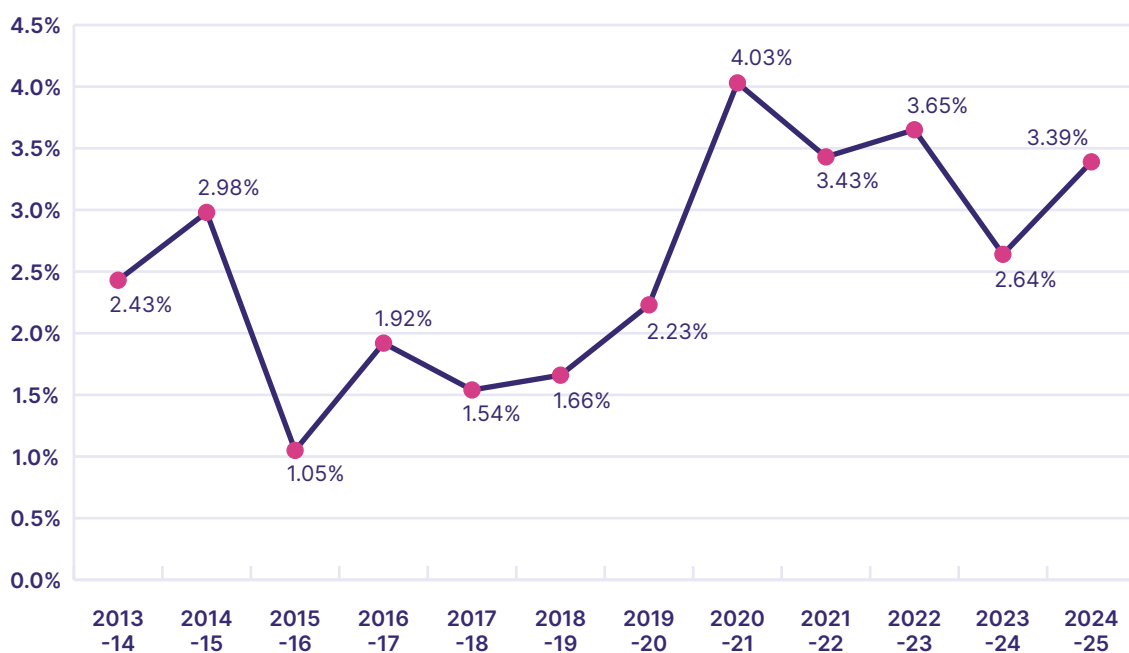
In 2024/25, on average, children's hospices received £163,298.12 from local authorities, increasing by 47.4% from an average of £110,767.56 in 2023/24.<sup>16</sup> Correspondingly, the proportion of children's hospices' charitable expenditure funded by local authorities has also increased from 2.6% in 2023/24 to 3.4% in 2024/25.

While this rise may appear positive, further analysis suggests it does not indicate a shift towards a more consistent and sustainable funding solution. In many cases, it actually reflects an increase in one-off or short-term payments for emergency placements rather than secure core service funding.

For example, Jigsaw Children's Hospice received approximately £6,000 in 2023/24 to provide emergency respite care. In 2024/25, this rose to £45,000 as the hospice responded to a higher number of emergency placement requests. However, to date, no funding commitments have been made for 2025/26, underlining the lack of secure, and consistent financial support.

In addition, even with this year's increase, it seems that local authority funding is still yet to recover to the levels witnessed in 2020/21 and 2022/23.<sup>x</sup>

### Mean contribution to charitable expenditure from local authorities



<sup>x</sup> Analysis based on responses from 29 children's hospices in England that provided accurate information about their statutory funding.

At an individual hospice level, the picture is even more uneven. In 2024/25, nearly half (48%) of the children's hospices that responded to our survey did not receive any funding from their local authority. Among those that did, the amounts received ranged from a little as £3,700 to as much as £1,192,100.

This inconsistency also extends to the proportion of hospices' charitable expenditure covered by local authorities. Over four fifths (83%) of children's hospices received less than 10% of their charitable expenditure from local authorities, while 76% received less than 5%. Only one children's hospice received more than 30% of their charitable expenditure from local authorities.

**"Funding from the ICB for short breaks ceased from 01/04/2025 with a view this is the local authority responsibility. These local authorities have not provided any funding for short breaks. This continues to be an issue for us."**

– Keech Hospice Care

### **Looking ahead to 2025/26, the outlook is particularly concerning.**

Despite most children's hospices (65%) expecting their local authority funding to either decrease or remain at the same level,<sup>xi</sup> we have estimated the average amount received from local authorities will fall by 2.3% to £159,567.72. As a proportion of charitable expenditure, this represents a drop to just over 3%.

While the projected decline may be partly explained by an increase in the number of spot purchases made in 2024/25, it ultimately highlights the underlying uncertainty and lack of secure, sustainable and long-term funding.

Without a more consistent approach, families face growing uncertainty about the support they can expect, and hospices are left struggling to plan and sustain essential services.

<sup>xi</sup> Calculated as a percentage of all hospices expecting to provide care to seriously ill children in 2025/26. Five children's hospices in England did not respond to the survey.

# Statutory funding for children's hospices in Northern Ireland

Like their counterparts in England, the Northern Ireland Children's Hospice (NICH) is continuing to grapple with sustained and significant financial pressures.

In 2024/25, the hospice received £1,923,370 from health and social care trusts – down by 5.3% from £2,031,357 in 2023/24. This decline is particularly concerning given that the hospice's charitable expenditure over the same period has only marginally reduced from £4,610,710 in 2023/24 to £4,590,330 in 2024/25 – with pay increases offsetting any savings from a reduction in staffing numbers.

In addition to declining in cash terms, the share of the hospice's charitable expenditure that statutory funding covers has also fallen. While in 2023/24, statutory funding accounted for approximately 44%, in 2024/25, this has decreased to 41.9%.

Unfortunately, these financial difficulties are not new. In the summer of 2023, the Department of Health withdrew a recurrent funding of £170,000. Although former Health Minister Robin Swann later reinstated £85,000 of this and confirmed that a £420,000 portion of core funding would become recurrent, the hospice made clear that restoring the full £170,000 alone would not be enough to reverse planned service reduction decisions already taken.

This led the minister to acknowledge that the challenges faced by NICH extend well beyond the reduction in departmental support and highlighted the need for the hospice to develop longer-term funding solutions – stating that the Executive would be prepared to support such efforts.

Nevertheless, the situation continued to deteriorate. In February 2024, the hospice announced it would be forced to scale back services due to the confirmed loss of government funding for one of its beds.

**“Cuts in statutory income saw the closure of the seventh bed and a reworking of our service model to less than 1:1 care for some children. Decreased economies of scale with the loss of the seventh bed then led to further cuts to six beds Monday to Friday and three beds at the weekend. Luckily, we have been able to secure specific corporate funding to reverse this and are currently running six beds all week.”**

– Northern Ireland Children's Hospice

Looking ahead to 2025/26, it is expected that these financial difficulties will continue. With the hospice's charitable expenditure set to rise by 13.5% to £5,208,893, it is disappointing to see that statutory funding is only projected to increase by a mere 6.3%.

As such, in 2025/26, we expect the statutory funding that the hospice receives to account for just 38.9% thereby continuing this downward trajectory.

Adding to the financial strain, the UK Government's decision to increase employer National Insurance contributions is expected to drive hospice costs up significantly. NICH estimates this that this tax rise will increase their costs by £65,000 per year.

## Statutory funding for children's hospices in Scotland

In Scotland, Children's Hospices Across Scotland (CHAS) operates as the single national provider of hospice care to children, with staff working across hospices, hospitals, and local communities.

Thanks to the backing of the Scottish Government, the Convention of Scottish Local Authorities (COSLA), and the generosity of the Scottish public, CHAS offers all care at no charge.

However, the growing number – and complexity – of children in Scotland with palliative care needs is putting increasing pressure on CHAS, and not every child and family who could benefit from its services is currently being reached.

While the Scottish Government has pledged to provide "high-quality child palliative care, regardless of location," supported by at least £7 million per year in sustainable funding through CHAS, this funding is no longer sufficient to meet the rising costs.

Inflationary pressures, service change to meet increasing acuity (including in hospitals), and NHS pay awards have significantly raised CHAS's cost base. As a result, the £7 million of pledged annual funding from the Scottish Government now only covers about 30% of CHAS's total expenditure.

While the commitment to link hospice funding to NHS pay awards in the Scottish Budget is hugely welcome, detailed work is needed to get the baseline right.

Urgent help is also needed to address the underlying funding gap faced by hospices across Scotland, including CHAS.

CHAS is urgently calling for a renewed commitment from the Scottish Government to cover 50% of its agreed costs, including inflation-based increases, to ensure a sustainable long-term funding arrangement.

This investment would be highly beneficial, as the care provided by CHAS can prevent children from needing hospitalisation, enable earlier discharges, reduce the strain on the most expensive NHS beds, and help prevent families from reaching a crisis point – all of which have significant preventative spending implications.

Independent analysis has shown that for every £1 of statutory funding CHAS receives from the Scottish Government and COSLA, CHAS generates £6.24 in public value, demonstrating the substantial return on investment that supporting this essential service provides.

We call on the Scottish Government to reaffirm its commitment to covering 50% of CHAS' agreed costs. Given that Scottish hospices are facing more than £2.5 million in additional National Insurance Contributions in 2025/26, action must be taken to avoid further financial strain on services supporting vulnerable children and families. Specifically, if the Scottish Government intends to cover these additional costs in the NHS using Barnett consequentials, they should do so in hospices too.

## Statutory funding for children's hospices in Wales

In Wales, the two children's hospices, Tŷ Hafan and Tŷ Gobaith, provide crucial care and support to children and young people with life-limiting and life-threatening conditions.

Despite their importance, these hospices are currently guaranteed only 12% of their total costs of delivering palliative care from statutory sources. Of this, 67% is provided by the Welsh Government and the remaining 33% by local health boards.

In 2022, the Welsh Government took a positive step by allocating an additional £2.2 million to hospices in Wales as part of the Lifeline Fund – of which £888,000 specifically directed to the two children's hospices. This marked the first increase in statutory funding for children's hospices in Wales since 2007, raising the proportion of care costs covered by statutory funding to approximately 21%.



This funding was instrumental in enabling the hospices to recruit more nurses, enhance their resilience both in hospices and in the community, expand their services, and provide more respite care to families in need. It also helped reduce the burden of unplanned and crisis admissions on the NHS.

However, the benefits of this funding have since been reduced by inflationary pressures and associated rising costs – particularly those linked to inflation and increased pay settlements under Agenda for Change. As a result, the funding previously awarded no longer represents 21% of the hospices' care costs, once again making the current level of statutory support unsustainable.

At the end of the 2023/24 financial year, the Welsh Government provided an additional £770,000 to the two children's hospices as part of its end of life care review. While this one-off payment helped bring coverage closer to the 21% mark for that year, it was non-recurrent and came too late in the financial year to allow for effective long-term planning.

More recently, in 2024/25, £5.5 million was provided to the 12 commissioned hospices (including adults) in Wales. For Tŷ Hafan and Tŷ Gobaith, this funding meant that approximately 25% of their care costs were covered by statutory funding in that financial year.

Despite this progress, this funding was yet again non-recurrent leaving the children's hospices facing renewed uncertainty as they enter 2025/26.

**"More visibility of statutory funding and knowing funding amounts in advance would be greatly beneficial to the hospices' ability to plan and align services in advance. Not knowing about additional funding until the last minute makes planning difficult for the charity."**

– Tŷ Gobaith Children's Hospice

For 2025/26, the Welsh Government's Budget has committed to providing £3 million in recurring funding to the hospice sector.<sup>17</sup> While the commitment to providing recurring funding is a positive and much-needed development, the allocations for Tŷ Hafan and Tŷ Gobaith remain to be seen. As such, we remain concerned that additional funding will still be required to address the scale of the challenges facing the two hospices.

In particular, both hospices now face additional cost pressures from the UK Government's decision to increase employer National Insurance contributions from April 2025. According to the children's hospices, this uplift will cost them an additional £550,000 per year, placing even greater strain on their ability to provide lifeline care to seriously ill children and their families.

# Gibson's story

**Gibson Greene isn't your average three-year-old. He is only one of 100 people worldwide with a diagnosis of a rare genetic condition called trichothiodystrophy, or TTD for short.**

TTD ages children internally, and as a dystrophy, he will have a much shorter life span than most others.

Mum Sarah explains: "Gibson will hit a point where his development stops, and degeneration begins. To try to maintain a healthy Gibson we currently have 16 specialists in Scotland from Glasgow to Annan that help care for him and a further 10 specialists at the rare disease centre at Guys and St Thomas Hospital in London."

The condition is complex and has many side effects. Gibson was born with double congenital cataracts, for which he has already had three eye surgeries to remove the lenses and is visually impaired, he has problems with his teeth and the enamel not forming properly and issues with his hair, which is sparse, brittle and will leave bald patches.

He was born weighing just two pounds and three ounces and has struggled to gain weight ever since. Gibson, who is from Gretna in Dumfriesshire, also has global development delay which means he currently cannot speak other than a few words.

Additionally, Gibson has XP skin disorder, meaning that at birth he had an extra layer of skin resulting in certain limbs being held in unusual positions. The lasting effects of trying to correct this mean he has a much higher sensitivity to UVB rays and therefore he will burn in the sun easier and is at a much higher risk of skin cancer in the future.



## Jigsaw comes into Gibson's life

Jigsaw, Cumbria's Children's Hospice supports Gibson's care and has become a favourite place of his. However, mum Sarah admits she was sceptical at first about bringing him to the hospice.

**"When Jigsaw was first suggested to us a family, my instant reaction was no, not a chance," she said.**

**"My only experience with a hospice was somewhere people went to die. I could only imagine a building that felt sad the second you walked through the doors and the nurses to be cold and unwelcoming."**

However, a referral was made by the specialist team in London who'd been supporting Gibson and his family, and Sarah reluctantly agreed to give it a go, expecting to attend once and then make her excuses.

**"I'm happy to say, however, that I have never been more wrong about anything my whole life. Jigsaw is one of our favourite places to go and the staff feel like family.**

**"The second you walk in the door you are greeted with a huge smile, a cuddle for Gibson and the offer of a brew. The facility itself is colourful and modern, and you can hear laughter floating down the corridor."**

And now, the only children's hospice in Cumbria has become an extended part of the family.

**"Jigsaw to us is a magical place where Gibson's disability is hung up at the door alongside his coat," Sarah adds.**

**"The toys are all adapted so he can play like any other child, the sensory room is soft and safe so he can explore and push the boundaries, because if he does fall, he simply bounces. The staff don't question why he can't walk or talk, instead they love and accept him as he is and will crawl along with him if that's what makes him happy.**

**"The artwork he made at Jigsaw is something we will treasure forever, it comes home at Easter and Mother's Day etc, just like it would if he was able to attend nursery."**





"Amazing as all those things are, though, the most special thing about Jigsaw is the people that work there. No one is ever too busy to spend time with Gibson, whether it's a cuddle, dancing along to the song Baby Shark or letting him fall asleep.

"When we started going, I had a little boy who was shy and wouldn't go more than an arm's length from me to now, a boy who will say hello to everyone and crawls off to the sensory room the second his knees touch the floor.

"Jigsaw has become a huge part of our lives that we will be forever grateful for."

## Extra support

The support Jigsaw offers hasn't just been for Gibson, but for Sarah also in helping her to navigate the future and her son's condition.

"Although Gibson was the one that the referral was made for, I have also been given help with counselling," Sarah adds.

"Having someone to talk to about anticipatory grief has been so helpful and made a real difference to my own attitude and outlook."



# Income and expenditure of children's hospices across the UK

As part of our survey, we also collected data on the income and expenditure of children's hospice organisations across the UK, offering a broader understanding of the financial pressures they face.<sup>xii</sup>

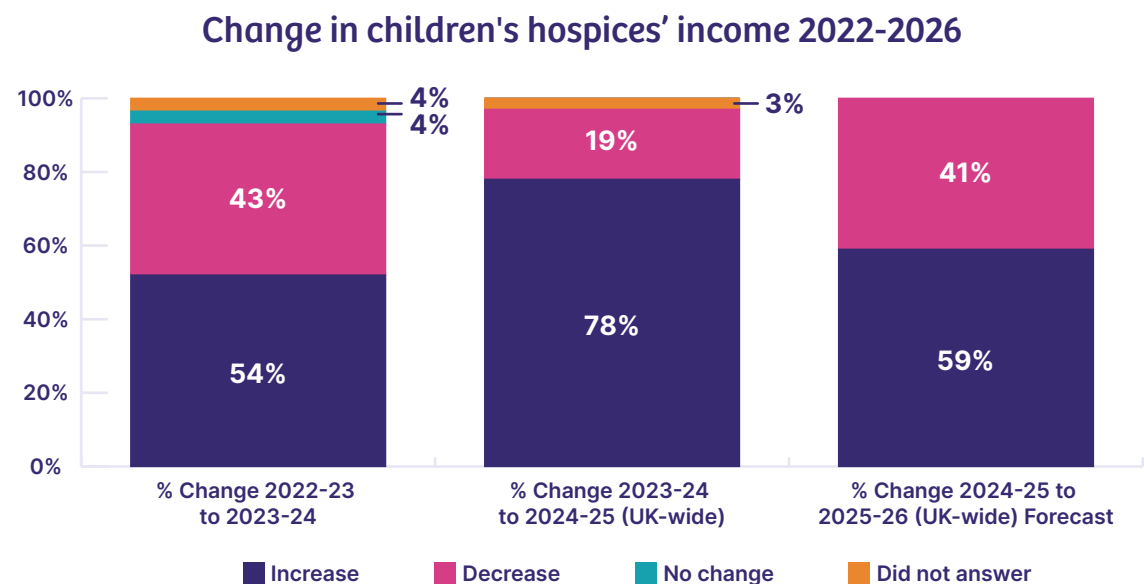
## Income

In total, 32 children's hospices across the UK shared information about their income.<sup>xiii</sup>

On average, children's hospices' income in 2024/25 equalled £8,591,007. This represents a 17.5% increase on the average income of £7,313,881 received in 2023/24.<sup>18</sup>

Despite this overall increase, the income received by individual children's hospices has continued to vary. In 2024/25, over three quarters (78%) of hospices that responded to our survey saw their income increase, while 19% witnessed a decrease. We excluded one children's hospice from this comparison due to incomplete income data for 2023/24.

Looking ahead to 2025/26, we have estimated that the income received by children's hospices will increase by 2.7% to an average of £8,824,400.



<sup>xii</sup> UK-wide data is based on responses received from children's hospice organisations in England, Northern Ireland, Scotland and Wales.

<sup>xiii</sup> Due to providing services for adults as well as children, some hospices were not able to separate their income for children and adults' services. To ensure our analysis was representative of children's hospice services alone, data covering both adult and children's services was omitted from the analysis.

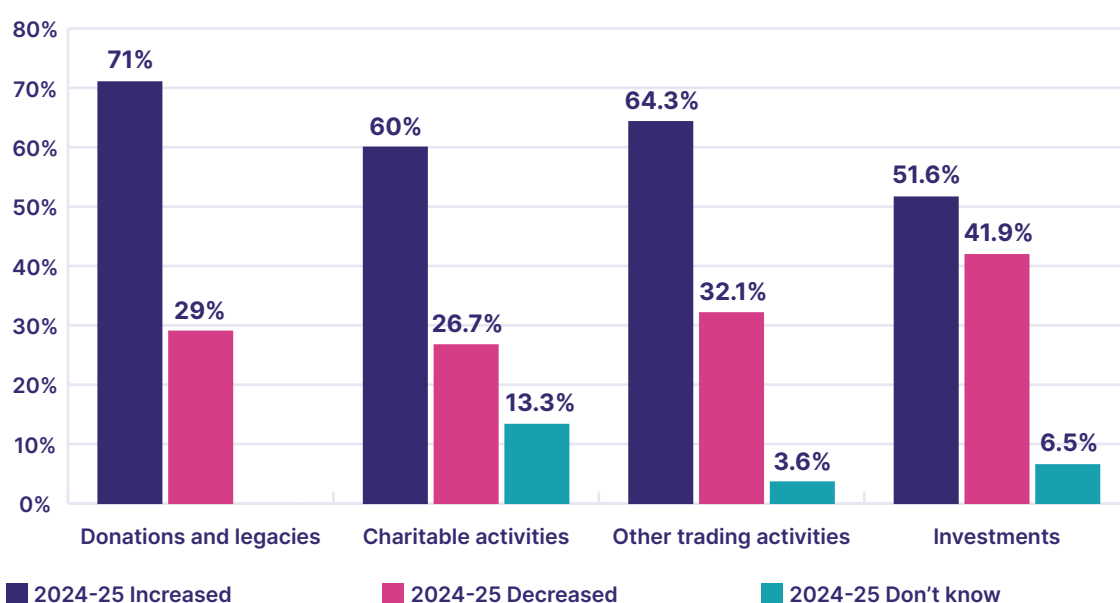
However, variance is also projected to remain between individual children's hospices. According to our survey analysis, nearly three fifths (59%) will see their income increase over the coming year while two fifths (41%) will experience a drop in their income.

## Income by source

Through our survey, we have also been able to examine individual sources of income to identify streams that have increased and those that have decreased over the past year:<sup>xiv</sup>

- **Donations and legacies:** In 2024/25, children's hospices received an average income of £4,063,097.74 from donations and legacies. According to the majority (71%) of hospices, this particular income stream has increased over the past year, while 29% claim it has decreased.
- **Charitable activities:** An average of £1,290,359.60 was received from charitable activities in 2024/25. For 60% of children's hospices, this source of income has grown since 2023/24, while 27% noted a decrease and 13% were unsure.
- **Other trading activities:** Income from trading activities (including retail) averaged £2,527,103.71 per hospice in 2024/25. While 64% of hospices saw growth in this area, 32% reported a decrease.
- **Investments:** Children's hospices received an average income of £219,385.90 from investments in 2024/25. Half (52%) of hospices saw an increase in investment income, while 42% reported a fall.

### Change in children's hospices' average income by source in 2024-25



<sup>xiv</sup> A total of 31 children's hospices across the UK told us about their income from donations and legacies and investments respectively. Meanwhile, 30 hospices told us about income from charitable activities while 28 provided information on their trading activities.



In 2025/26, children's hospices are anticipating the following shifts across these income streams:

- **Donations and legacies** are expected to fall by 4.7% to an average of £3,871,055.26.
- **Income from charitable activities** is expected to rise by 4.7%, reaching an average of £1,351,201.47.
- **Other trading activities** are expected to result in a 12.8% increase in income, averaging £2,900,279.18.
- **Investment income** is forecast to decline by 3.6%, falling to £211,510.13.

"People's ability to 'give' has been impacted by the cost of living and recent changes to benefits. We sense a general 'funding fatigue' as everyone is asking for money and in crisis."

– Jessie May

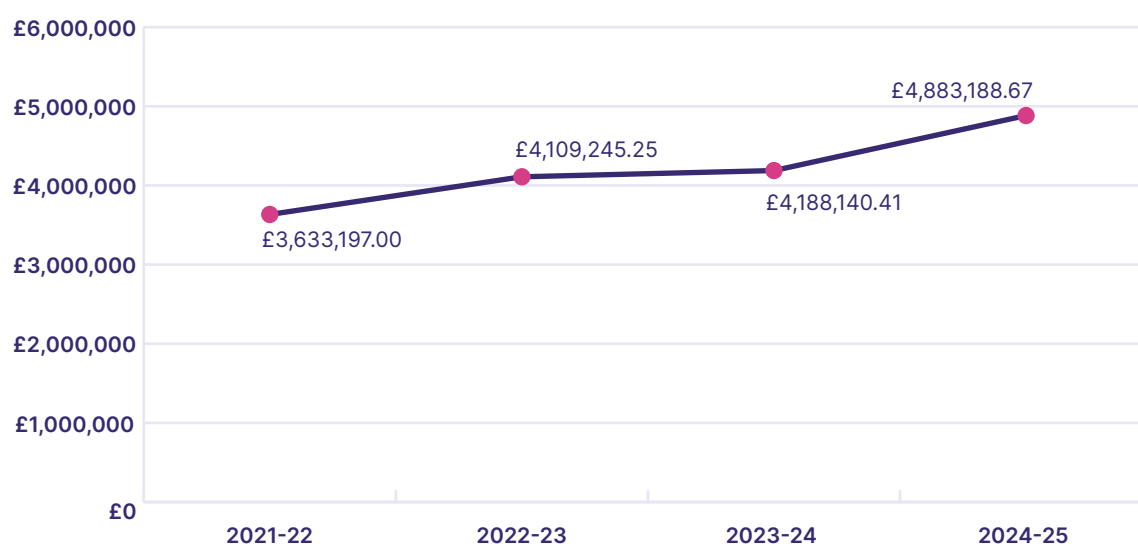
## Charitable expenditure

Overall, 34 children's hospice organisations across the UK told us about their charitable expenditure, 30 of which were based in England.

We have found that over the past year, children's hospices' average charitable expenditure has grown by 15.3% from £4,608,856.03 in 2023/24 to £5,314,246.12 in 2024/25.

For children's hospices in England, when compared to 2021/22, we have found that charitable expenditure has increased by a staggering 34.4% from an average of £3,633,197.00 to £4,883,188.67 in 2024/25.

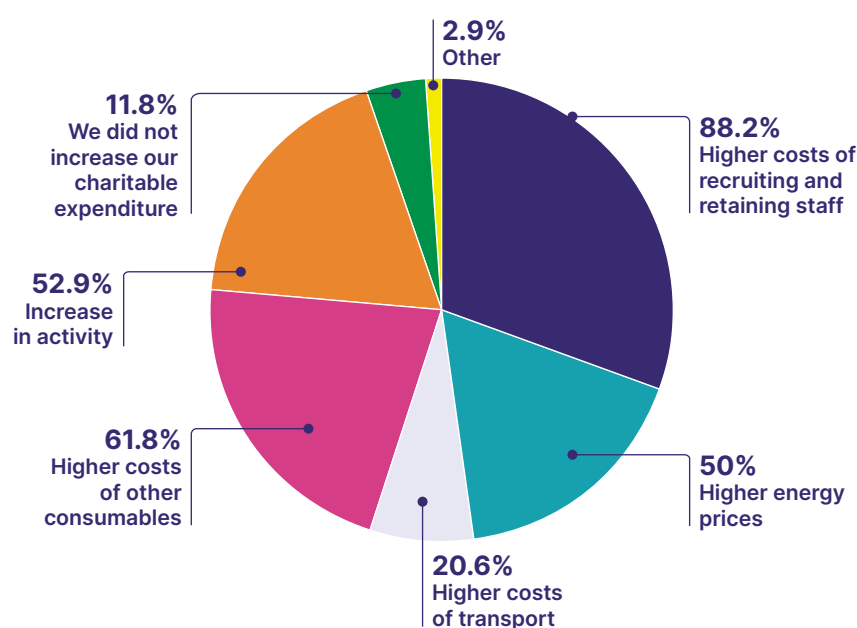
**Mean charitable expenditure by children's hospices in England 2021-22 – 2024-25**



When asked about the reasons for any increase in charitable expenditure over the past year, a significant number of children's hospices (62%) attributed rising costs to a higher cost of consumables. Meanwhile, over half cited higher energy prices (50%) and increased activity levels (53%) as key factors.

Furthermore, the majority (88%) of children's hospices said that higher costs of recruiting and retaining skilled staff was a key factor behind the increase.

### If your charitable expenditure increased between 2023-24 and 2024-25, please tell us why that was



Children's hospices compete directly with the NHS for clinical staff. As such, when Agenda for Change salary bands increase, hospices must raise pay accordingly – without receiving proportionate increases in statutory funding – placing significant pressure on their finances.

Despite strong efforts to match NHS pay and retain skilled professionals, the lack of any improved support from governments means many are falling short.

Looking ahead, children's hospices expect their charitable expenditure to rise by a further 8.7% in 2025/26, reaching an average of £5,779,000.50. This projected increase is being driven by several factors, most notably the rise in staffing costs.

In April 2025, the National Insurance Contributions (Secondary Class 1 Contributions) Act came into force, increasing the rate at which employer National Insurance Contributions is paid from 13.8% to 15%.<sup>19</sup> This alongside increases to the National Minimum Wage, is expected to significantly raise the cost of recruiting and retaining the skilled staff needed to deliver lifeline care.

Further compounding this, the NHS pay award for 2025/26 includes an above-inflation pay rise of 3.6% for all Agenda for Change staff. This means that the band five salary will now be around £31,050 which is nearly £4,000 more than three years ago.<sup>20</sup>

Given their need to remain competitive with NHS pay rates, this latest rise will place even more pressure on children's hospices' already stretched finances.

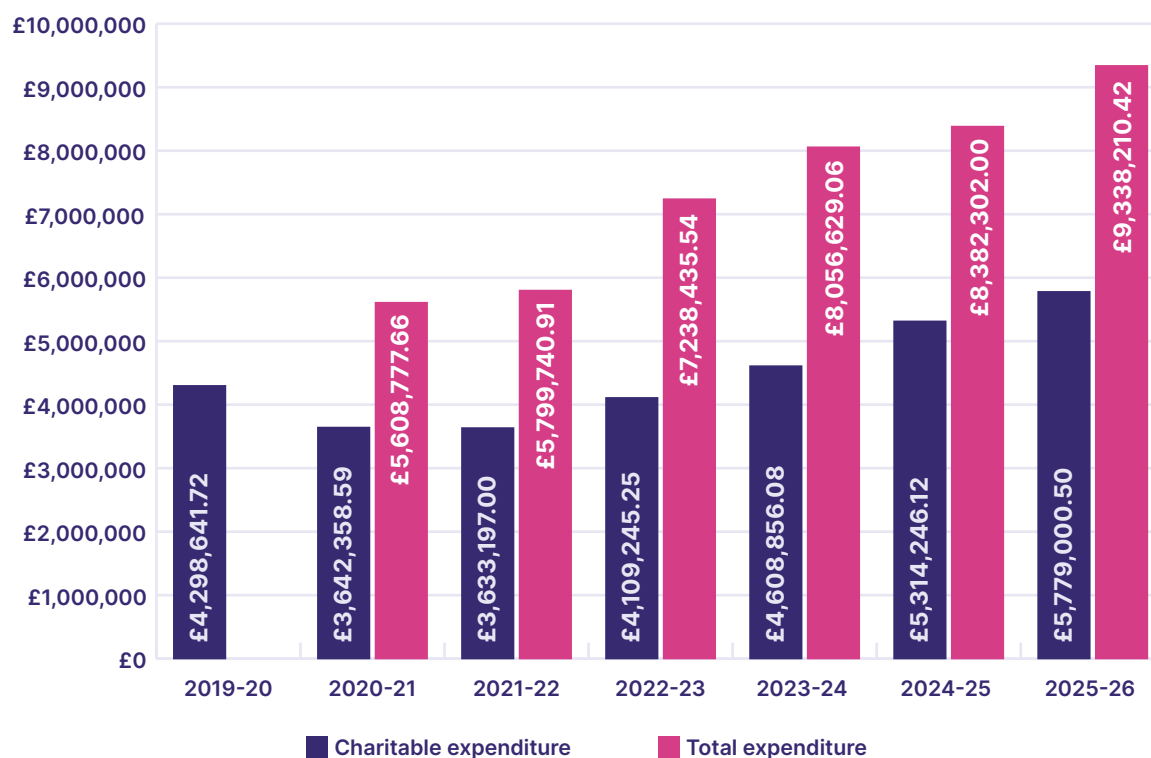
## Total expenditure

When asked about their total expenditure, 33 children's hospices across the UK provided us with relevant information.<sup>xv</sup>

On the whole, we have found children's hospices' total expenditure, which includes fundraising costs, to have risen on average by 4% from £8,056,629.06 in 2023/24 to £8,382,302.00 in 2024/25.

In 2025/26, we have estimated that this trend will continue with hospices' total expenditure rising again by a further 11.4% to £9,338,210.42.

**Mean charitable and total expenditure  
by children's hospices 2019-2026**



<sup>xv</sup> Due to providing services for adults as well as children, one hospice was not able to separate their total expenditure for children and adults' services. To ensure our analysis was representative of children's hospice services alone, data covering both adult and children's services was omitted from the analysis.

## Balance between total income and total expenditure

To assess the financial sustainability of the sector, we calculated the difference between total income and total expenditure for 32 children's hospices across the UK.

Of those that responded and were included in the analysis, two fifths (41%) of children's hospices ended the 2024/25 financial year with a net surplus. Meanwhile, nearly two thirds (59%) of hospices ended the year with a deficit.

When examining the data across all 39 hospices that provided care to seriously ill children across the UK in 2024/25, only one third (33%) of children's hospices ended the year with a net surplus – up slightly from 23% in 2023/24.

On the other end of the spectrum, nearly half (49%) of all 39 children's hospices reported a net deficit – down from 54% in the previous year. The remaining 18% either did not respond or their data was omitted.

Taking all respondent's surpluses and deficits into account, we have estimated the average deficit in 2024/25 to be £24,172.66. When extrapolated across all 39 children's hospices, this represents a shortfall of £942,733.59.

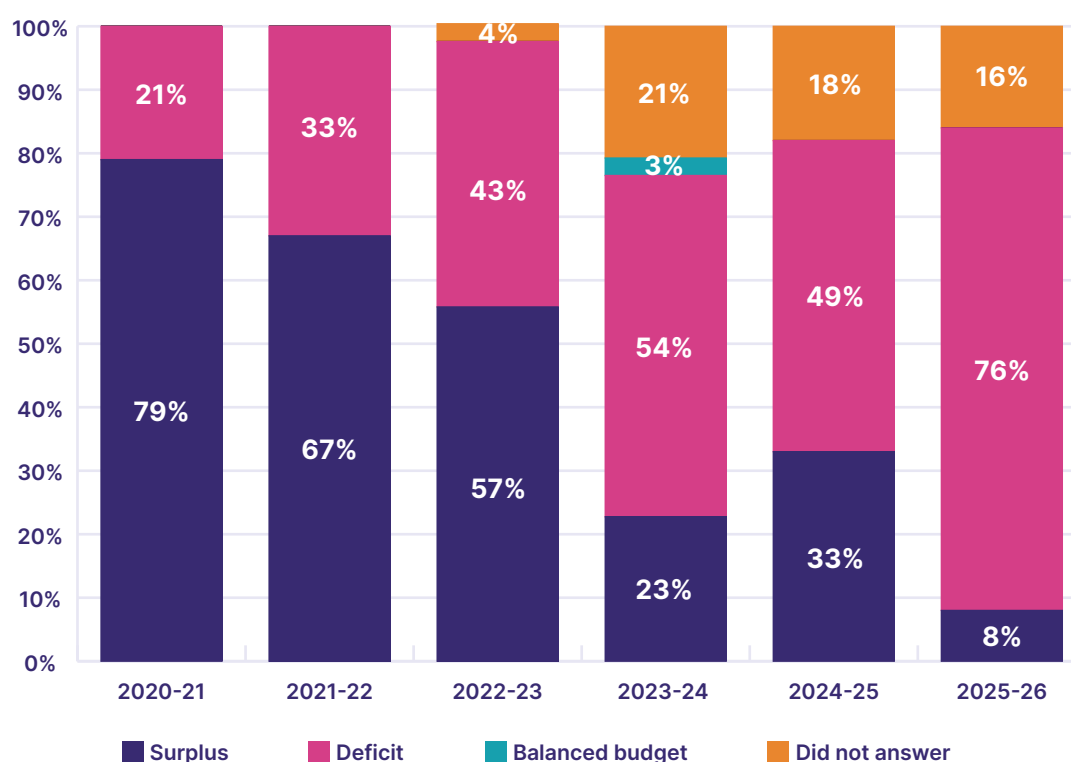
Although this marks an improvement on the 2023/24 average deficit of £218,491.84, the outlook for 2025/26 is considerably more concerning.

Of those that responded, we have estimated that almost all (91%) children's hospices will be forecasting a net deficit in 2025/26, while only three (10%) of children's hospices set to end the year with a net surplus.

When examining the data across all 38 hospices that will provide care to seriously ill children in 2025/26, over two thirds (76%) are forecast to have a net deficit while only 8% are estimated to have a surplus.<sup>xvi</sup>

On average, we have estimated that children's hospices across the UK will have a deficit of £770,131.03 in 2025/26. When extrapolated across all 38 children's hospice organisations in the UK, this would represent a total shortfall of £29,264,979.19 in 2025/26.

**% of children's hospices reporting surpluses, deficits and balanced budgets**



<sup>xvi</sup> At the end of 2024/25, Rennie Grove Hospice Care ceased providing services for children. As such, this report uses a total of 39 children's hospice organisations for the analysis of 2024/25 data. For 2025/26 and beyond, the total number of children's hospice organisations is 38.

## Impact of funding changes on services and seriously ill children

To understand how recent changes in funding have affected service provision, we asked children's hospices to reflect on the impact these changes have had over the past year. A total of 34 children's hospices across the UK provided responses.

Encouragingly, across the core areas of care and support, the majority of children's hospices reported that they had been able to maintain service levels despite growing financial pressures:

- **79%** of children's hospices were able to maintain their **end of life care** at current levels.
- **79%** maintained the **emotional** and/or **psychological support** they provide.
- **85%** maintained their **symptom management support**.

Despite many hospices being able to avoid cuts, others have not. According to the responses to our survey, 12% have cut the end of life care and 15% have reduced the amount of respite care they offer. Meanwhile, 6% have had to cut hospice at home services.<sup>xvii</sup>

**"We have had to reduce our overnight respite and day care. We have had to decline an end of life."**

– Alexander Devine Children's Cancer Trust

Additionally, it is particularly concerning to hear that in order to maintain services at current levels, children's hospices have had to utilise their reserves and run deliberate budget deficits – a model that is unsustainable in the long term.

**"The changing funding landscape has not impacted our services this year because the organisation has decided to operate a £1m deficit position, however this is**

**unsustainable."**

– Claire House  
Children's Hospice

**"We haven't cut any of our services for children as we have managed to fund services from reserves, however this is not sustainable long term for the organisation."**

– Ellenor

**"Please note that the reason for no impact is that we have managed to sustain all services and manage increase in costs by using our charitable reserves to fund any shortfall."**

– St Oswald's Hospice

**"We have protected services and have not cut them – yet."**

– Jigsaw Children's  
Hospice

<sup>xvii</sup> Please see appendix E for a graph illustrating the impact that changes in funding between 2023/24 and 2024/25 have had on the services provided by children's hospices.



## Active caseloads

Through our survey, we have also found that children's hospices are supporting more children than ever before. In 2024/25, hospices' active caseloads increased by 21%, rising from an average of 248 children in 2023/24 to 301.

When asked about services that should be commissioned by the NHS and local authorities, hospices reported the following year-on-year increases:

- **End of life care** was provided to an average of 17% more children, rising from 18 in 2023/24 to 21 in 2024/25.
- **Respite care** was provided to 2% more children, increasing from 154 to 157.

### At the same time, some areas of care saw a decline:

- **Symptom management** was provided to 42% fewer children, falling from 65 to 37.
- **Step-down care** was delivered to 33% fewer children, dropping from four in 2023/24 to three in 2024/25.
- **Hospice at home services** were delivered to 1% fewer children, decreasing from 92 to 91.

Despite these decreases, when examining the trends witnessed over the past six years, it is evident that children's hospices are providing significantly more of the care that the state should be funding.<sup>xviii</sup>

In this time, symptom management support has been provided to 108% more children and young people, while end of life care has been provided to 98% more children and young people.

This sustained growth not only reflects the rising number of children and young people living with life-limiting and life-threatening conditions, but it also illustrates the essential role that children's hospices play in relieving pressure on the NHS and wider health and care systems. Without appropriate investment, this vital contribution remains at risk.

# Policy recommendations

Across the UK, children's hospices are under growing financial pressure – despite the essential lifeline care they provide to seriously ill children and their families. To ensure that children's hospice care remains sustainable for the long term, we recommend the following actions:

## England

- We call on the UK Government to commit to protecting and maintaining ringfenced NHS funding for children's hospices, formerly known as the Children's Hospice Grant, beyond 2025/26.
- Ministers should increase this funding annually to make sure it contributes to at least the same proportion of children's hospices' expenditure as it did when NHS England increased the grant to £25 million in 2023/24.
- As a minimum, this would mean that the grant is increased to the following amounts in the years to come:

2026/27: £28 million	2028/29: £29 million
2027/28: £28.5 million	2029/30: £30 million
- To make sure the funding is ringfenced for children's hospices – and paid in full and on time – the government should also maintain the safeguards that NHS England (NHSE) has put in place as part of the 2025/26 payment process.
- As part of the NHS 10-Year Plan, the UK Government should commit to reviewing the way in which children's palliative care is planned and funded.
- This should lead to multi-year long-term NHS funding for the health elements of children's palliative care in England that fills the £310 million gap that we have identified to sustain lifeline services, including children's hospices.<sup>21</sup>
- A review should also examine whether children's palliative care would be more effectively commissioned at a national or regional level to create economies of scale.
- The Department of Health and Social Care (DHSC) should conduct its own modelling to determine how much the NHS should spend on the health elements of children's palliative care – and then hold local NHS bodies to account for the extent to which they spend money for this purpose.

## Northern Ireland

- The Northern Ireland Executive should commit to providing additional and sustainable statutory funding to Northern Ireland Children's Hospice for the long term. This funding should be sufficient to cover 50% of the costs incurred in providing lifeline care and support to children and their families.
- The Executive should ensure that any additional and recurrent statutory funding that is awarded is tied to and increases in line with the rising costs caused by inflationary pressures.
- The Northern Ireland Executive should make sure sustainable funding is in place to implement 'Providing High Quality Palliative Care for Our Children: A Strategy for Children's Palliative and End-of-Life care 2016-26' in full.<sup>22</sup>

## Scotland

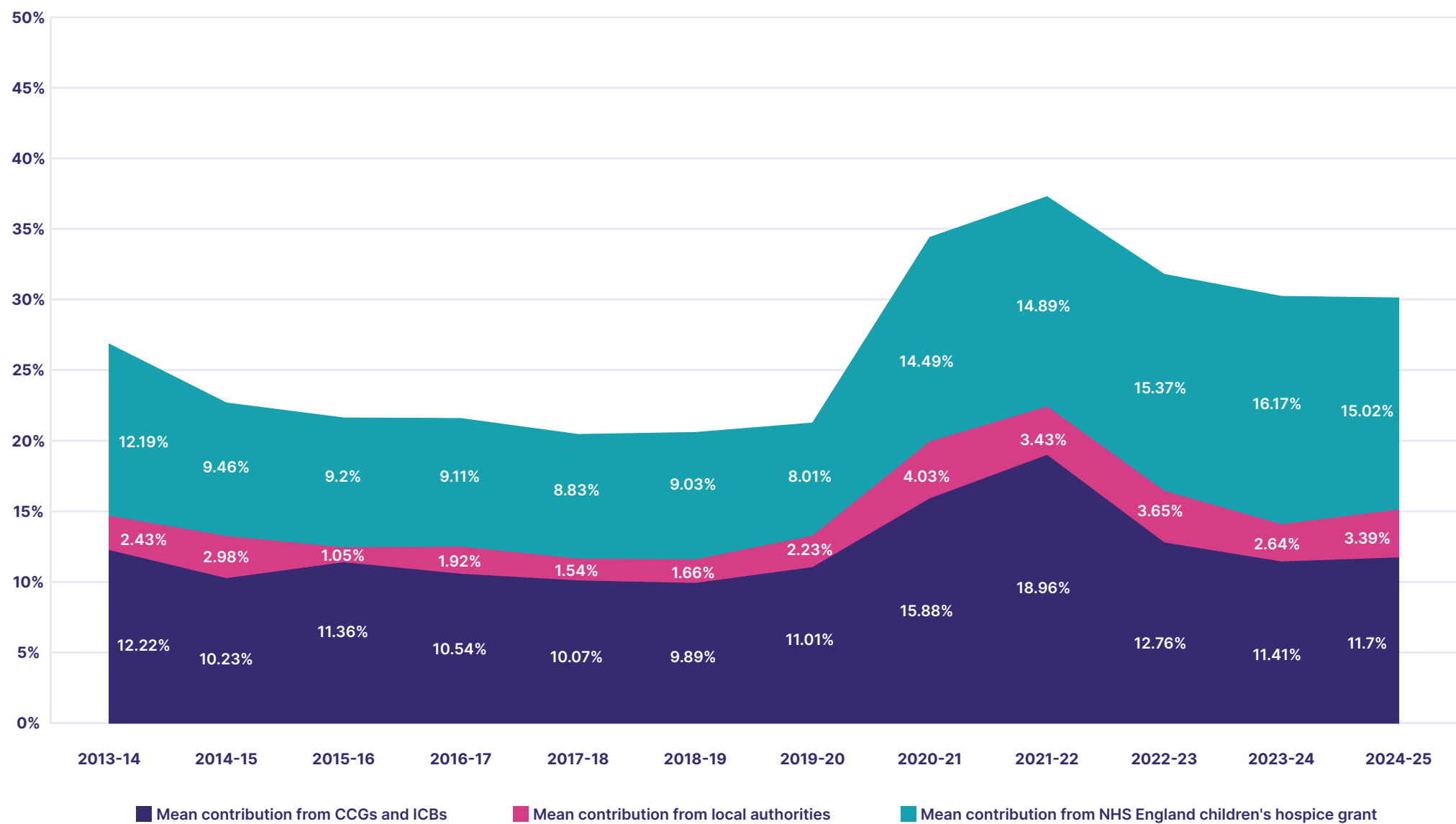
- The Scottish Government should re-commit to providing additional and sustainable statutory funding to Children's Hospices Across Scotland (CHAS) for the long term.
- This funding should be sufficient to cover 50% of agreed costs in providing lifeline care to children and their families, alongside additional costs associated with rising employer National Insurance Contributions and achieving pay parity with the NHS.
- The Scottish Government should ensure that any additional and recurrent statutory funding that is awarded is tied to and increases in line with the rising costs caused by inflationary pressures.
- The Scottish Government should provide sustainable funding so that its new national strategy for palliative and end of life care can be implemented in full.<sup>23</sup>

## Wales

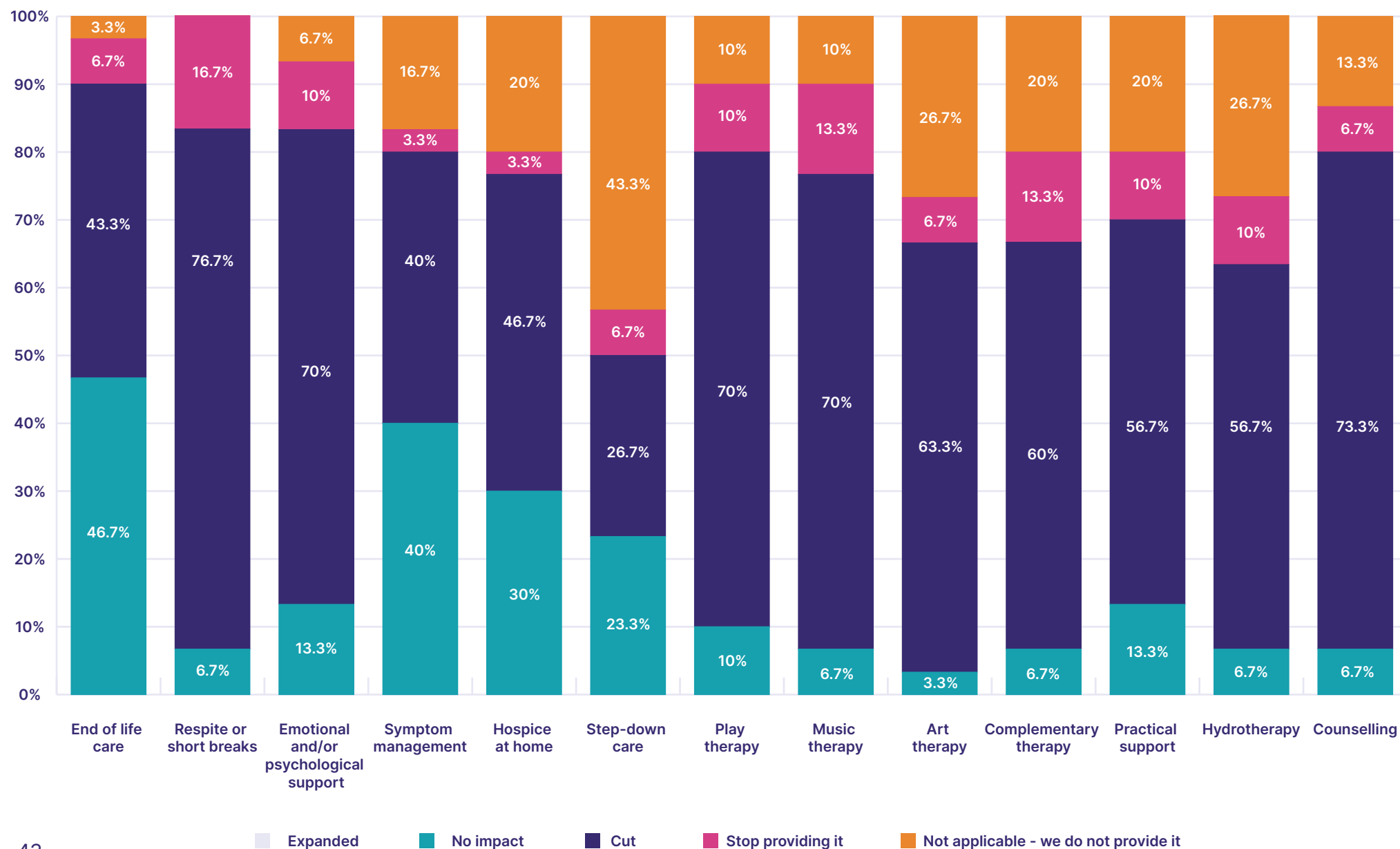
- We join Tŷ Hafan and Tŷ Gobaith in calling for all Welsh political parties to commit to sustainable, fair funding for both children's hospices. That means committing to 25% of care costs in 2025, rising to 30% by 2030.
- The Welsh Government should ensure that any additional and recurrent statutory funding that is awarded is tied to and increases in line with the rising costs caused by inflationary pressures.

# Appendices

Appendix A: Proportion of charitable expenditure for children’s hospices in England covered by the state 2014-25

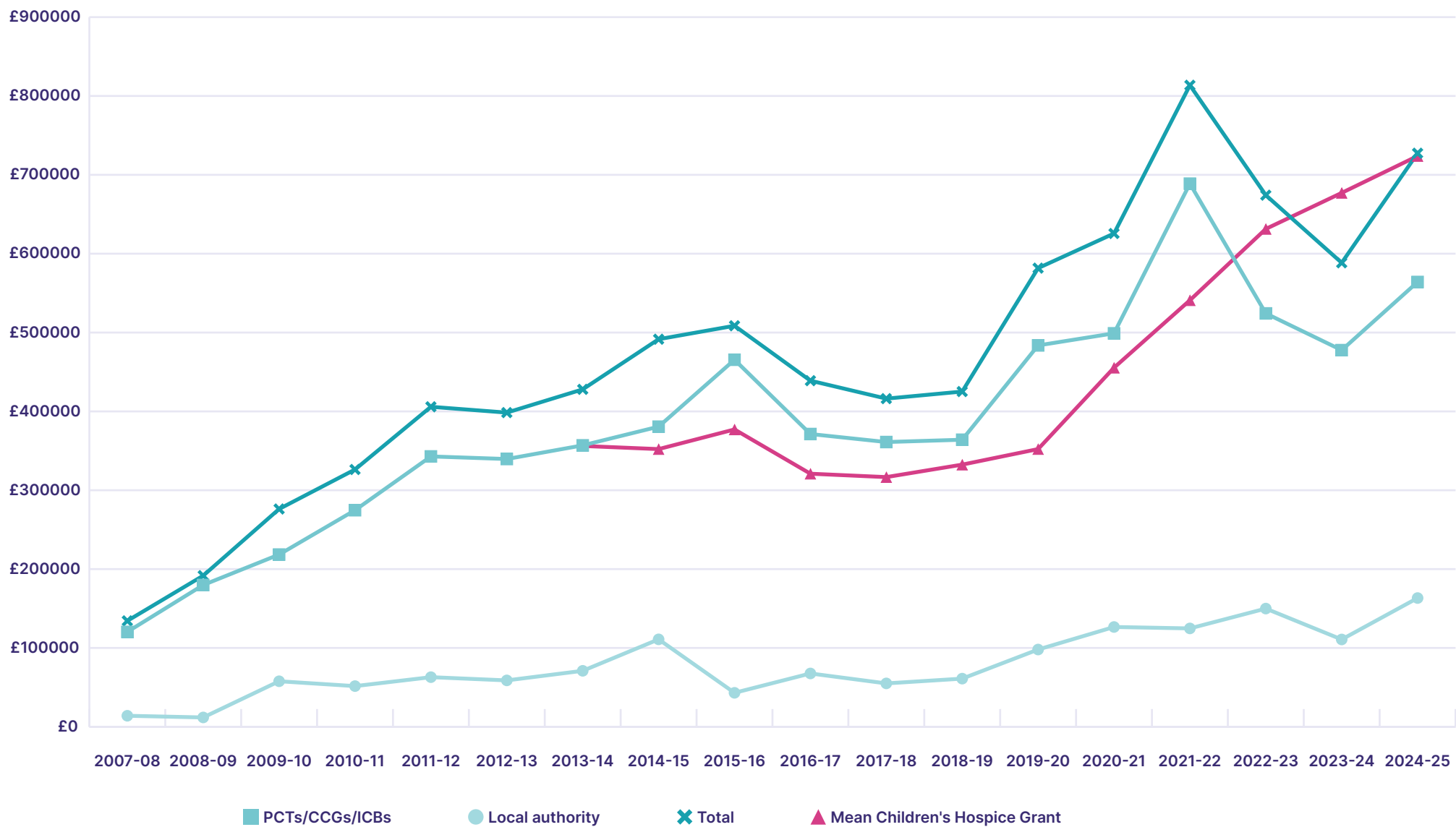


## Appendix B: The predicted impact on children's hospice services if NHSE funding for children's hospices was not available from 2026/27 onwards





Appendix C: Change in mean local funding for children’s hospices in England 2007-25

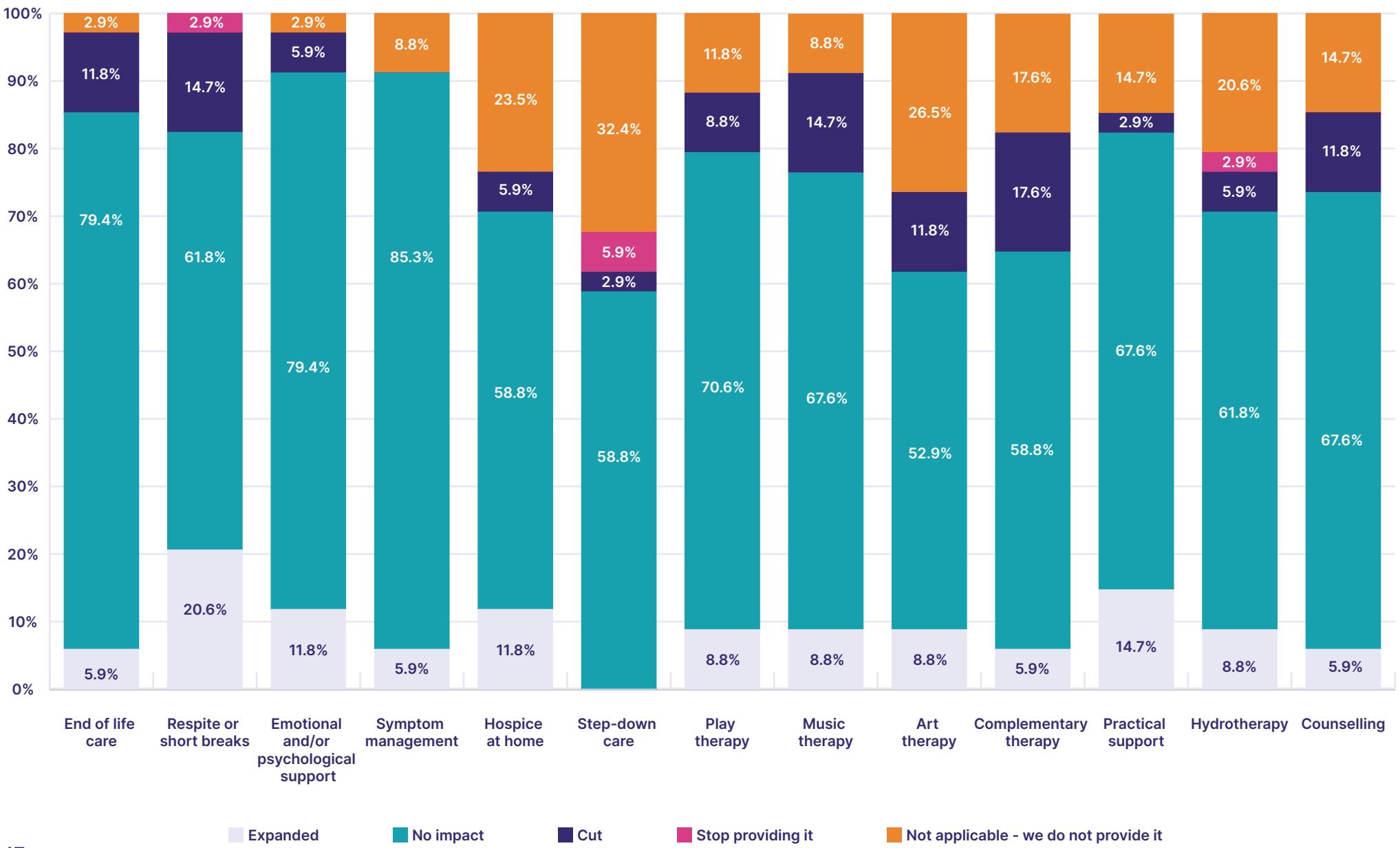


## Appendix D: Overview of responses from ICBs to our freedom of information requests

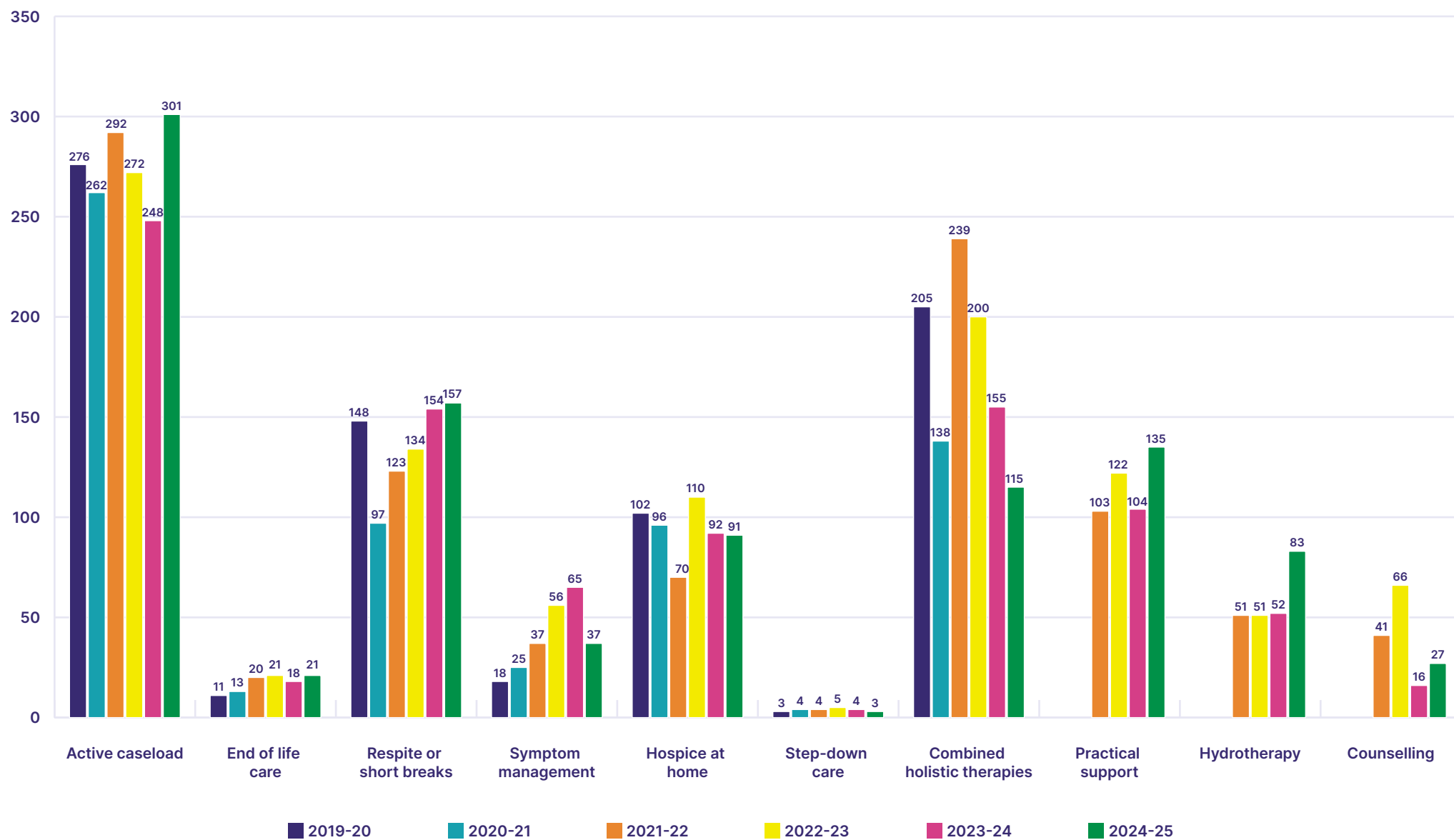
Integrated care board	2024/25 total spending by ICB on children's hospice care	Total # of children & young people aged 0-18 accessing hospice care in ICB footprint	Total # of children & young people who could benefit from children's hospice care	2025/26 total spending by ICB on children's hospice care	# of cases of life-limiting & life-threatening conditions (LLCs & LTCs) among children & young people aged 0-24 in ICB area	2024/25 total spending by ICB on children's hospice care per # of cases of life-limiting & life-threatening conditions (LLCs and LTCs) among children & young people aged 0-24 in each ICB area (£ per child and young person)
Bath & North East Somerset, Swindon & Wiltshire	£223,295.00	Unable to provide a response		£179,825.00	1,456	£153.36
Bedfordshire, Luton & Milton Keynes	£185,272.00	276	Unable to provide a response		2,101	£88.18
Birmingham & Solihull	Response omitted pending further clarification	Less than 10	Unable to provide a response		2,871	
Black Country	£606,756.00	Unable to provide a response			3,104	£195.48
Bristol, North Somerset & South Gloucestershire	£567,362.00	Unable to provide a response		£566,000.00	1,859	£305.20
Buckinghamshire, Oxfordshire & Berkshire West	£304,519.47	Unable to provide a response	2,399	Unable to provide a response	2,945	£103.40
Cambridgeshire & Peterborough	Response omitted pending further clarification	223	Unable to provide a response		1,540	
Cheshire & Merseyside	Response omitted pending further clarification	Unable to provide a response		£1,030,890.00	4,856	
Cornwall & Isles of Scilly	£116,889.00	Unable to provide a response		£116,889.00	1,076	£108.63
Coventry & Warwickshire	£243,737.00	Unable to provide a response			1,596	£152.72
Derby & Derbyshire	£126,722.00	Unable to provide a response		£131,284.00	1,746	£72.58
Devon	£299,000.00	Unable to provide a response		£311,000.00	2,075	£144.10
Dorset	£214,650.00	Unable to provide a response	1,038	Unable to provide a response	1,251	£171.58
Frimley	Response omitted pending further clarification	Unable to provide a response		£614,067.00	1,297	
Gloucestershire	£193,947.41	162	Unable to provide a response	£198,961.95	1,105	£175.52
Greater Manchester	£1,025,000.00	Unable to provide a response			6,241	£164.24
Hampshire & the Isle of Wight	Unable to provide a response		3,373	Unable to provide a response	3,373	
Herefordshire & Worcestershire	£269,291.50	122	Unable to provide a response	£264,000.00	1,257	£214.23
Hertfordshire & West Essex	£465,978.00	Unable to provide a response			2,552	£182.59

Integrated care board	2024/25 total spending by ICB on children's hospice care	Total # of children & young people aged 0-18 accessing hospice care in ICB footprint	Total # of children & young people who could benefit from children's hospice care	2025/26 total spending by ICB on children's hospice care	# of cases of life-limiting & life-threatening conditions (LLCs & LTCs) among children & young people aged 0-24 in ICB area	2024/25 total spending by ICB on children's hospice care per # of cases of life-limiting & life-threatening conditions (LLCs and LTCs) among children & young people aged 0-24 in each ICB area (£ per child and young person)
Humber & North Yorkshire	£131,600.00	Unable to provide a response		£137,100.00	2,755	£47.77
Kent & Medway	Response omitted due to incomplete data	Unable to provide a response	1,415	Unable to provide a response	3,301	
Lancashire & South Cumbria	£453,891.00	Unable to provide a response	377	£466,936.00	3,437	£132.06
Leicester, Leicestershire & Rutland	£99,893.00	Unable to provide a response		£99,893.00	1,739	£57.44
Lincolnshire	£66,049.00	119	Unable to provide a response	£67,468.00	1,113	£59.34
Mid & South Essex	£688,797.00	246	311	£585,503.00	2,079	£331.31
Norfolk & Waveney	£362,143.00	163	1,323	£368,118.00	1,477	£245.19
North Central London	£63,284.95	Unable to provide a response			2,719	£23.28
North East & North Cumbria	Unable to provide a response				6,019	
North East London	£1,739,634.00	375	3,343	Unable to provide a response	4,006	£434.26
North West London	Did not respond to the FOI request				4,068	
Northamptonshire	£44,154.00	Unable to provide a response		£44,154.00	1,373	£32.16
Nottingham & Nottinghamshire	£94,983.00	Unable to provide a response			1,926	£49.32
Shropshire & Telford & Wrekin	£265,461.00	187	Unable to provide a response	£271,168.00	881	£301.32
Somerset	£169,602.00	Unable to provide a response			1,011	£167.76
South East London	£139,535.00	Unable to provide a response			3,400	£41.04
South West London	£342,384.00	Unable to provide a response			2,860	£119.71
South Yorkshire	£108,180.00	Unable to provide a response		£110,506.00	3,270	£33.08
Staffordshire & Stoke-on-Trent	£185,720.00	Unable to provide a response		£185,720.00	2,027	£91.62
Suffolk & North East Essex	£342,193.00	2,995	Unable to provide a response	£349,035.00	1,553	£220.34
Surrey Heartlands	£454,217.00	Unable to provide a response			1,744	£260.45
Sussex	Response omitted pending further clarification	38	142	Unable to provide a response	2,980	
West Yorkshire	£1,275,154.00	Unable to provide a response			5,318	£239.78

# Appendix E: Impact that changes in funding between 2023/24 and 2024/25 have had on the services provided by children’s hospices



## Appendix F: Change in average caseloads from 2019/20 to 2024/25





## Appendix G: Responses from ICBs to our freedom of information requests

[NHS Bath and North East Somerset, Swindon and Wiltshire ICB](#)

[NHS Bedfordshire, Luton and Milton Keynes ICB](#)

[NHS Birmingham and Solihull ICB](#)

[NHS Black Country ICB](#)

[NHS Bristol, North Somerset and South Gloucestershire ICB](#)

[NHS Buckinghamshire, Oxfordshire and Berkshire West ICB](#)

[NHS Cambridgeshire and Peterborough ICB](#)

[NHS Cheshire and Merseyside ICB](#)

[NHS Cornwall and Isles Of Scilly ICB](#)

[NHS Coventry and Warwickshire ICB](#)

[NHS Derby and Derbyshire ICB](#)

[NHS Devon ICB](#)

[NHS Dorset ICB](#)

[NHS Frimley ICB](#)

[NHS Gloucestershire ICB](#)

[NHS Greater Manchester ICB](#)

[NHS Hampshire and Isle of Wight ICB](#)

[NHS Herefordshire and Worcestershire ICB](#)

[NHS Hertfordshire and West Essex ICB](#)

[NHS Humber and North Yorkshire ICB](#)

[NHS Kent and Medway ICB](#)

[NHS Lancashire and South Cumbria ICB](#)

[NHS Leicester, Leicestershire and Rutland ICB](#)

[NHS Lincolnshire ICB](#)

[NHS Mid and South Essex ICB](#)

[NHS Norfolk and Waveney ICB](#)

[NHS North Central London ICB](#)

[NHS North East and North Cumbria ICB](#)

[NHS North East London ICB](#)

[NHS Northamptonshire ICB](#)

[NHS Nottingham and Nottinghamshire ICB](#)

[NHS Shropshire, Telford and Wrekin ICB](#)

[NHS Somerset ICB](#)

[NHS South East London ICB](#)

[NHS South West London ICB](#)

[NHS South Yorkshire ICB](#)

[NHS Staffordshire and Stoke-on-Trent ICB](#)

[NHS Suffolk and North East Essex ICB](#)

[NHS Surrey Heartlands ICB](#)

[NHS Sussex ICB](#)

[NHS West Yorkshire ICB](#)

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