Vital care, fragile funding

Why children's hospices can't keep filling the gap

Foreword

For thousands of families caring for children with serious illness across the UK, children's hospices are vital. They provide a broad range of support, from end of life care and symptom management to short breaks, emotional and psychological support. Through all of it, they stand alongside families so they can live as well as possible and experience moments of happiness and joy.

Yet these amazing services, and the families they care for, continue to be let down by a system which varies wildly according to where they live and, too often, overlooks them.

As demand for children's hospice care grows and becomes more complex, unfair and unsustainable funding is pulling us further away from the government's goal: that every person – including babies, children and young people – in England who needs palliative or end of life care will have equitable access to high quality support, shaped by what matters to them, their families and carers.

We cannot accept this. In England, I support the £80 million allocated to children's hospices until 2029, the £125 million in capital expenditure funding for

both adult and children's hospices and the government's work to develop a new all-age palliative care modern service framework to address these challenges.

But I urge ministers to act now to fairly and sustainably support children's hospices by fully-funding children's hospice's clinical care year on year, filling the £310 million children's palliative care funding gap and better supporting NHS bodies. We cannot wait for a new government framework. If they do not, more demands will be loaded onto overstretched hospital services and too many families will be isolated and alone.

We must seize this moment. By acting on the evidence before us, we have an opportunity to ensure that every child with serious illness and their family can access the care and support they need, when and where they need it.

Nick Carroll
Chief Executive,
Together for Short Lives

Executive summary

• Children's hospices provide vital support which means that thousands of families of children with serious illness can live as well as possible as they navigate their child's life, death and bereavement.

• As demand rises across the UK, children's hospices are, on average, providing more care and support than ever before – and spending more on clinical care that would otherwise fall to the NHS.

• Despite this, funding from local NHS bodies and councils is failing to keep pace; children's hospices are being forced to rely on charitable income and financial reserves just to maintain essential services, and nearly two thirds ended 2025/26 with a budget deficit.

• This is worrying because some children's hospices are now cutting services: across the UK, one third of children's hospices (33%) have been forced to reduce the short break for respite care they provide.

• The system is taking us further away from the UK Government's goal that every person who needs palliative or end of life care will have equitable access to high quality support, shaped by what matters to them, their families and carers; we will not accept this, and we urge ministers to act now to fairly and sustainably fund children's hospices.

Key findings

• Across the UK, children's hospices are providing more care and support than ever before, including increasing volumes of clinical care that would otherwise fall to the NHS.

• In 2025/26, demand has grown significantly: the number of children supported at the end of life has increased by 4%, while those receiving symptom management has risen by 40%.

• In England, children's hospices are also supporting the government's shift from hospital to community-based care, delivering 9% more hospice at home support.

• Alongside this growth in activity has been rapidly rising costs. Between 2024/25 and 2025/26, children's hospices' average charitable expenditure increased by 18% from from £5.3 million to £6.2 million, driven by higher demand, rising energy prices and the growing cost of recruiting and retaining skilled staff.

• However, despite increasing expenditure, statutory funding has failed to keep pace, forcing hospices to rely more on charitable income and financial reserves to maintain essential services.

• In England, while funding from NHS integrated care boards (ICBs) has risen by 4%, this

has been outstripped by cost pressures. As a result, the share of expenditure covered by ICB funding has fallen to just 10%, with average ICB funding now 15% below levels seen in 2021/22.

• Freedom of information (FOI) requests have also shown funding from ICBs to vary significantly across the country. While NHS Shropshire, Telford and Wrekin ICB spent an average of £407 per child or young person with a serious illness on children's hospice care, Northamptonshire ICB spent just £32.

• Meanwhile, funding from local authorities has seen a sharp decline, falling by 53% with the proportion of children's hospices' charitable expenditure covered by local authority funding also falling from 3% to just 1%.

• As a result, for every £1 invested by the state, children's hospices in England are now providing nearly £4 in care and support, with the majority funded through charitable income.

• In Northern Ireland, Scotland and Wales, similar challenges persist: while one-off funding uplifts have provided short-term support, the rising cost of providing lifeline support continues to exceed statutory income.

• This funding model is deeply unsustainable. In 2025/26, three fifths (60%) of children's hospices ended the year with an operating deficit. Across all 38 hospices, this equates to an estimated total shortfall of £4.4 million.

• Without action, the situation is expected to worsen with 84% of hospices forecasting an operating deficit in 2026/27 and an estimated UK-wide shortfall of £34.3 million.

• Urgent action is therefore required to ensure children's hospice care is funded in a way that is fair, equitable and sustainable for the long term.

England

1. The government should implement Hospice UK's four-point plan for fair hospice funding. Specifically, we call on the UK Government to ensure that 100% of the costs incurred by children's hospices in providing clinical care, that would otherwise fall to the NHS, is covered by the state.

2. The government should commit to multi-year long-term NHS funding for the health elements of children's hospice and palliative care in England that fills the £310 million gap that we have identified to sustain lifeline services provided in hospitals, the community and in children's hospices by the end of 2027/28.

3. This funding should be scaled-up alongside investment to increase the number of professionals with the skills and experience to meet the needs of seriously ill children.

4. DHSC should conduct its own modelling to determine how much local NHS bodies should spend on the health elements of children's hospice and palliative care—and then hold them to account for the extent to which they spend money for this purpose.

5. The government should establish clear accountability mechanisms to underpin the MSF and ensure its implementation, including actions that will be taken if ICBs do not meet the required expectations.

Northern Ireland

1. 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.

2. 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 for both salary and non-salary expenditure.

Scotland

1. The Scottish Government should re-commit to providing additional and sustainable statutory funding to Children's Hospices Across Scotland (CHAS) for the long term.

2. 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.

3. 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.

4. 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.

Wales

1. We join Tŷ Hafan and Tŷ Gobaith in calling for the new Welsh Government to commit to sustainable, fair funding for both children's hospices. That means committing to provide statutory funding that covers 30% of the hospices' care costs by 2030.

2. 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.

Contents

Introduction

Across the UK, children's hospices are a lifeline for thousands of babies, children and young people with serious illness and for the families who care for them. Through a broad range of services, from end of life care and symptom management to respite care and psychological support, children's hospices help ensure that no family has to navigate their child's short life – and death – alone.

The value that children's hospices provide extends far beyond the families they support. Children's hospices also play a vital role within the wider health and care system, contributing directly to the delivery of national ambitions including the three key shifts outlined in the UK Government's 10-Year Health Plan.[1] By delivering care closer to home, embracing digital innovation and working in partnership with NHS and other providers, they relieve pressure on acute services and offer strong value for money in doing so.

Despite this, it is well-documented that children's hospices are continuing to face significant challenges in securing fair and sustainable funding for the long term. Concerns about the inadequate and variable nature of statutory funding for children's hospices have been highlighted by the House of Commons Health and Social Care Committee's Expert Panel in England,[2] the Health Committee in Northern Ireland,[3] and in debates across the UK's parliaments. As the complexity of care continues to increase, these pressures risk undermining hospices' ability to plan ahead and meet growing demand consistently.

There have, however, been some encouraging signs of progress over the past year. In England, October 2025 saw the UK Government announce £80 million of ringfenced NHS funding for children's hospices over three years,[4] providing some much-needed clarity and reassurance. In Scotland, the 2026/27 Budget included an additional £2.4 million for adult and children's hospices to support pay parity with the NHS,[5] in Wales an additional £4.3 million of in-year funding was provided,[6] and in Northern Ireland, one-off funding worth £500,000 was made available for the children's hospice.[7]

Looking ahead, there are important opportunities for governments across the UK to build on this progress. In Scotland and Wales, implementation of the new palliative care strategy and service specification respectively will be key. Meanwhile in England the UK Government is continuing to develop a Modern Service Framework for all-age palliative and end of life care.[8] Due to be published in autumn 2026, this framework presents an important opportunity to strengthen accountability for how ICBs and local authorities fund children's hospices.

Given the encouraging steps taken and the developments underway, we conducted a survey in April 2026 to better understand the current state of children's hospice funding across the UK. We asked all 38 hospice organisations that provided care to seriously ill children how they were funded in 2025/26 and the impact this has had on the services they have been able to provide.[i] We also asked how they expect this to change in 2026/27.

[i] During the 2025/26 financial year, Richard House Children's Hospice closed down. However, Liverpool Zoe's Place also emerged as a new legal body in its own right. For both 2025/26 and 2026/27, this report considers the total number of children's hospice organisations across the UK to be 38.

In total, 27 children's hospice organisations responded—including providers based in Northern Ireland, Scotland and Wales.

Alongside this, and in light of the significant variation in funding by integrated care boards (ICBs) in England previously uncovered, we issued a series of freedom of information (FOI) requests to all 36 ICBs in April 2026. These requests sought to understand how much ICBs or any predecessor ICBs that they now represent had spent on children's hospice care in 2025/26, and how much they plan to spend in 2026/27. ICBs were asked to exclude any funding disseminated on behalf of NHS England (NHSE) to ensure a clear picture of locally commissioned support.[ii]

Specifically, we asked ICBs to report:

- The total amount spent on hospice care for children and young people with life-threatening conditions, life-shortening conditions or with severe medical complexity between 6 April 2025 and 5 April 2026, with a breakdown by hospice organisation, excluding any funding ICBs disseminated on behalf of NHSE as part of the £26 million for children's hospices.

- The number of children and young people with life-threatening conditions, life-shortening conditions or with severe medical complexity who accessed hospice care in that period, with a breakdown by hospice organisation.

- The number of children and young people in their area who could benefit from children's hospice care.

- The total amount they plan to spend on children's hospice care between 6 April 2026 and 5 April 2027, with a breakdown by hospice organisation, excluding any funding they will distribute from the first year allocation of the £80 million three year funding commitment for children's hospices that NHSE has asked ICBs to pass on.

In total, 32 (89%) ICBs responded to the FOI request.

This report brings together the findings from both the survey and the FOI requests, offering an up-to-date picture of children's hospice funding across the UK. It sets out the challenges facing the sector before offering a series of recommendations for governments and health and care systems across the UK, aimed at ensuring children's hospices are funded in a way that is equitable, sustainable and fit for the future.

[ii] At the start of April 2026, many ICBs merged to form new legal entities. This reduced the overall number of ICBs down from 42 to 36. Given that this report is analysing spend from the 2025/26 financial year, the analysis is based on there being a total of 42 ICBs. For the 2026/27 year, projections are based on a total of 36 ICBs.

Noah and Ella's story

Noah was born a healthy twin with his sister Ella in December 2015. Dad, Nick, described him as "a strong-willed little boy, who had a love of life."

At 18 months, Noah's balance affected his ability to walk. By age three, he'd developed a squint and his speech was delayed, but still found ways to communicate with his family. He loved playing hide and seek, swimming and digging in the sand.

On 7th February 2019, after being referred to a neurologist, a large brain stem tumour was discovered – cancerous, aggressive, inoperable and terminal. The tumour was a 'Diffused Intrinsic Pontine Glioma', otherwise known as DIPG.

The average survival time is nine months from diagnosis and only 10% of children survive for two years.

Noah has extensive treatment to shrink the tumour – a biopsy, radiotherapy and daily general anaesthetic to keep him still throughout the sessions.

Following Noah's diagnosis, one of the nurses from Little Havens visited the family at home. She explained how the hospice could support Noah, his twin sister Ella and their parents through the most difficult time in their lives.

The family focused on making memories once his treatment ended, thanks to the generosity of their friends, family and local community making donations to 'Noah's Fund,' many of which featured dinosaurs, Noah's obsession!

Six months after his first radiotherapy, the tumour began growing again. Noah died on 3rd May 2020, aged 4, surrounded by his family.

Above: twins Noah and Ella

Noah's Mum Kat says: "After our initial shock at Noah's diagnosis, we were put in touch with Little Havens Hospice.

"One of the nurses visited us at home and shared how the charity could support us, even whilst Noah was doing well. Having a friendly face explain that hospices are not all about the end of life was enlightening. Little Havens strives to make every day count for children with lifelong illnesses, offering their families a special place to be together.

"We booked our first respite stay, which meant that we could make full use of all the facilities the hospice had to offer. Noah was allocated a nurse 24 hours a day and we also had a member of the Care Team available to play with the children whilst we had a break. Noah was really well in himself, and it was really difficult to believe the prognosis that we were facing. When we came to Little Havens it was wonderful, and to be reminded of why we were here was almost difficult to believe.

"We made incredible memories at Little Havens. Ella adored the ball pit and Noah loved the unlimited supply of dinosaurs, trains and animals. We enjoyed the hydrotherapy pool, beautiful gardens, sensory room, music sessions and craft area.

Dad, Nick, added, "It was really hard to get a place that suited looking after Noah, especially as he got sleepier and needed medication, and then for Ella, who is a typical child that just wants to run around and play and have fun. But coming here and seeing the gardens for them to play together, we knew this was a great place for both of them."

Kat continued, "Our family room was upstairs was nicer than many hotels we have stayed in. Noah had his own room and lounge on the care floor so we could stay with him if we wanted to.

"He preferred a large bed to spread out his dinosaurs, so the staff adapted the room to suit his needs. Nothing was too much trouble.

"Throughout Noah's illness, we stayed at Little Havens many times. When he became poorly, we visited for symptom management stays.

"This meant that when Noah's pain or symptoms became difficult for us to manage at home, the hospice team provided a calm and reassuring environment. Noah's medical care was their responsibility, and we could enjoy time together as a family with the pressure off.

"There were times when we just said, "Can we go to Little Havens?". It was just too unmanageable. His pain and symptoms

were up and down all the time, so we came here, and we just handed all of that over which was such a relief. It was amazing despite COVID, despite lockdown that they were still available to us for that."

Nick added, "A lot of the doors shut, and this was one of the few doors that always stayed open."

Kat continued, "I remember once he was really quite tired. He wanted to play but he couldn't physically play for too long, so the Care Team set him up a little camp with his iPad and the toys out in the play area. Because Noah knew that he wanted to be near the toys, but he wouldn't necessarily be able to play for too long. Little Havens adapted to his needs and our needs really well."

"Ella, Noah's sister, was only three at the time with her own needs, she didn't have an understanding of what was happening. She knew her brother was poorly, we had told her that, but then he had an operation on his head, and she felt that he was going to get better. I felt really anxious and overwhelmed supporting Ella and not knowing how on earth we explain this to her, what did we say to her? How is she going to respond? How is she going to feel? But Jane, the Little Havens Counsellor was amazing. I was constantly in touch with her whether than be face to face or by ringing her up with advice. Having Jane help us support Ella has made a huge difference, without that I don't think I would have coped the way I have.

"Now that we are a bereaved family, Little Havens still continues to offer support. Ella can have sessions with an experienced counsellor, and we can visit for annual memorial events.

"Coming to Little Havens feels like a second home. You just feel at ease, you feel supported. You've got everything you need, the only reason you don't want to be here is that your child is ill.

"Everything we have received from the hospice has been free of charge. They offer families such as ours a lifeline at the most difficult time.

Nick, continued, "What makes it sad coming back, and emotional as you drive down the driveway, is remembering how much fun Noah and Ella had together at Little Havens, all those happy memories come flooding back. If people didn't donate before, then we wouldn't have had all those precious memories, and you can't put a price on that?

Kat added "It's hard to put into words, but thank you to everyone that supports Little Havens because it makes such a difference to us and our little boy."

Noah's legacy lives on through 'Noah's Rainbow,' fundraising to support Abbie's Army (an organisation supporting specific research into DIPG) and Little Havens which supported the family throughout Noah's illness and continues to do so.

Kat explained, "Every pound we get, we split halfway. Halfway between Little Havens and halfway between Abbie's Army. And we really hope by doing that we're affecting, with Noah's legacy, other families through Little Havens and hopefully for research.

"We hope to raise money to express our gratitude for their care, as well as supporting other families who are going through the most challenging time."

Statutory funding for children's hospices in England

For children's hospices in England, statutory funding is derived from three predominant sources: NHS England (NHSE), integrated care boards (ICBs) and local authorities. Together, these funding streams support the operation of children's hospices and the delivery of vital palliative and end of life care for babies, children and young people with serious illness.

In 2025/26, we have found that while, on average, statutory funding has increased modestly, by 1% overall, it is still being significantly outpaced by rising costs and inflationary pressures. As a result, statutory funding now accounts for just over a quarter (25.8%) of children's hospices' charitable expenditure. This means that for every £1 invested by the state, children's hospices provide nearly £4 in care and support, with the majority funded through charitable income.

Breaking this down further, each source of statutory funding accounts for the following proportions of children's hospices' charitable expenditure:

- **NHS England: 14.1%**
- **Integrated care boards: 10.3%**
- **Local authorities: 1.4%**

Notwithstanding the challenging landscape, there have been some positive developments over the past year. The continuation and increase of the vital funding stream from NHSE,[9] coupled with the provision of £125 million in capital expenditure funding for both adult and children's hospices,[10] has provided important support to the sector. In particular, the capital funding has enabled many hospices to upgrade their facilities and further enhance their care environments.

> "We've made significant improvements to our gardens, making them fit for purpose, refurbished our hydrotherapy pool, replaced our generator, purchased clinical equipment, renovated our family accommodation, all making the hospice experience better."
> **Rainbows Hospice for Babies, Children and Young People**

However, this progress has come at a time of rapidly increasing costs. In 2025/26, charitable expenditure for children's hospices in England rose by 16.3% and is projected to increase by a further 7.7% in 2026/27. Consequently, many children's hospices are still being forced to draw on financial reserves and increase their reliance on fundraising to maintain essential services.

As such, there is still an urgent need for a more equitable and sustainable funding solution.

Funding from NHS England

In England, funding from NHS England (NHSE), previously known as the Children's Hospice Grant, remains a vital contribution to the delivery of children's palliative care.

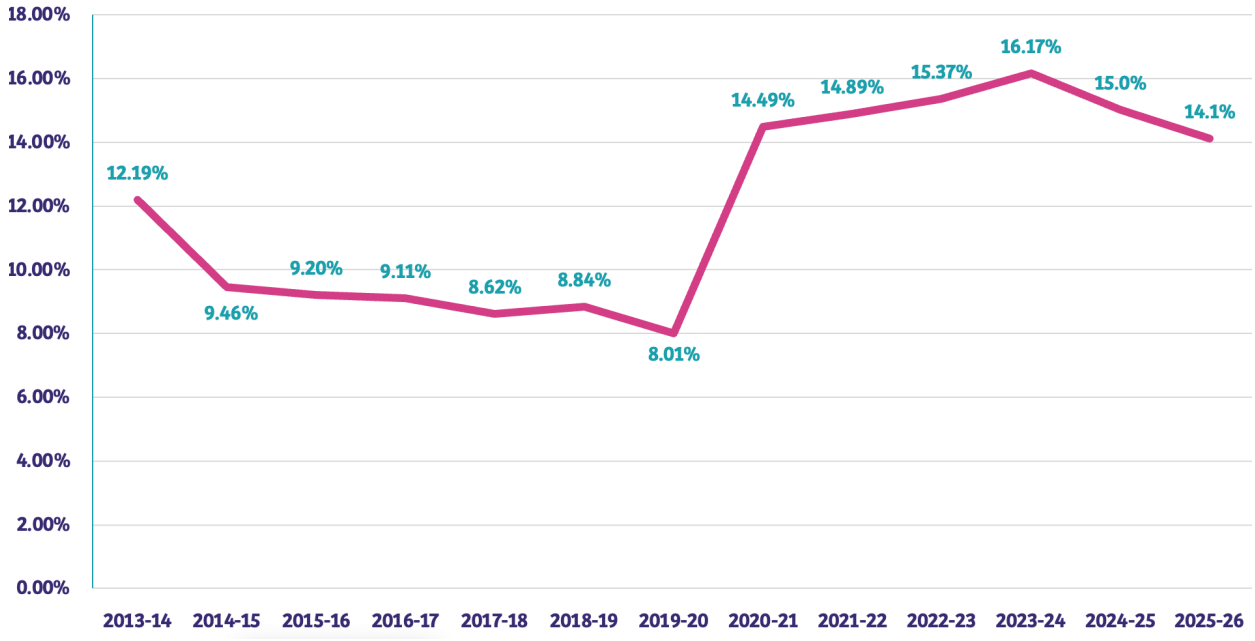
In December 2024, the UK Government confirmed that this funding would increase to £26 million in 2025/26.[11] This meant that in 2025/26, children's hospices responding to our

survey received an average allocation of £801,724.88, representing a 10.8% increase on the previous year.

> "We receive a tiny amount of funding from our ICB (integrated care board) and no contribution from local authorities. The Children's Hospice Grant keeps us afloat."
> **Jigsaw Cumbria's Children's Hospice**

Despite this uplift, this funding has not kept pace with the rising cost of providing care. While NHSE funding accounted for approximately 15% of children's hospices' charitable expenditure in 2024/25, the past year has seen this figure fall to 14%. As a result, hospices have had to bridge the gap by 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



Looking ahead, 2026/27 will mark the first year of the government's £80 million, three-year ringfenced funding commitment for children's hospices.[12] Announced in October 2025, this multi-year settlement has provided some much-needed clarity and reassurance, following several years in which the funding was only confirmed on an annual basis.

With the total settlement expected to be worth £27 million in 2026/27,[13] we have estimated that average allocations for each children's hospice will rise to £833,372.21, representing a 3.9% increase.

However, even with this increase, NHSE funding is projected to fall further as a proportion of charitable expenditure, to 13.6% in 2026/27.

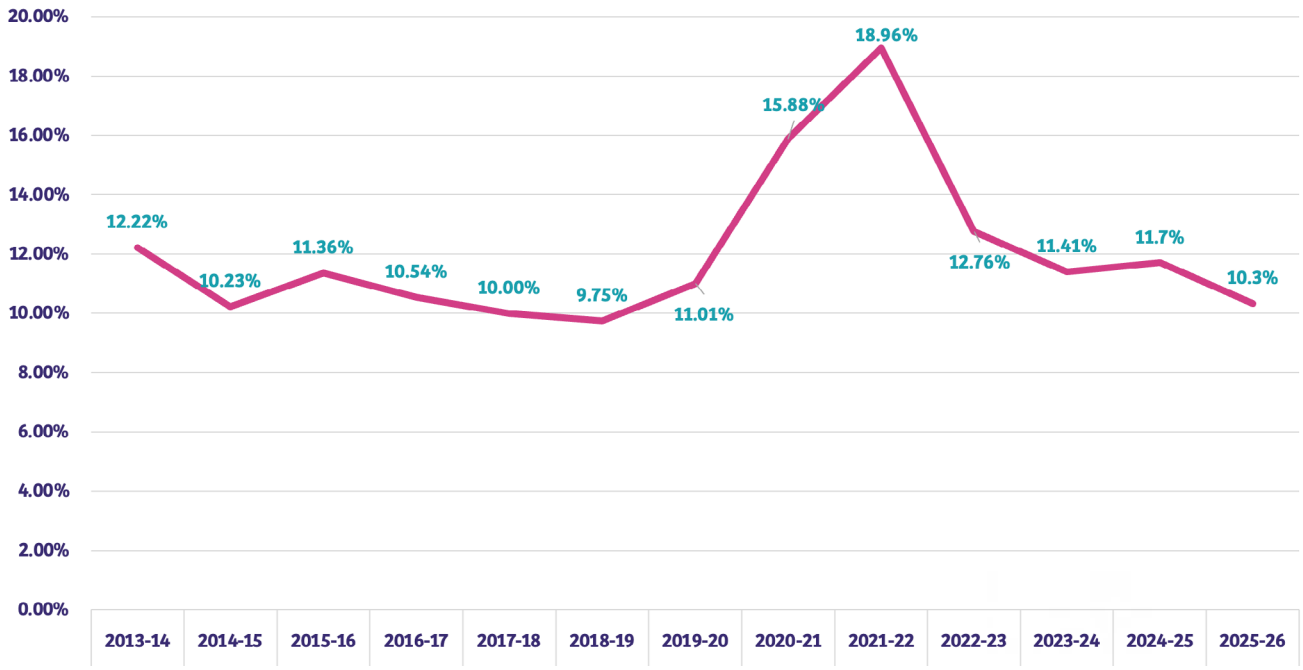
Funding from integrated care boards

Failing to keep pace with rising costs

Children's hospices also receive funding from integrated care boards (ICBs), which have a statutory duty under the Health and Care Act 2022 to commission palliative care services that meet the reasonable requirements of their populations.[14]

In 2025/26, average funding received from ICBs increased by 4% to £586,587.75, up from £564,126.17 in 2024/25. While this growth is encouraging, closer examination reveals that it has not kept pace with children's hospices' rising costs. Consequently, the proportion of children's hospices' charitable expenditure covered by ICB funding has fallen from 11.7% in 2024/25 to 10.3% in 2025/26.

Mean contribution to charitable expenditure from ICBs/CCGs



This trend is particularly concerning given that children's hospices are delivering increasing volumes of clinical care that would otherwise fall to the NHS.

Through our survey, we have found that over the past year:

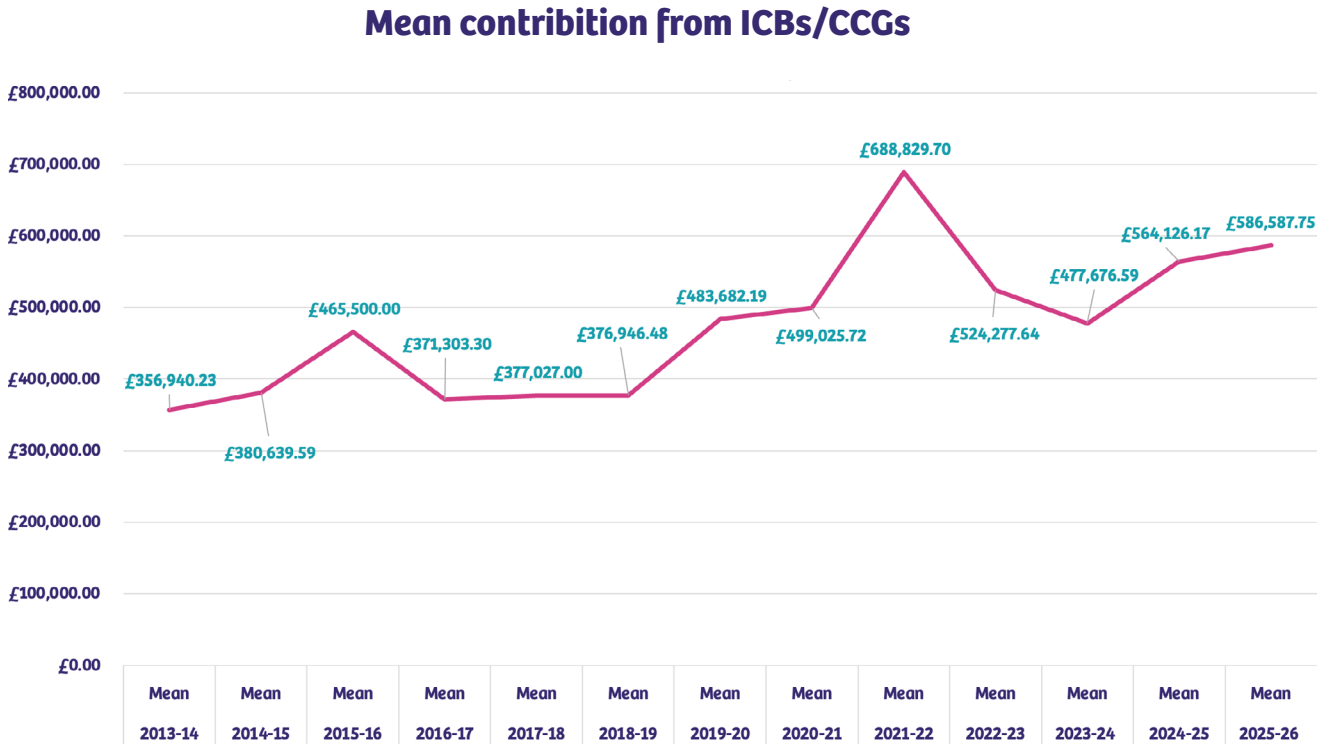
- the number of children that children's hospices provided symptom management support to increased by 56%
- the number of children they provided end of life care to increased by 1%
- the number of children they provided hospice at home care to increased by 9%.

This shows that children's hospices are helping to deliver the government's ambition to shift care out of hospitals and into the community.

At an individual level, the variation is ICB funding in also particularly stark. Half of children's hospices received less than 10% of their charitable expenditure from ICBs in 2025/26, while over one fifth (21%) received less than 5%. Meanwhile, no hospice at all received 30% or more.

> "It's shocking how little we get - we are now down to 7% statutory funding specifically for Brian House."
> **Brian House Children's Hospice**

Worryingly, 2025/26 appears to be part of a longer-term trend. In 2021/22, average ICB (and predecessor CCG) funding stood at £688,892.70. By 2025/26, this has fallen by 15% in cash terms, while the share of charitable expenditure covered has also dropped from 19% to just over 10%. In effect, after inflation, average ICB funding for children's hospices has fallen by approximately a third in real terms between 2021/22 and 2025/26, from covering £1 in every £5 of expenditure to just £1 in every £10.



Looking ahead to 2026/27, ICB funding is expected to rise by 5.5% to £618,762.79. However, with charitable expenditure set to rise by a further 7.7%, the proportion covered is likely to fall to 10.1%.

At an individual hospice level, less than two fifths (38%) of children's hospices expect any increase at all in their ICB funding while 21% expect their funding to decrease, and 12% anticipate no change.[iii] All of this reinforces concerns that this downward trajectory will continue unless decisive action is taken.

[iii] Calculated as a percentage of all hospices expecting to provide care to seriously ill children in 2026/27. 10 children's hospices in England did not respond to the survey.

Continuing to vary significantly

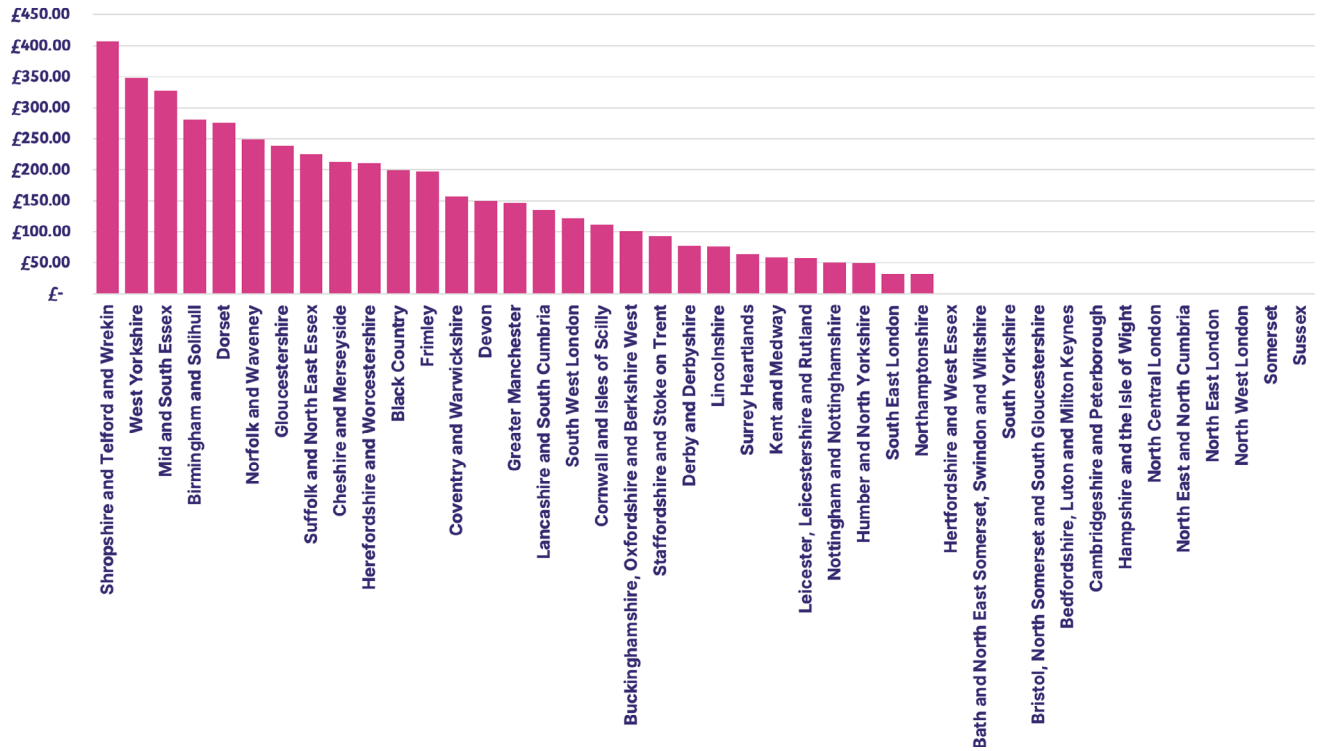
To better understand the current variation in local ICB funding, we issued a series of freedom of information (FOI) requests to all 36 ICBs in April 2026. In total, 32 ICBs responded.

For 2025/26 spending, figures were analysed on the basis of there being 42 ICBs, reflecting the structure in place during that financial year. Of these, usable spending data was obtained from 29 ICBs.[iv] Data from Hertfordshire and West Essex ICB was excluded due to being incomplete. In addition, local spending data for Bristol, North Somerset and South Gloucestershire ICB, Bath and North East Somerset, Swindon and Wiltshire ICB, and South Yorkshire was excluded due to concerns that it included funding from the £26 million NHS England allocation.

Where ICBs reported on a financial year running from 1 April 2025 to 31 March 2026, these responses were included in the analysis.

Overall, we have found that in 2025/26, ICBs spent an average of £161.75 per child or young person with a life-shortening condition, life-threatening condition or severe medical complexity. This average spend represents an 4.3% increase from the £155.12 spent in 2024/25.vv
While this increase is encouraging and aligns with what children's hospices have reported, significant regional variation is persisting. This year, we have found ICB spending to vary by as much as £375.04 per child or young person.

2025/26 total spend per child or young person by ICB on children's hospice care



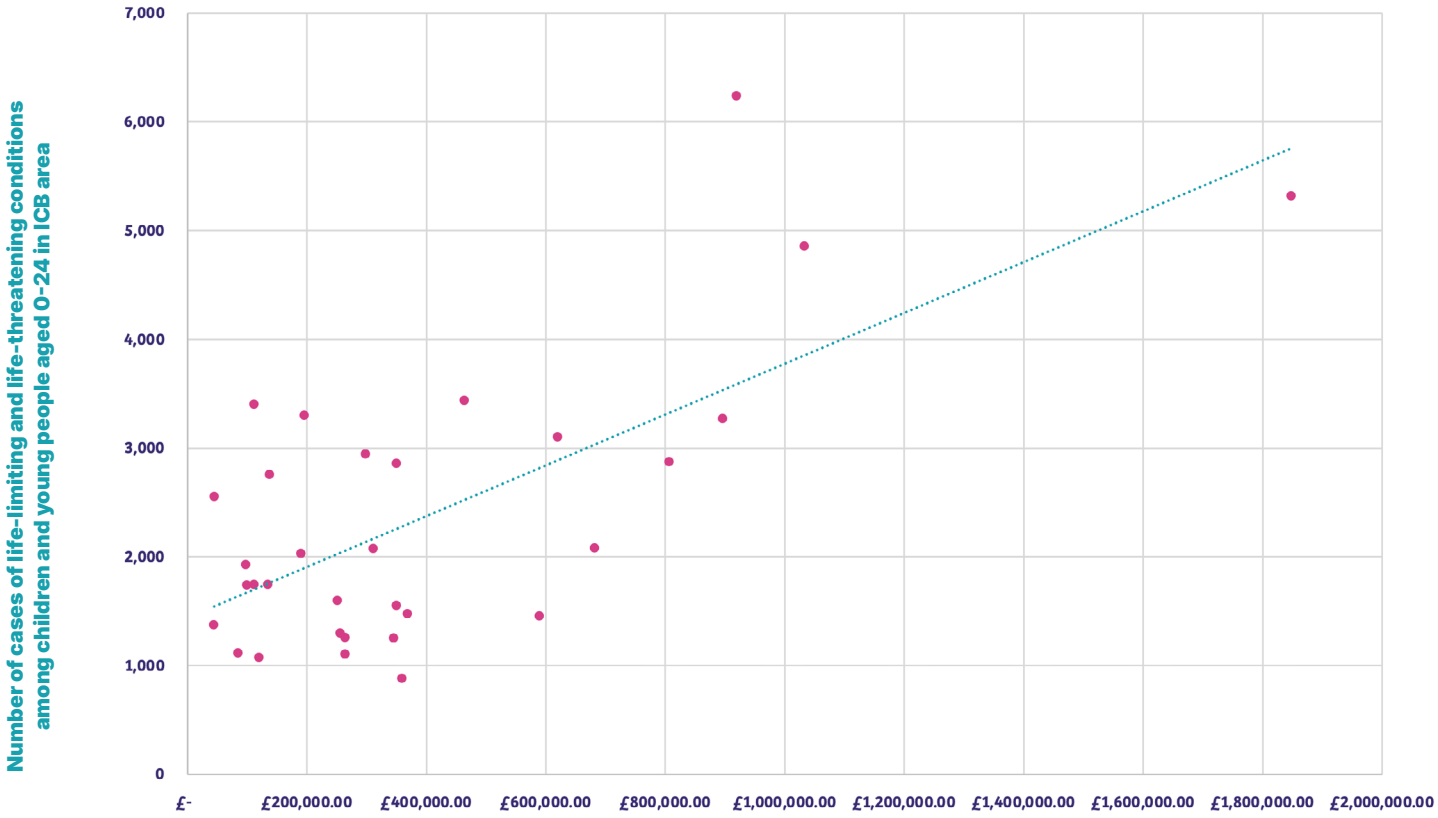
[iv] When responding to our FOI request, Surrey and Sussex ICB could only provide data for 2025/26 covering the former Surrey Heartlands ICB area. Equally, North East and North Cumbria ICB and North East London ICB both responded but stated they were unable to provide the information requested.

While Shropshire, Telford and Wrekin ICB spent the most with an average of £407.20 per child or young person, Northamptonshire ICB spent the least with an average of £32.16.

It is important to note that not all ICBs responded to the request, meaning a more complete dataset could have influenced the overall average. Variations in spending may also reflect differences in local need and service configuration. At any given time, many children with life-shortening and life-threatening conditions are relatively stable and may not require active hospice care. As a result, the level of funding an ICB allocates to a children's hospice will depend not only on need, but also on how local children's palliative care services are structured across hospital, community, and hospice settings.

Nevertheless, the scale of the variation observed cannot be fully explained by these factors. The wide disparities in spending point to inconsistencies in how ICBs are interpreting and fulfilling their statutory responsibility to commission palliative care in line with local need.

2025/26 total spending by ICB on children's hospice care per number of cases of life-limiting and life-threatening conditions among children and young people aged 0-24 in ICB area



A lack of local data held by ICBs

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

Of the 32 ICBs that responded, we have found that only 28% (9 ICBs) were able to

provide figures on the number of children and young people who had accessed hospice care in 2025/26. Where data was available, the average number was 188 children and young people per ICB.

Similarly, only five ICBs (16%) 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. 84% (27 ICBs) stated that they do not hold this data.

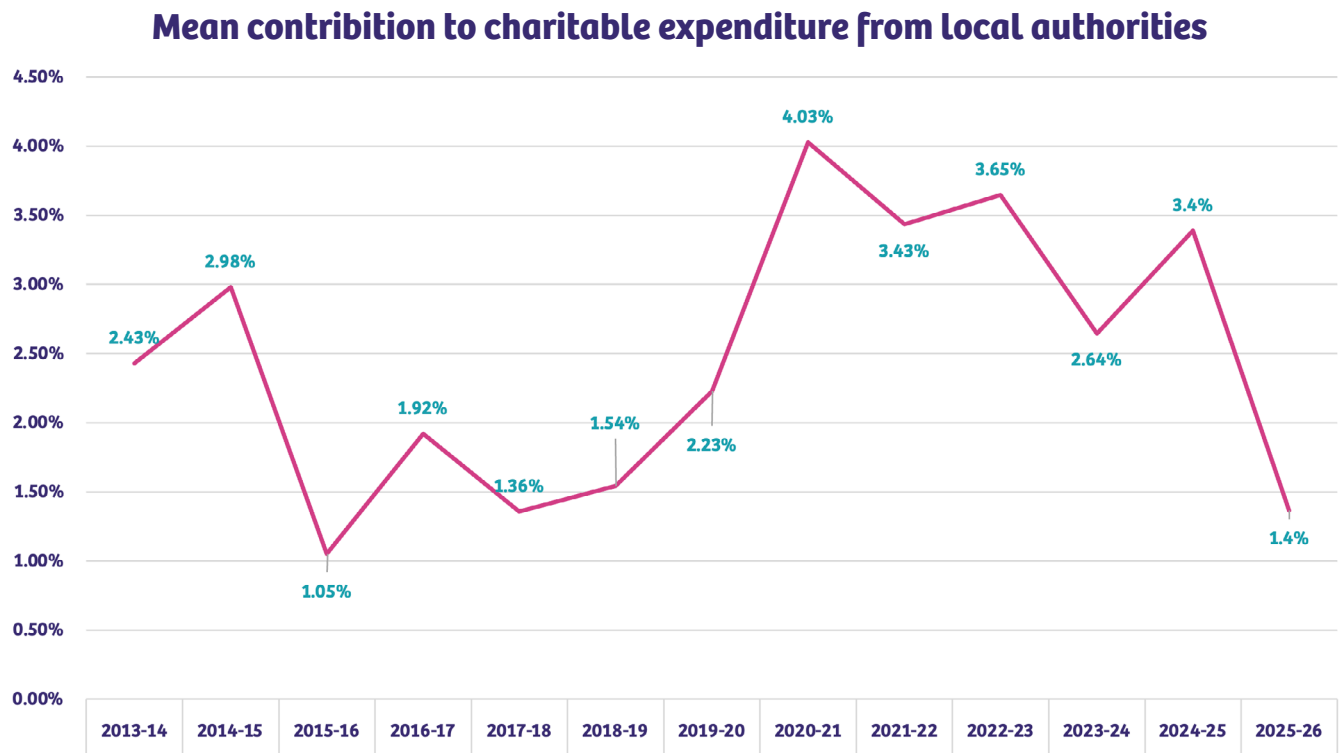
This lack of data is particularly concerning given the legal requirement for ICBs to commission services that meet the 'reasonable requirements' of their local populations. Without accurate information on the size and needs of the population, we question how ICBs can plan effectively and make fair funding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

Unfortunately, this appears to be a persistent issue. Last year, our FOIs found that only 32% of ICBs could provide data on the number of children and young people who had accessed hospice care in 2024/25. It is therefore concerning to see little improvement here.

Funding from local authorities

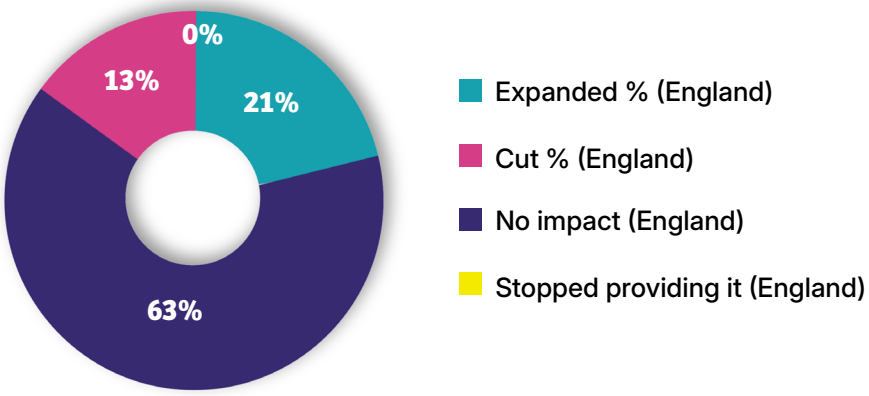
Children's hospices in England also receive funding from local authorities to help deliver respite care and other vital services. In fact, local authorities have a statutory duty under the Children Act 1989 to provide services to assist family carers of disabled children—specifically by giving them breaks from caring.

In practice, however, the level of funding provided suggests that this duty is not being consistently met. Through our survey, we have found that in 2025/26, children's hospices received an average of £77,641.88 from local authorities, representing a sharp decrease of 52.5% from £163,298.12 in 2024/25. As a result of this sharp decline, the proportion of children's hospices' charitable expenditure covered by local authority funding has also fallen from 3.4% to 1.4%.



At the same time, due to funding changes over the past year, nearly two fifths (38%) of children's hospices in England have reporting cutting their respite or short breaks offer, indicating a possible impact of the declining local authority funding.

Impact that changes in funding between 2024/25 and 2025/26 have had on respite or short breaks provided by children's hospices in England



For thousands of families of children with serious illness, respite care is a lifeline that helps to reduce emotional exhaustion and prevent mental health problems.[12] 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.[13]

The reduction in funding is therefore deeply concerning and risks exacerbating existing inequalities. It is essential that local authorities fulfil their statutory responsibilities and commission sufficient, high-quality care to meet families' needs.

At a provider level, we have found the funding hospices receive from local authorities continues to vary significantly. In 2025/26, over half (58%) of the children's hospices that responded to our survey did not receive any funding from their local authority. 96% reported receiving less than 10% of their charitable expenditure and 92% received less than 5%. Among those that did, the amounts received ranged from a little as £3,100.00 to as much as £864,252.00.

> "We receive no funding from local authorities."
> **Bluebell Wood Children's Hospice**

> "We do not receive any money from the local authority, even where there are circumstances where the responsibility would ordinarily fall on the local authority – such as providing housing when a renovation is being done on a child's residential property."
> **Helen and Douglas House**

> "Funding from the ICB for short breaks ceased from 01/04/2025 with a view this is the local authorities' responsibility. These local authorities have not provided any funding for short breaks and the local authority who we had an agreement with has significantly reduced the number of children and young people that they will fund short breaks for."
> **Keech Hospice Care**

Looking ahead, local authority funding is projected to increase by 18.7% to an average of £92,183.25 in 2026/27. While this seems encouraging, we estimate that the proportion of charitable expenditure covered by local authority funding in 2026/27 will only reach 1.5%, which remains well below historic levels. Moreover, only 15% of hospices expect an increase in funding, while 56% anticipate funding will either fall or remain unchanged.

A more consistent and reliable approach to local authority commissioning is therefore essential to ensure families can access respite care and support when they need it most.

Statutory funding for children's hospices in Northern Ireland

In Northern Ireland, statutory funding for children's hospice care is provided through Health and Social Care Trusts and remains a critical component of the overall funding model.

In 2025/26, the Northern Ireland Children's Hospice (the only children's hospice in Northern Ireland) received £2.19 million in total statutory funding (including £0.279 million in non-recurrent funding), representing a 14% increase from the £1.92 million received in 2024/25 (which included £0.1 million in non-recurrent funding). However, when non-recurrent funding is excluded, the recurrent uplift falls to just 4.9%, which has not kept pace with the rising costs of delivering increasingly complex palliative and end of life care.

Over the same period, the children's hospice's charitable expenditure has grown significantly, rising by 12.2% from £4.59 million in 2024/25 to £5.15 million in 2025/26. As a result, the proportion of charitable expenditure covered by recurrent statutory funding has fallen from 41.8% to 37%, highlighting a widening gap between income and costs.
This imbalance has placed further financial pressure on the hospice in 2025/26.

Despite these pressures, the hospice has avoided cutting or stopping any services. However, this has only been possible by utilising financial reserves and by implementing cost-saving measures, including the reduction or freezing of pay for non-care staff. Neither of which is sustainable in the long term.

Looking ahead, these financial challenges are expected to continue with charitable expenditure forecast to rise by a further 4.8% in 2026/27, to a total of £5.4 million. As a result, the hospice is again predicting to finish the forthcoming financial year with an operating deficit.

In recognition of these mounting pressures, in May 2026, the Department of Health announced a one-off emergency support package, which includes £500,000 for the children's hospice.[14] With this additional funding, total recurrent statutory funding is expected to rise to £2.47 million in 2026/27, covering approximately 45.7% of the hospice's charitable expenditure.

However, while this support is deeply welcome, it does not provide a long-term solution. As a one-off intervention, it falls short of providing the certainty and stability required for effective service planning. As such, there is still an urgent need for a more sustainable funding settlement that covers at least 50% of charitable expenditure on a recurring basis and is indexed to Agenda for Change uplifts, ensuring that funding keeps pace with rising workforce costs.

> "Ideally we need a palliative care strategy in Northern Ireland that provides multi-year contracts to allow strategic planning, fair 50:50 funding that is index linked to Agenda for Change uplifts and a mechanism for over delivery on the contract service KPIs."
> **Northern Ireland Children's Hospice**

Without decisive and sustained action, the financial position of the hospice is likely to deteriorate further, potentially forcing difficult decisions about staffing and service provision.

Statutory funding for children's hospices in Scotland

Children's Hospices Across Scotland (CHAS) is the sole specialist provider of hospice services for babies, children and young people aged 0–21, and their families, in Scotland working across hospices, homes and hospitals. This gives families choice about the care and support they receive, wherever they live.

With the continued backing of the Scottish Government, COSLA, and the generosity of the public, all care is provided free at the point of need.

Thanks to medical advancements, many children are living into adulthood, but with multiple, serious health conditions requiring more specialist, flexible support across hospital, hospice and home settings.

At the same time, the cost of providing this care is rising and is expected to increase further driven primarily by workforce costs, which account for around three-quarters of overall spending.

While statutory funding remains a vital component of the funding model, it has not kept pace with these pressures. In 2025-26, CHAS received £9.6 million in core Scottish Government funding, alongside additional contributions for pay parity for hospice staff aligned to NHS Agenda for Change. This funding is welcome and continues to support delivery of CHAS' services but only covers around one third of total expenditure.

As a result, CHAS remains heavily reliant on fundraised income (donations and legacies), which covered over 50% of CHAS' total costs. This reliance is unstainable and creates ongoing uncertainty in an increasingly challenging fiscal environment.

Volunteers have continued to make a significant contribution to the sustainability of services, providing both practical and emotional support to children and families. The social value of volunteering at CHAS is estimated to exceed £1 million each year, representing a vital and often overlooked contribution to the overall delivery of care.

The new Scottish parliamentary term (2026-2031) is an opportunity for Scottish Government take a sustainable approach to funding children's hospice care. As policymakers focus on public service reform, prevention and community-based care, there is strong alignment with the role CHAS plays in supporting families at home and reducing pressure on acute services.

To ensure CHAS' unique contribution to Scotland's health and care system is future-proofed, CHAS is calling for statutory funding to cover at least 50% of agreed costs, including inflationary pressures and workforce costs.

Moving towards this model would provide a more stable and proportionate funding framework, reduce reliance on fundraised income, and better align investment with the scale and system value of children's hospice care in Scotland to guarantee equitable access to world-class children's palliative care for all who need it.

Statutory funding for children's hospices in Wales

In Wales, the two children's hospices, Tŷ Hafan and Tŷ Gobaith, provide vital care and support to children and young people with life-shortening and life-threatening conditions, as well as those with severe medical complexity.

Despite their importance, both hospices continue to face significant and persistent financial pressures. In 2025/26, statutory funding covered approximately 25% of their care costs. However, this level of support did not reflect a stable or planned funding settlement. Instead, it was the result of a one-off, in-year allocation of £4.3 million for both adult and children's hospices, announced late in the financial year by the Welsh Government.[15]

Unfortunately, this approach appears to be part of an ongoing trend in Wales. While additional funding is often made available to close the gap, it is typically confirmed too late and on a non-recurrent basis. As a result, hospices are unable to plan services, invest in their workforce, or respond effectively to rising demand, increasing prevalence, and the growing complexity of children's care needs.[16]

This pattern has been particularly consistent in recent years. For example, in 2024/25, an additional £5.5 million was allocated to the 12 commissioned hospices across Wales, again late in the financial year and on a non-recurrent basis. While this brought statutory funding for Tŷ Hafan and Tŷ Gobaith up to around 25% of care costs, it left both organisations entering 2025/26 without clarity or stability.

Similarly, in 2023/24, the Welsh Government provided an additional £770,000 to the two children's hospices as part of its end of life care review.[18] However, yet again, this was a one-off payment that came too late in the financial year to allow for effective long-term planning.

> "It is disjointed. No funding from local authorities and lots of different NHS pots. A big proportion of our funding in 24/25 and 25/26 came as an unplanned lump sum at the end of the year."
> **Tŷ Hafan Children's Hospice**

Looking ahead to 2026/27, the position is particularly concerning. The two children's hospices are currently guaranteed only around 12% of their total care costs from statutory sources, with 67% provided by the Welsh Government and 33% by local health boards. Without further in-year intervention, this represents a significant shortfall and reinforces the instability of the current model.

Taken together, this evidence highlights an urgent need for reform. The two hospices urgently need a sustainable funding model that moves beyond the current reliance on late, one-off allocations and instead provides multi-year certainty. This would enable children's hospices to plan effectively, invest in their staff and infrastructure, and meet growing demand with confidence.

Specifically, by 2030, statutory funding in Wales should increase to at least 30% of care costs, delivered through a predictable, multi-year settlement. This would provide the stability required to support long-term planning and ensure that children and families continue to receive high-quality, equitable care.

Ayla's story

Caroline Johnstone lives in Sauchie, Clackmannanshire in Scotland with her daughter Ayla (pronounced Isla), who suffers from Edwards' Syndrome, a rare genetic condition otherwise known as trisomy 18.

In addition, Ayla suffers from seizures, skeletal issues, gastrointestinal problems, cognitive delay and breathing problems due to congenital lung abnormalities.

Ayla has been supported by CHAS since she was born in 2011. Children with Edwards' Syndrome usually die before or shortly after birth, with very few reaching their first birthday.

This means Ayla, now 15, is something of a medical miracle, with Caroline and Ayla's dad Kerem counting every single day of their little girl's life as a milestone.

Caroline says she knows that any time she needs CHAS "they are just a phone call away and I can access vital clinical advice any time, night or day."

"I've phoned at midnight and during the day and they're always there. If I'm lying awake during the night worrying about something to do with Ayla and need to chat to someone, I know I can phone CHAS.

"That truly is a lifeline as Ayla suffers from breathing difficulties and has a weakened immune system. When she gets a cold she can become seriously ill".

Caroline and Kerem credit their daughter continuing to thrive thanks to the team at Rachel House in Kinross, where Ayla went for respite two nights every month after her birth. Nowadays she now goes for respite for three to four nights every three months.

Ayla has formed extremely close attachments with the nurses and staff there and loves taking part in arts and crafts sessions offered by the activities team.

"She also absolutely loves the sensory room and going out for walks around the beautiful grounds there and also going in the Jacuzzi. Ayla is quite sassy and loves a bit of nonsense but is also really tactile and affectionate and the staff all know her personality so well. She generally just loves all the attention, enjoying nothing better than sitting on your knee, being read a story.

"It's not just medical advice I get from CHAS – the emotional support I receive is invaluable. I have made so many friends and confidantes there over the years and truly cherish those relationships."

Income and expenditure of children's hospices across the UK

As part of our survey, we also gathered detailed information on the income that children's hospice organisations across the UK received from non-statutory sources in 2025/26, what they expect to receive in 2026/27 and how their expenditure is continuing to change.[v] This allowed us to generate a broader understanding of the financial pressures facing the sector, and the extent to which hospices are relying on reserves to mitigate deficits and sustain services.

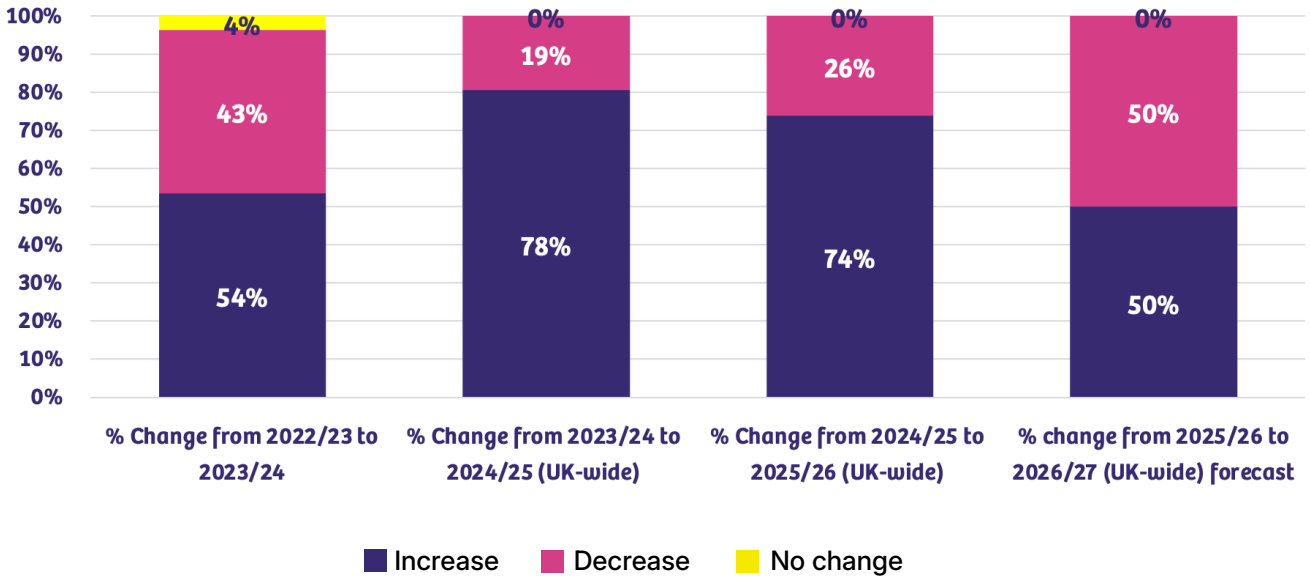
Income

In total, 24 children's hospices shared information on their total income for the 2025/26 financial year, as well as projections for 2026/27.[vi] On average, total income in 2025/26 received by children's hospices was £10,737,039.92, representing a 25% increase on the average income of £8,591,007 received in 2024/25.[19]

Despite this overall growth, the income received at an individual hospice level remains uneven across the country. In 2025/26, just under three quarters (74%) of hospices that responded to our survey saw their income increase, while 26% witnessed a decrease. We excluded one children's hospice from this comparison due to incomplete income data for 2024/25.

Looking ahead, income growth is expected to stagnate. For 2026/27, we have estimated that average income will increase by just 0.1% to £10,745,339.25. At the same time, variation between children's hospices is expected to persist, with 50% anticipating increases in income and the other 50% expecting a decline.

Change in children's hospices' income 2022-2027



[v] UK-wide data is based on responses received from children's hospice organisations in England, Northern Ireland, Scotland and Wales.

[vi] Due to providing services for adults as well as children, some hospices were not able to separate their income for children and adults' services. Where this was the case, responses were omitted to ensure our analysis was representative of children's hospice services alone.

Income by source

Through our survey, we have also examined the different sources of income to identify where noticeable increases and decreases have occurred and to assess what is expected to happen in 2026/27.[vii]

• **Donations and legacies:** In 2025/26, donations and legacies remained a large source of income, averaging £4,888,525.83 per hospice. Encouragingly, 67% of children's hospices reported an increase in this income stream over the past year, while a third (33%) saw a decline.

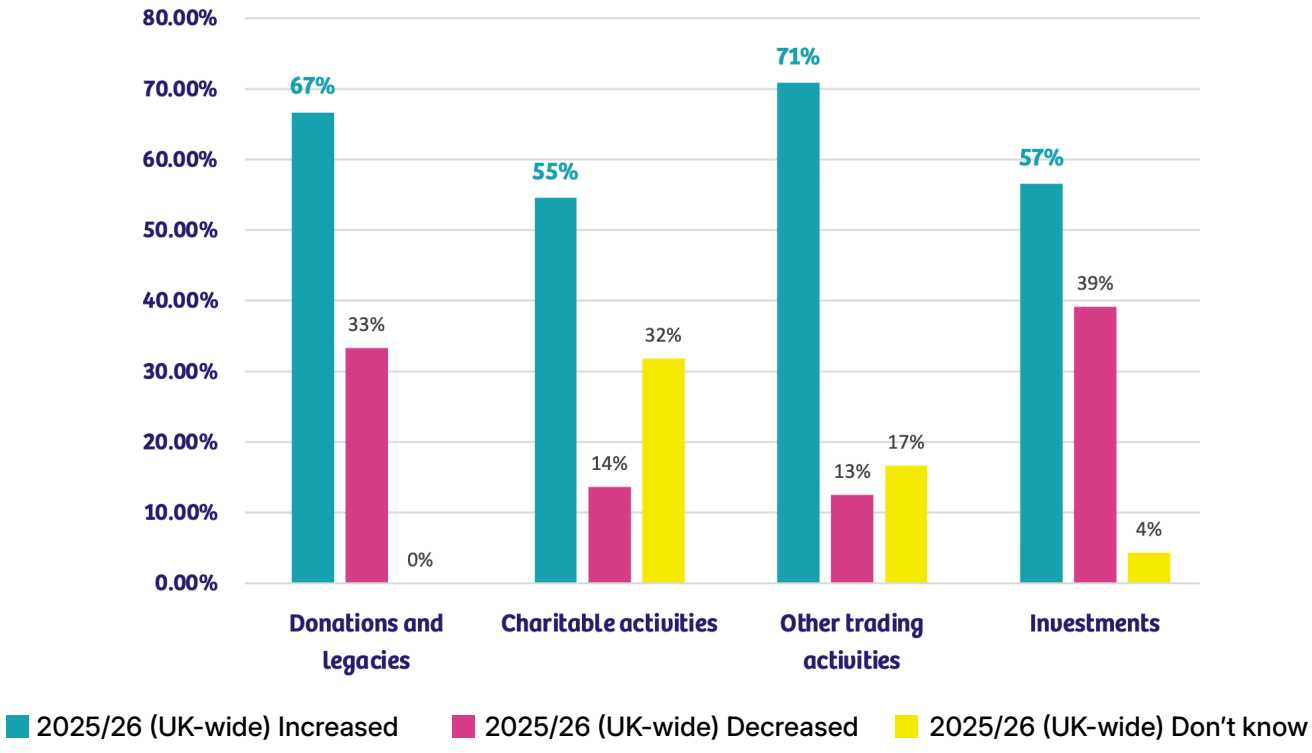
• **Charitable activities:** An average of £1,195,837.80 was received from charitable activities in 2025/26. For 55% of children's hospices, this source of income has grown since 2024/25, while 14% noted a decrease and 32% were unsure.

• **Other trading activities:** In 2025/26, income from trading activities (including retail) averaged £2,852,364.04 per hospice. This was one of the strongest performing income streams, with 71% of hospices reporting growth, although 13% experienced a fall and 17% were unsure.

• **Investments:** Investment income was comparatively modest in 2025/26, averaging £306,035.17. While 57% of hospices saw an increase, a substantial 39% reported a decline.

> "An increase in donations and legacies has enabled us to maintain our services at a time when costs are continually increasing."
> **Claire House Children's Hospice**

Change in children's hospices' average income by source in 2025/26



[vii] While 24 children's hospices across the UK provided data on their total income and income streams, only 20 provided information on income from charitable activities.

Looking ahead, we have found that children's hospices anticipate a mixed picture across income streams in 2026/27, with several key sources expected to come under pressure.

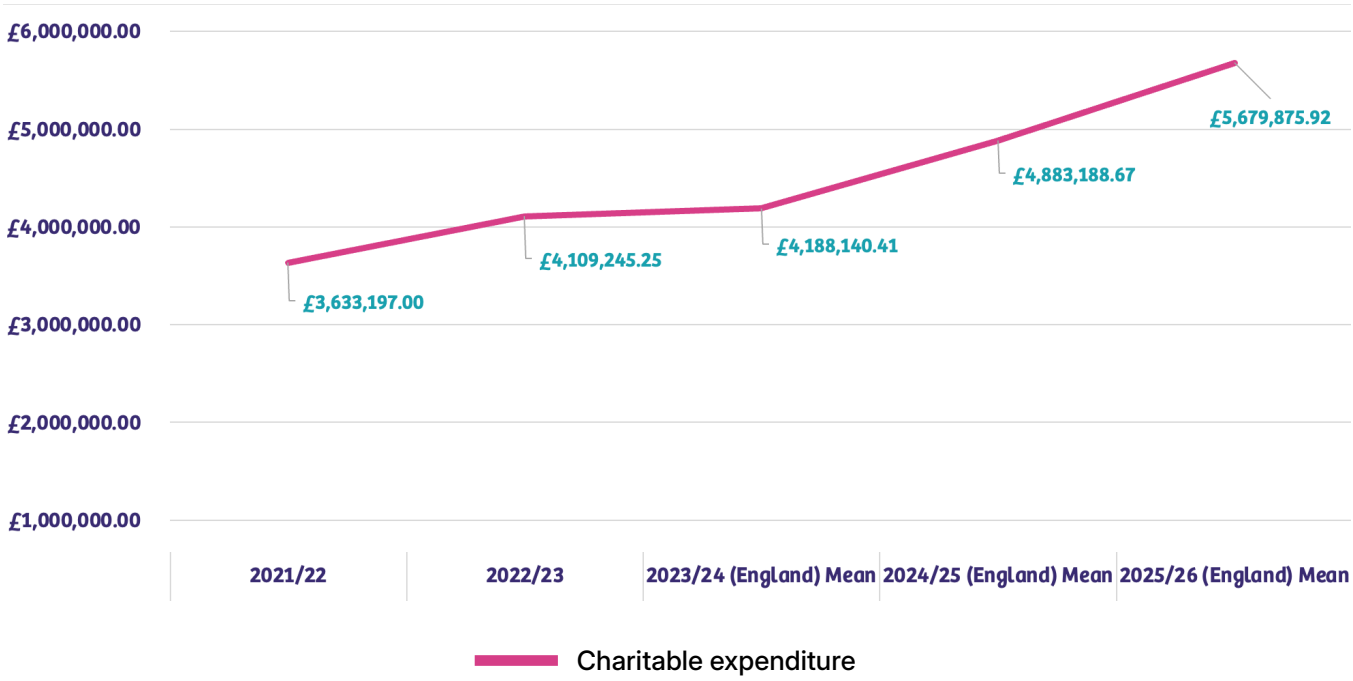
- Donations and legacies are forecast to fall by 1.5% to an average of £4,817,042.96.
- Income from charitable activities is expected to fall by 12.5% to an average of £1,046,514.25.
- Income from other trading activities is expected to grow by 12.9% reaching an average of £3,219,281.08.
- Investment income is forecast to decrease significantly by 22.7% to £236,463.54.

Charitable expenditure

A total of 27 children's hospice organisations provided data on their charitable expenditure, including 24 based in England. All in all, the figures provided this year highlight the scale of the cost pressures facing the sector and how they are continuing to intensify.

Over the past year, average charitable expenditure across children's hospices has increased by 18%, rising from £5,314,246.12 in 2024/25 to £6,270,159.63 in 2025/26.[viii] This contributes further to the clear upward trend that has been observed in recent years. In England in particular, charitable expenditure has risen sharply since 2021/22, by 56.3%, from £3,633,197.00 to £5,679,875.92.

Mean charitable expenditure by children's hospices in England 2021/22-2025/26

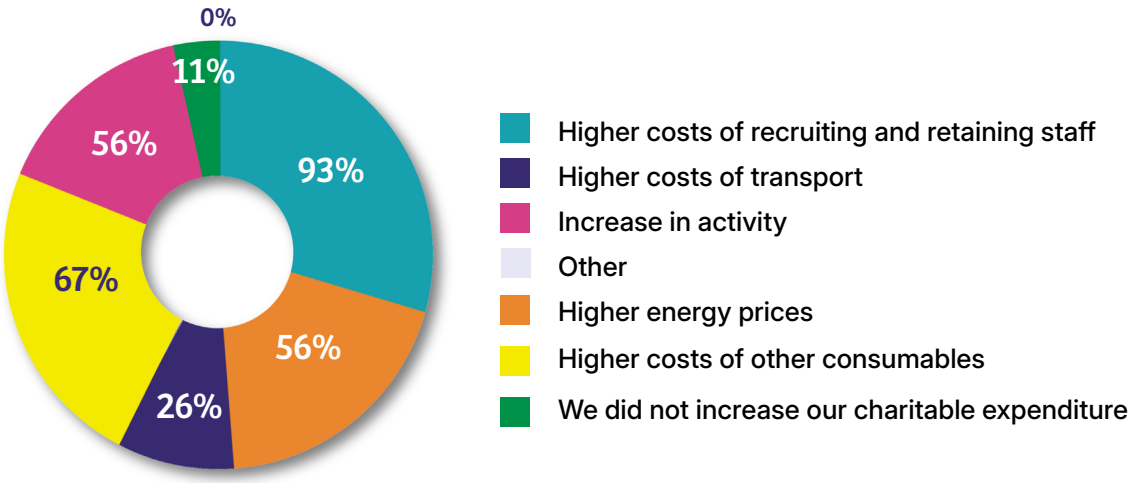


[viii] For children's hospices in England, charitable expenditure increased by 16.3% from an average of £4,883,188.92 in 2024/25 to £5,679,875.92 in 2025/26.

There are several factors driving this increase in expenditure. Specifically, a significant number of children's hospices (67%) have attributed rising costs to a higher cost of consumables. Meanwhile, over half (56%) have cited higher energy prices and increased activity levels as key factors.

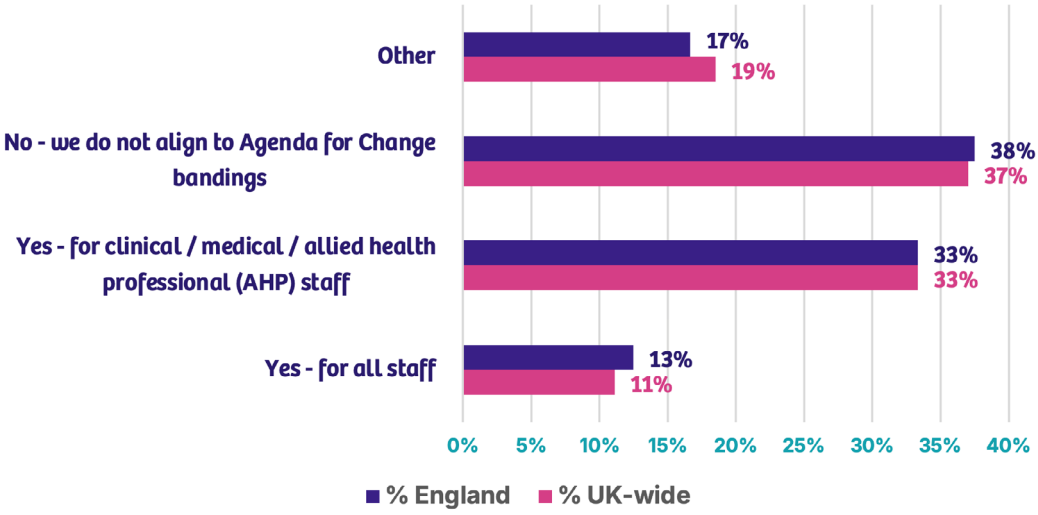
However, workforce pressures remain the most significant driver, with 93% of hospices identifying the cost of recruiting and retaining skilled staff as a key factor behind rising expenditure.

If your charitable expenditure increased between 2024/25 and 2025/26, please tell us why that was



Across the UK, children's hospices operate in direct competition with the NHS for clinical staff. As such, through our survey, we have found a substantial proportion of hospices now align their pay with NHS Agenda for Change (AfC) pay scales. While 33% of children's hospices align to AfC bandings for clinical, medical and allied health professionals, a further 11% align to it for all staff.

Does your organisation align its pay structures with Agenda for Change (AfC) bandings?



This alignment reflects the ambition to remain competitive with NHS salaries, but it also places considerable strain on hospice finances. As 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, the pressures from rising expenditure show no signs of easing. Children's hospices expect their charitable expenditure to rise by a further 6.8% in 2026/27, reaching an average of £6,699,319.93. For hospices in England, charitable expenditure is projected to increase by 7.7% to £6,116,146.

We believe this continued growth is likely to be driven in large part by ongoing workforce cost pressures. The NHS pay award for 2026/27 includes a 3.3% increase for Agenda for Change staff, bringing the entry-level Band 5 salary to £32,073 – more than £7,000 higher than four years ago.[20]

Without additional support, children's hospices will therefore find it increasingly difficult to remain competitive in the labour market.

Total expenditure

Overall, 26 children's hospice organisations provided data on their total expenditure in 2025/26 and their projected expenditure in 2026/27.[ix]

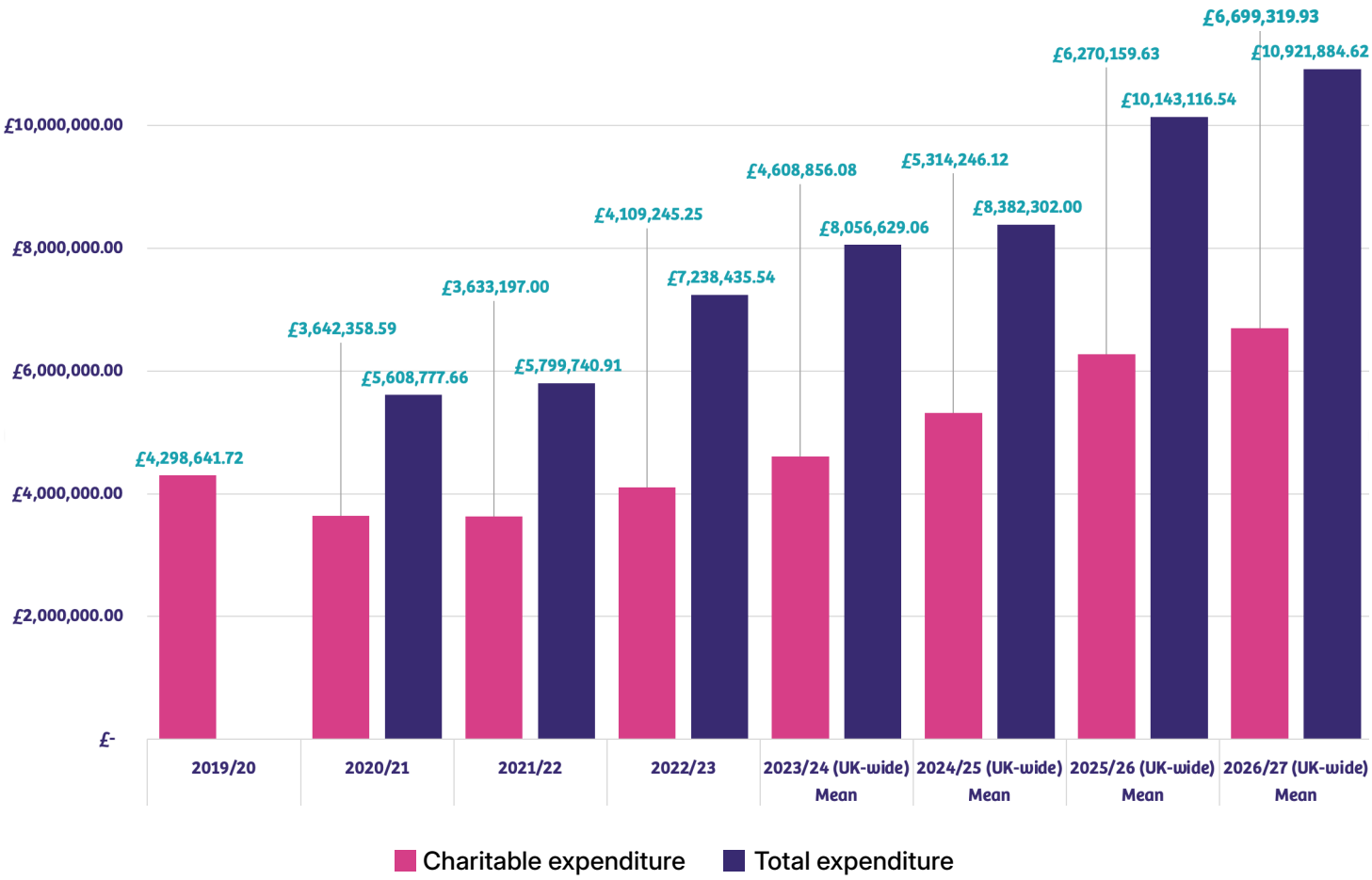
In 2025/26, average total expenditure, which includes both charitable spending and fundraising costs, rose by 21%, increasing from £8,382,302.00 in 2024/25 to £10,143,116.54 in 2025/26. This represents a significant acceleration compared to the previous year, when total expenditure increased by just 4% on average.

We believe that a key factor behind this sharp rise is likely to be increased capital spending, supported by the £125 million of capital funding provided by the UK Government to adult and children's hospices in England.[21] While this investment has enabled hospices to enhance their facilities and infrastructure, it has also contributed to higher overall expenditure in the short term.

Looking ahead, with no further capital funding confirmed, the rate of growth in total expenditure is expected to slow to 7.7% in 2026/27, reaching an average of £10,921,884.62 and bringing growth more in line with recent trends.

[ix] While 27 children's hospices originally told us about their total expenditure, one hospice's response was omitted from the analysis as it was not possible to separate expenditure relating specifically to children's services from their adult provision.

Mean charitable and total expenditure by children's hospices 2019-2027



Balance between total income and total expenditure

To assess the financial sustainability of the sector, we analysed the difference between total income and total expenditure for 25 children's hospices across the UK, including 22 hospices based in England.

Of those that responded and were subsequently included in the analysis, we have found that the majority of children's hospices experienced an operating deficit in 2025/26. While two fifths (40%) ended the financial year with a net surplus, nearly two thirds (60%) reported their expenditure to be outstripping income resulting in an operating deficit.[x]

When calculated as a percentage of all 38 children's hospices that provided care in 2025/26, the picture remains particularly concerning. Just over a quarter (26%) of hospices recorded a net surplus, down from 33% in 2024/25. At the same time, two fifths (39%) reported an operating deficit.

Although this represents a slight reduction from 49% in the previous year, the proportion of hospices not captured in the dataset has increased to 34%, which may in part explain this apparent improvement. These hospices either did not respond to the survey or were unable to provide the income and/or expenditure data required for this calculation.

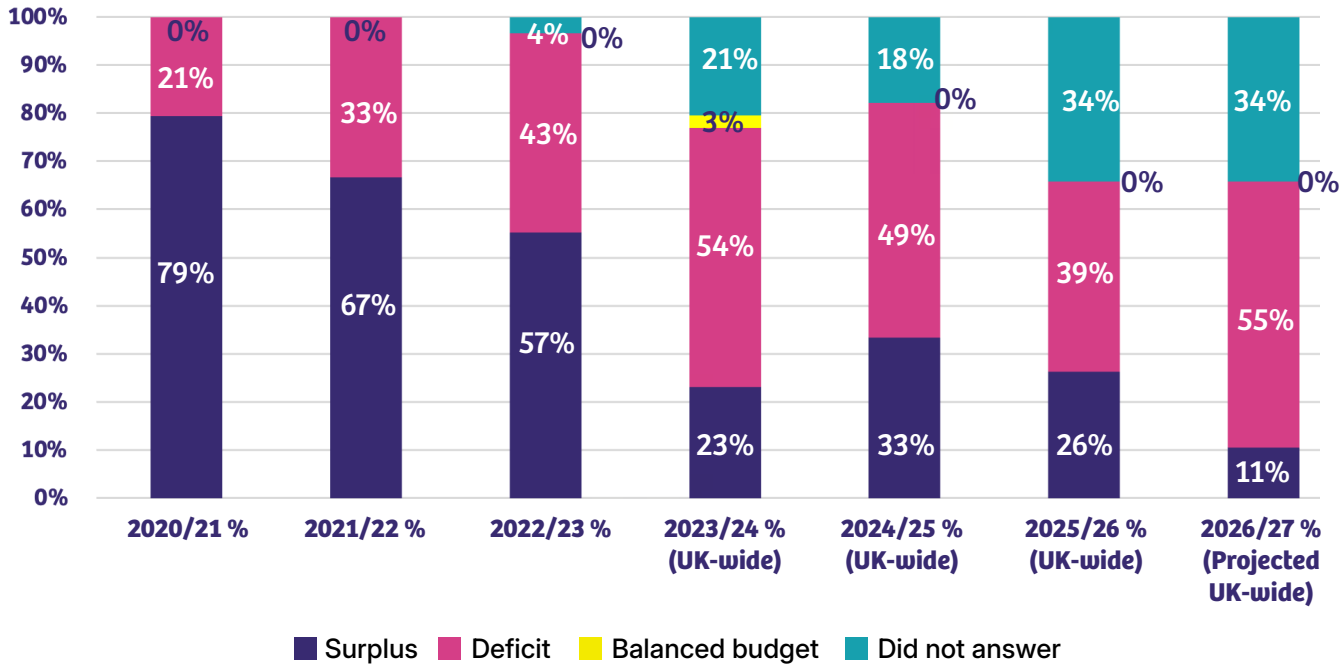
[x] In England, 59% of the children's hospices that responded to our survey ended the 2025/26 financial year with an operating deficit, while just 41% experienced a surplus.

Taking all reported surpluses and deficits into account, we have calculated the average operating deficit in 2025/26 to be £115,937.48. When extrapolated across all 38 children's hospices, this equates to a total sector-wide shortfall of £4,405,624.24. Both figures represent a sharp deterioration compared to 2024/25, when the average deficit was £24,172.66 and the total shortfall was £942,733.59.

Looking ahead, the financial outlook worsens significantly. Among hospices that responded to the survey, 84% expect to operate at a deficit in 2026/27, with only 16% anticipating a surplus.[xi] When projected across all 38 hospices, over half (55%) are expected to face a deficit, while just 11% are forecast to achieve a surplus.

On average, we have estimated that children's hospices across the UK will have an operating deficit of £903,909.88 in 2026/27. Extrapolated across the UK, this would amount to a total shortfall of £34,348,575.44.

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



Impact of funding changes on services and children with serious illness

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 27 organisations across the UK responded, providing valuable insight into how hospices are adapting to growing financial pressures.

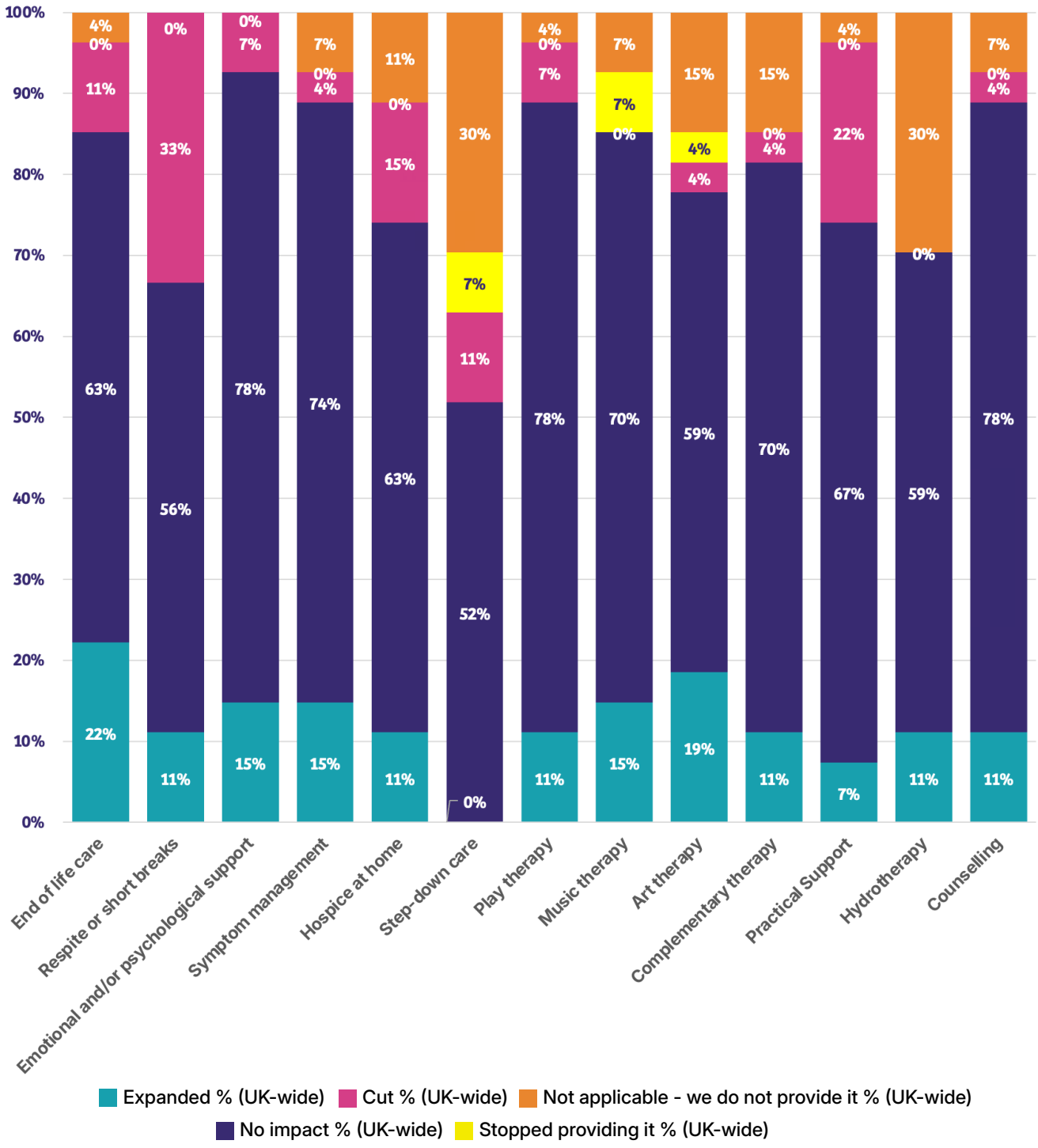
Encouragingly, across many areas of care and support, the majority of children's hospices reported that they have been able to maintain service levels. In particular, 63% of hospices

[xi] In England, 86% of children's hospices that responded to the survey forecast an operating deficit in 2026/27 while 14% expect a net surplus.

maintained end of life care at existing levels, while 78% sustained their provision of emotional and psychological support, and 74% maintained symptom management services.

However, despite this, not all hospices have been able to avoid reductions in care. According to survey responses, 11% of hospices have cut back on end of life care services, while one third (33%) have reduced the short breaks or respite care they provide. Similarly, despite the government's ambition to shift care closer to home, 15% of hospices reported cutting their hospice-at-home services.

Impact that changes in funding between 2024/25 and 2025/26 have had on the services provided by children's hospices (UK-wide)



"We have cut our community short breaks service - we no longer provide this."
Chestnut Tree House

Even where services have been maintained, this has often only been possible through short-term measures. For example, many children's hospices have reported drawing on financial reserves and increasing their reliance on charitable income to sustain current provision.

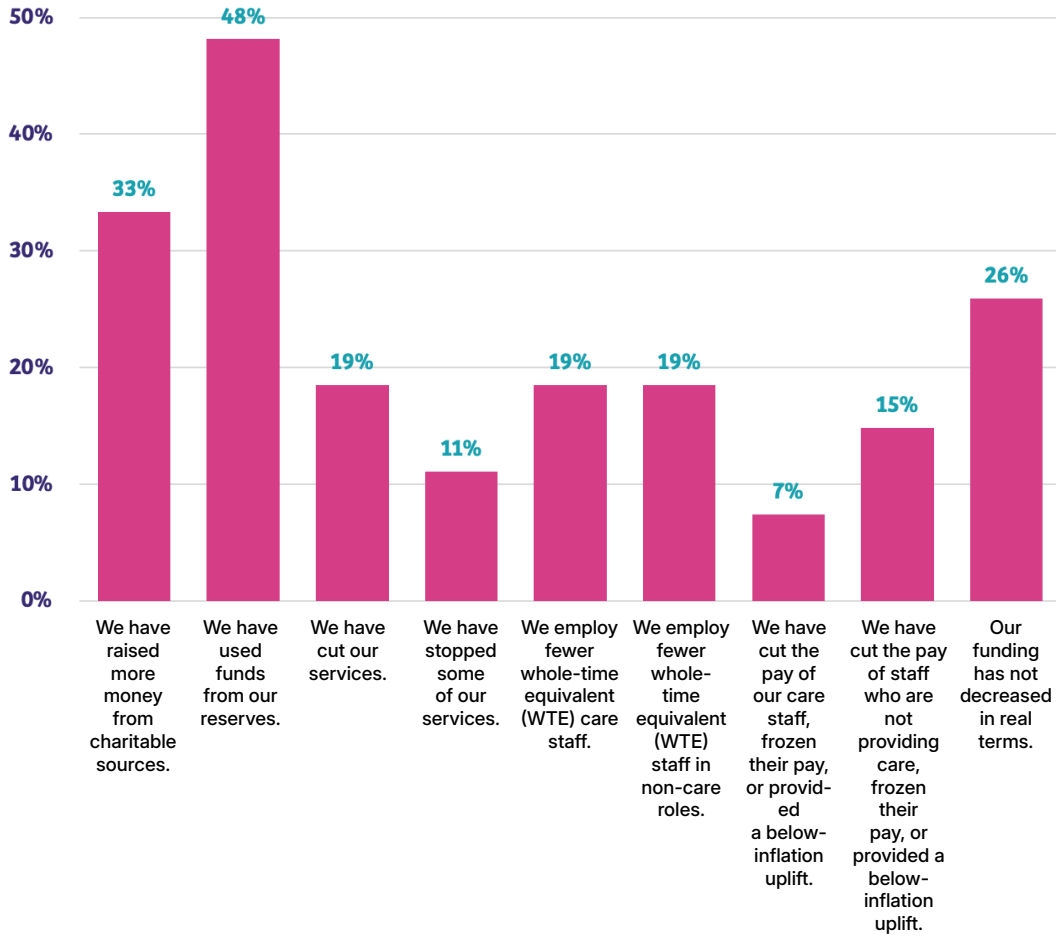
"We have used general reserves where there are funding gaps to ensure continuation of services."
St Oswald's Hospice

"The Trustees have taken the decision to use reserves again this financial year, but this is unsustainable."
Alexander Devine Children's Cancer Trust

Specifically, we have found that nearly half of hospices (48%) used their reserves to mitigate the impact of funding pressures, while 33% increased their fundraising efforts. At the same time, almost one in five (19%) reported cutting services or employing fewer staff as a direct response to the ongoing financial challenges.

"We are not able to expand services and reach all the children, young people and families who require our services, and without increased funding we must consider reduction in our clinical service spend."
Little Havens Children's Hospice

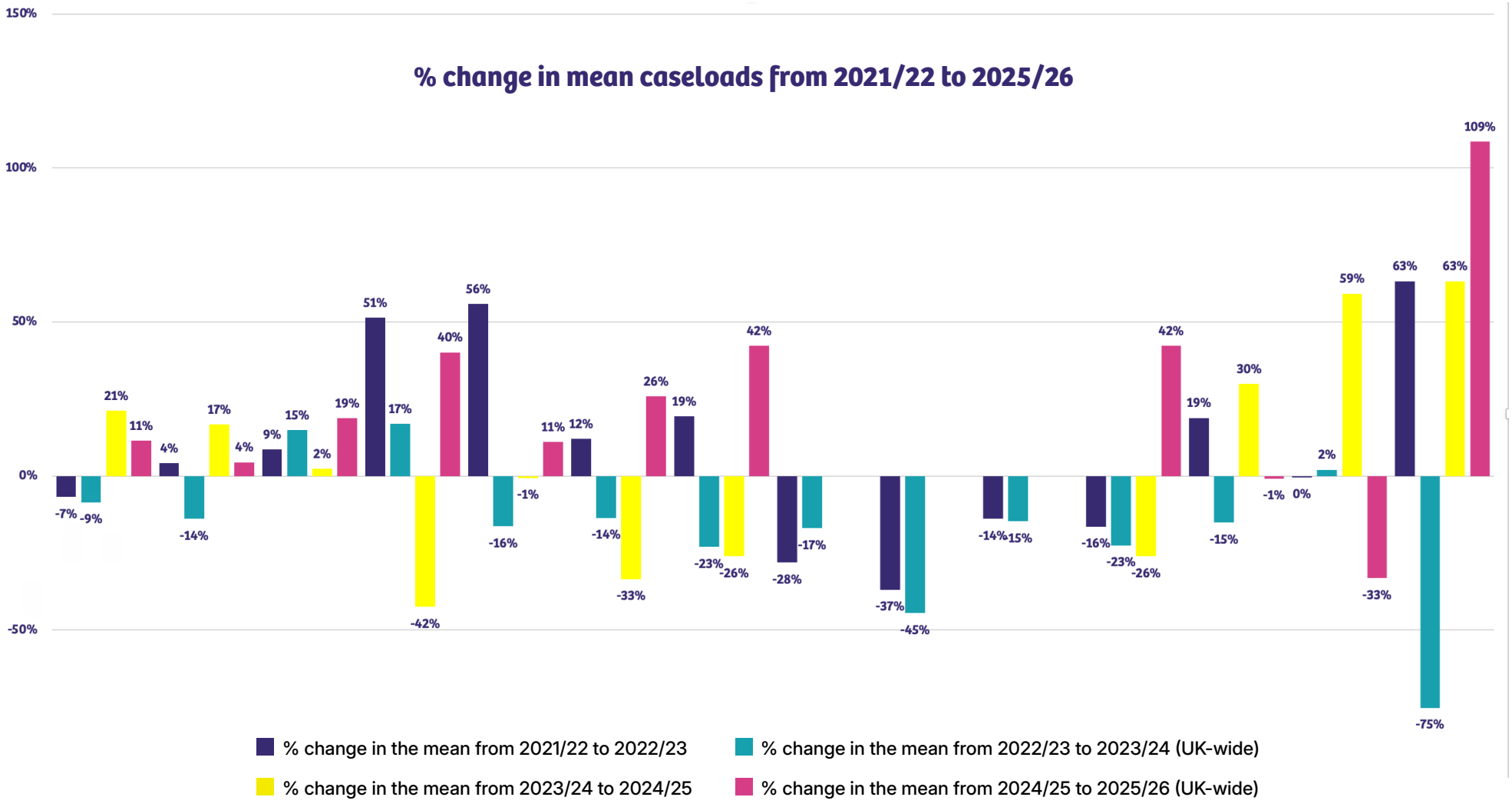
How children's hospices have mitigated the impact of funding changes on their services



Active caseloads

Through our survey, we have also found that children's hospices are providing more care than ever before, particularly by delivering more clinical support that might otherwise fall to the NHS.

In 2025/26, active caseloads of children's hospices across the UK increased by 11%, rising from an average of 301 children in 2024/25 to 336. This not only reflects the growing demand but also the expanding role that hospices are playing within the wider health and care system.



When asked about services that should be commissioned by the NHS and local authorities, hospices reported clear year-on-year increases across key areas of care.

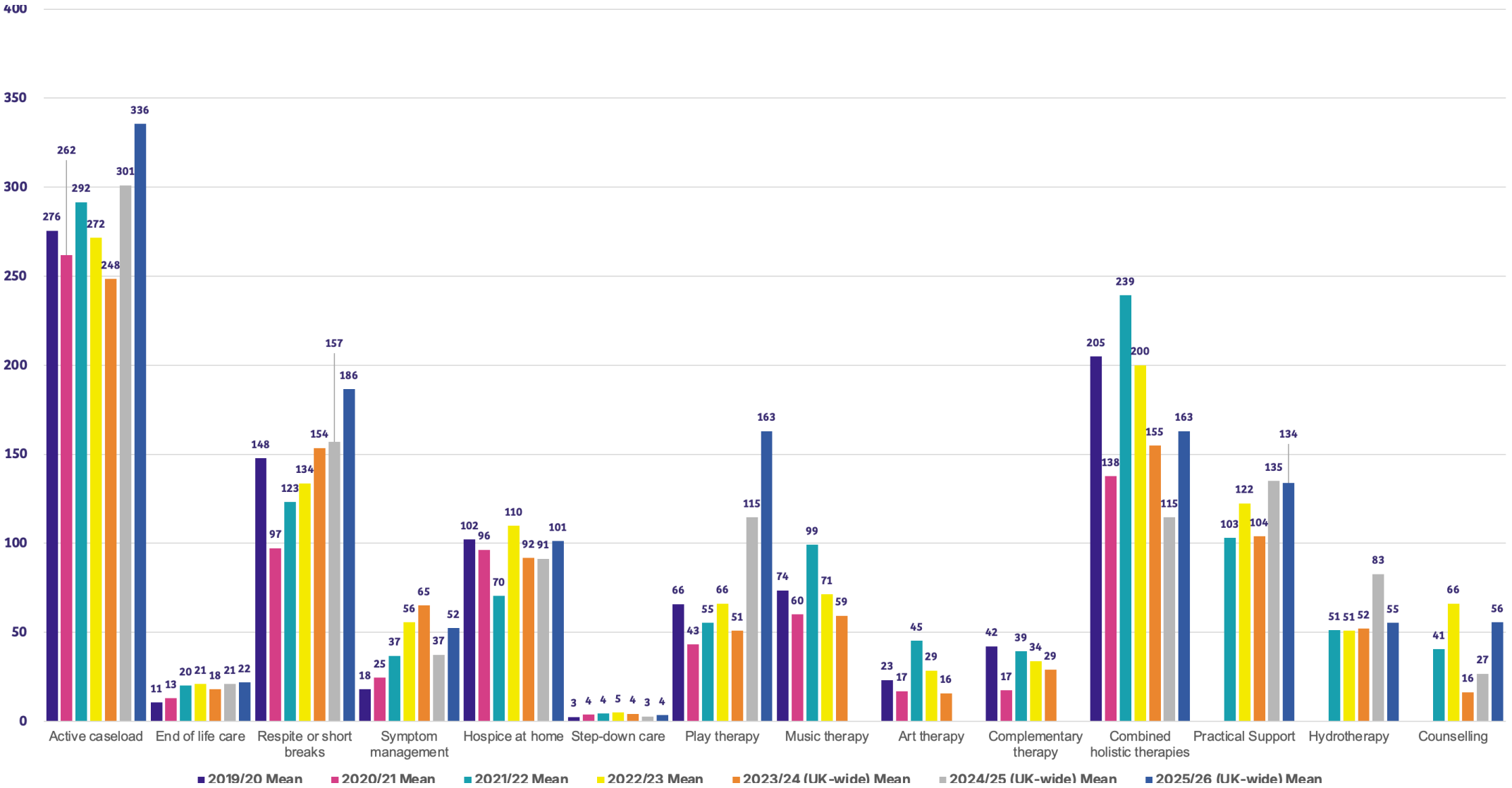
- **End of life care** was provided to 4% more children, rising from an average of 21 to 22.
- **Symptom management** support saw a sharp rise, increasing by 40% from 37 to 52 children.
- **Hospice at home** provision grew by 11%, from 91 to 101 children.

For the hospices able to maintain their respite offer, the number of children supported increased by 19%, rising from 157 to 186.

Looking at longer-term trends since 2019/20, the impact of children's hospices is even more striking with hospices drastically expanding the volume of care they provide. During this period, the number of children receiving symptom management support has increased by 192%, end of life care by 106%, and step-down care by 43%.

This sustained growth not only reflects the rising number of children and young people with serious illness, but it also illustrates the essential role that hospices play in relieving pressure on the NHS and wider health and care system by delivering specialist care in community and hospice settings. However, without fair and sustainable funding for the long term, this vital contribution is at risk.

Mean caseloads from 2019/20 to 2025/26



Policy recommendations

With children's hospices across the UK under increasing pressure, urgent action is needed from the UK's governments to ensure they can continue to provide lifeline care to children with serious illness and their families. To this end, we recommend the following actions to secure a sustainable future:

England

1. We support Hospice UK's four-point plan for fair hospice funding.[22] Specifically, we call on the UK Government to ensure that 100% of the costs incurred by children's hospices in providing clinical care, that would otherwise fall to the NHS, is covered by the state.

2. The government should commit to multi-year long-term NHS funding for the health elements of children's hospice and palliative care in England that fills the £310 million gap that we have identified to sustain lifeline services provided in hospitals, the community and in children's hospices by 2027/28.

3. This funding should be scaled-up alongside investment to increase the number of professionals with the skills and experience to meet the needs of seriously ill children.

4. DHSC should conduct its own modelling to determine how much local NHS bodies should spend on the health elements of children's hospice and palliative care—and then hold them to account for the extent to which they spend money for this purpose.

5. Through the upcoming Modern Service Framework, DHSC and NHS England should establish a national outcomes and assurance framework for children's palliative care commissioning, including measures relating to access to 24/7 support, place of death, advance care planning, symptom management, workforce capacity and family experience.

6. DHSC should make full use of new prevalence data and work with ICBs to strengthen their understanding of local need and demand for children's palliative care.

7. DHSC should work with children's hospice and palliative care services to bring about a consistent approach to collecting activity data to inform a sustainable funding approach which captures both the volume and complexity of the care they provide.

8. DHSC should examine whether children's palliative care would be more effectively commissioned at a national or regional level to create economies of scale and reduce variation.

9. DHSC should direct ICBs to work with neighbouring ICBs in their region to commission targeted and universal tiers of children's palliative care as set out in NHSE's service specification.

10. DHSC should link commissioning responsibilities of ICBs to guaranteed funding streams, preventing unfunded mandates and improving service sustainability.

11. DHSC should establish clear accountability mechanisms to underpin the MSF and ensure its implementation, including actions that will be taken if ICBs do not meet the required expectations.

Northern Ireland

1. 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.

2. 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 for both salary and non-salary expenditure.

Scotland

1. The Scottish Government should re-commit to providing additional and sustainable statutory funding to Children's Hospices Across Scotland (CHAS) for the long term.

2. 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.

3. 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.

4. 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.

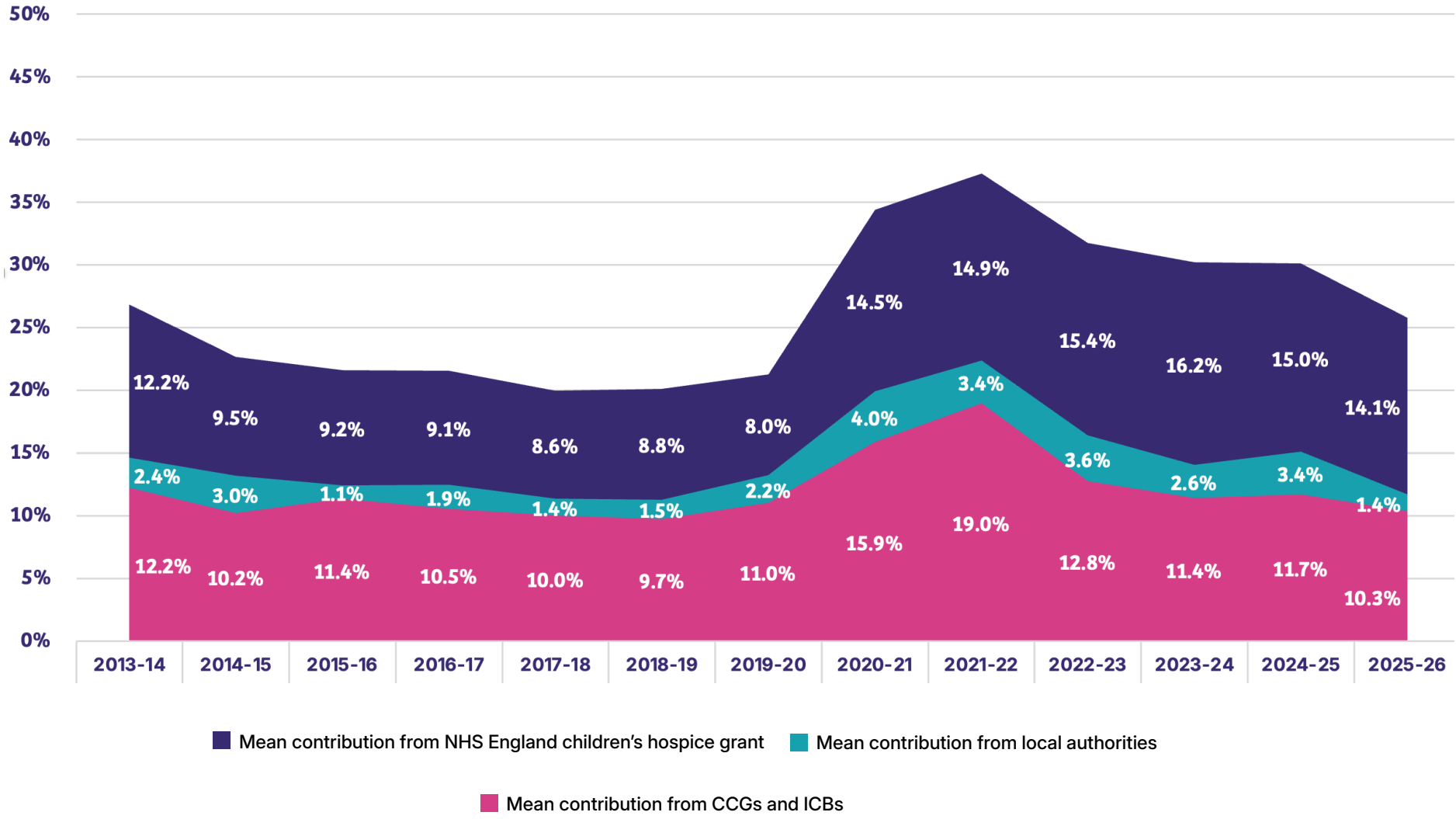
Wales

1. We join Tŷ Hafan and Tŷ Gobaith in calling for the new Welsh Government to commit to sustainable, fair funding for both children's hospices. That means committing to provide statutory funding that covers 30% of the hospices' care costs by 2030.

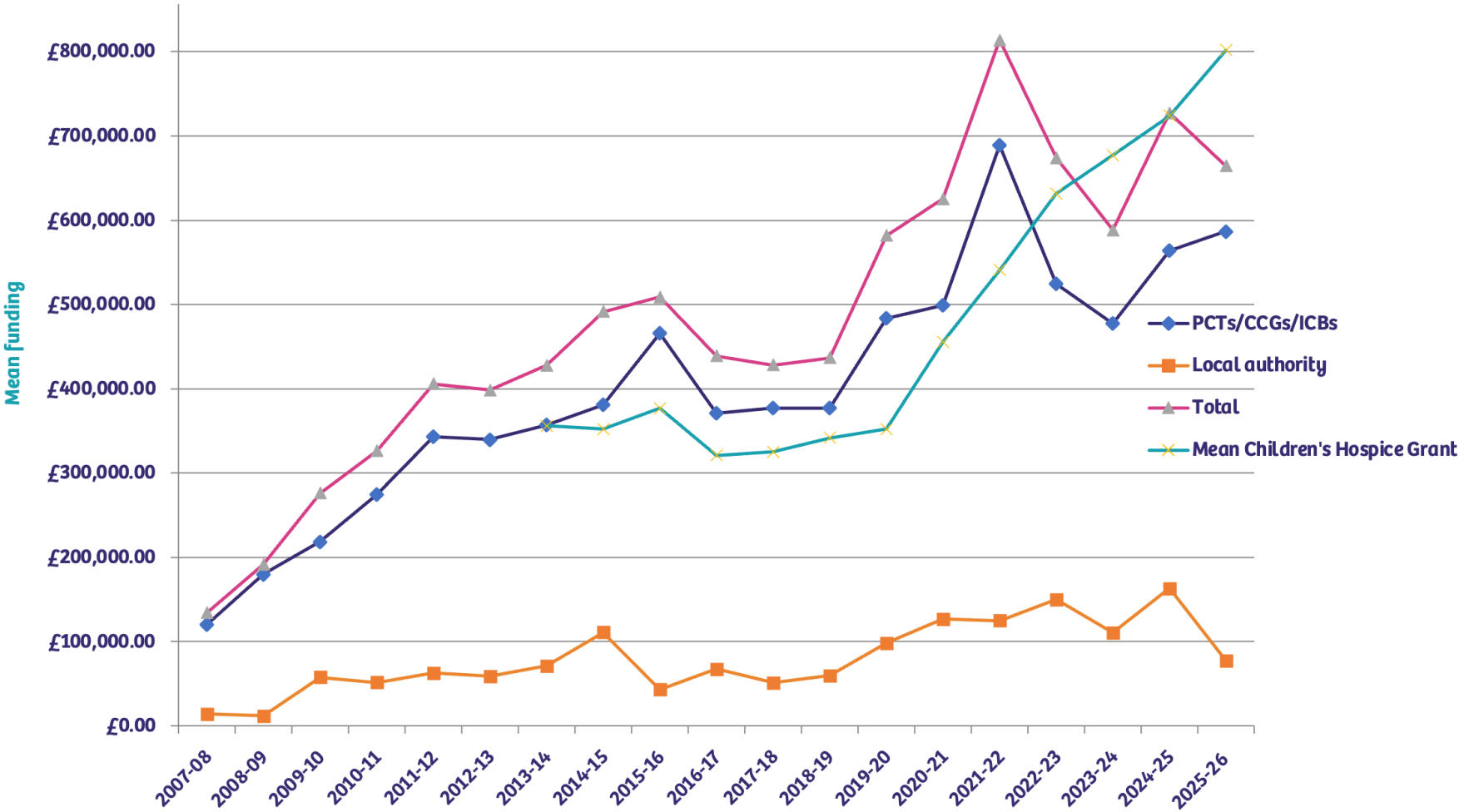
2. The Welsh Government should ensure that any additional and recurrent statutory funding that is awarded is tied to and increases in line with the rising costs caused by inflationary pressures.

Appendices

Appendix 1: The proportion of charitable expenditure for children's hospices in England reimbursed by the state 2014-26



Appendix 2: Change in mean local funding for children's hospices in England 2007-26



Appendix 3: Overview of remaining responses from ICBs to our freedom of information requests

Integrated care board	2025/26 total spending by ICB on children's hospice care	Number of cases of life-limiting and life-threatening conditions (LLCs and LTCs) among children and young people aged 0-24 in ICB area	2025/26 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 (£ per child and young person)
Bath and North East Somerset, Swindon and Wiltshire	Omitted	1,456	
Bedfordshire, Luton and Milton Keynes	No response	2,101	
Birmingham and Solihull	£806,000.00	2,871	£280.74
Black Country	£619,800.00	3,104	£199.68
Bristol, North Somerset and South Gloucestershire	Omitted	1,859	
Buckinghamshire, Oxfordshire and Berkshire West	£297,802.00	2,945	£101.12
Cambridgeshire and Peterborough	No response	1,540	
Cheshire and Merseyside	£1,033,139.00	4,856	£212.76
Cornwall and Isles of Scilly	£120,000.00	1,076	£111.52
Coventry and Warwickshire	£250,670.00	1,596	£156.73
Derby and Derbyshire	£135,000.00	1,746	£77.32
Devon	£311,000.00	2,075	£149.88
Dorset	£345,503.00	1,251	£276.18

Frimley	£256,000.00	1,297	£197.38
Gloucestershire	£264,165.43	1,105	£239.06
Greater Manchester	£919,000.00	6,241	£147.25
Hampshire and the Isle of Wight	No response	3,373	
Herefordshire and Worcestershire	£264,185.00	1,257	£210.17
Hertfordshire and West Essex	Omitted	2,552	
Humber and North Yorkshire	£137,000.00	2,755	£49.73
Kent and Medway	£195,737.25	3,301	£59.30
Lancashire and South Cumbria	£463,650.00	3,437	£134.90
Leicester, Leicestershire and Rutland	£99,893.00	1,739	£57.44
Lincolnshire	£85,175.00	1,113	£76.53
Mid and South Essex	£681,865.00	2,079	£327.98
Norfolk and Waveney	£368,118.00	1,477	£249.23
North Central London	No response	2,719	
North East and North Cumbria	Unable to provide data	6,019	
North East London	Unable to provide data	4,006	
North West London	No response	4,068	
Northamptonshire	£44,154.00	1,373	£32.16
Nottingham and Nottinghamshire	£97,701.00	1,926	£50.73
Shropshire and Telford and Wrekin	£358,740.00	881	£407.20
Somerset	No response	1,011	
South East London	£111,838.00	3,400	£32.89
South West London	£349,745.00	2,860	£122.29
South Yorkshire	Omitted	3,270	
Staffordshire and Stoke on Trent	£189,713.00	2,027	£93.59
Suffolk and North East Essex	**£349,550.00**	**1,553**	**£225.08**
Surrey Heartlands	**£111,680.36**	**1,744**	**£64.04**
Sussex	**No response**	**2,980**	
West Yorkshire	**£1,848,000.00**	**5,318**	**£347.50**

Appendix 4: Overview of remaining responses from ICBs to our freedom of information requests

Integrated care board	Total number of children and young people aged 0-18 accessing hospice care in ICB footprint	Total number of children and young people who could benefit from children's hospice care	2026/27 total spending by ICB on children's hospice care
Bath and North East Somerset, Swindon and Wiltshire	Unable to provide data		£633,001.83
Birmingham and Solihull	Unable to provide data		
Black Country	Unable to provide data		
Bristol, North Somerset and South Gloucestershire	Unable to provide data		£574,227.27
Central East	No response		
Cheshire and Merseyside	Unable to provide data		£1,033,449.00
Cornwall and Isles of Scilly	Unable to provide data		£120,000.00
Coventry and Warwickshire	Unable to provide data		£255,758.00
Derby and Derbyshire	Unable to provide data		£135,040.00
Devon	Unable to provide data		£320,000.00

Dorset	Unable to provide data		
Essex	Unable to provide data		£758,226.00
Gloucestershire	154	1105	£244,500.00
Greater Manchester	Unable to provide data		
Hampshire and the Isle of Wight	No response		
Herefordshire and Worcestershire	118	Unable to provide data	£264,185.00
Humber and North Yorkshire	Unable to provide data		£379,000.00
Kent and Medway	470	3301	£115,000.00
Lancashire and South Cumbria	Unable to provide data		
Leicester, Leicestershire and Rutland	162	1304	£99,893.00
Lincolnshire	82	Unable to provide data	£85,201.00
Norfolk and Suffolk	210	Unable to provide data	£586,447.00
North East and North Cumbria	Unable to provide data		

North East London	400	3300	Unable to provide data
Northamptonshire	Unable to provide data		£44,154.00
Nottingham and Nottinghamshire	Unable to provide data		
Shropshire and Telford and Wrekin	89	Unable to provide data	£366,022.00
Somerset	No response		
South East London	7	Unable to provide data	
South West London	Unable to provide data		£349,745.00
South Yorkshire	Unable to provide data		£896,000.00
Staffordshire and Stoke on Trent	Unable to provide data		£189,713.00
Surrey and Sussex	Unable to provide data		
Thames Valley	Unable to provide data	3200	£620,528.00
West and North London	No response		
West Yorkshire	Unable to provide data		£2,255,514.00

Appendix 5: Official responses from ICBs to our freedom of information requests

Bath and North East Somerset, Swindon and Wiltshire ICB

Birmingham and Solihull ICB

Black Country ICB

Bristol, North Somerset and South Gloucestershire ICB

Cheshire and Merseyside ICB

Cornwall and Isles of Scilly ICB

Derby and Derbyshire ICB

Devon ICB

Dorset ICB

Essex ICB

Gloucestershire ICB

Greater Manchester ICB

Herefordshire and Worcestershire ICB and Coventry and Warwickshire ICB

Humber and North Yorkshire ICB

Kent and Medway ICB

Lancashire and South Cumbria ICB

Leicester, Leicestershire and Rutland ICB

Lincolnshire ICB

Norfolk and Suffolk ICB

North East and North Cumbria ICB

North East London ICB

Northamptonshire ICB

Nottingham and Nottinghamshire ICB

Shropshire and Telford and Wrekin ICB

South East London ICB

South West London ICB

South Yorkshire ICB

Staffordshire and Stoke on Trent ICB

Surrey and Sussex ICB

Thames Valley ICB

West Yorkshire ICB

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