



Statutory funding for children's hospice and palliative care charities in England 2018/19

June 2019

www.togetherforshortlives.org.uk

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Executive summary

1. Children's hospice charities are spending more on providing care and support to an increasing number of children with life-limiting and life-threatening conditions and their families

- The total estimated charitable expenditure incurred by children's hospice charities in England in 2018/19 was £125,169,029.26 (based on an average of £3,681,442.04 per children's hospice charity).
- This is an above-inflation increase in costs of 4.5% since 2016/17 when the total was £119,803,481.70 (based on an average of £3,523,631.81 per children's hospice charity).
- Based on responses from 27 of the 34 children's hospices charities in England, we estimate that around 10,509 children were on the caseload of all 34 of these organisations in 2018/19. An estimated 8,159 children in England received active clinical care from children's hospice charities in 2018/19, either as inpatients or in the community.

2. Despite increasing demand and expenditure, the amount children's hospice charities receive from statutory sources is decreasing and doesn't look set to improve

The overall level of funding children's hospice charities received from the state

- The state's contribution to children's hospice charity spending fell from 22% in 2016/17 to 21% in 2018/19. This is a significant fall compared to the 27% contribution that the state made in 2013/14.

Funding from NHS clinical commissioning groups (CCGs)

- Between 2016/17 and 2018/19, the average funding each children's hospice charity received from local NHS clinical commissioning groups (CCGs) fell by 2% from £371,303 to £364,076.
- Between 2017/18 and 2018/19, nearly three quarters (74%) of children's hospice charities experienced a real-terms cut (a cut, freeze or increase below 1.8%) in the money they received from CCGs.

Funding from local authorities

- Between 2016/17 and 2018/19, the average funding each children's hospice charity received from local councils fell by 11% from £67,654 to £61,092.
- Between 2017/18 and 2018/19, over two thirds (70%) of children's hospice charities experienced a cut or freeze in the money they received from local councils.

The NHS Children's Hospice Grant

- The Children's Hospice Grant, which is allocated to all children's hospice charities by NHS England, is worth a total of £12million per year in 2019/20. This has grown incrementally from £8.8million in 2006/07, when the grant was introduced as a £27million award over three years.
- In 2006/07, the grant contributed an average of 14% towards the cost of providing clinical care in children's hospice charities. In 2018/19, when the grant was worth £11million, this contribution was just 9.1%.
- If charitable expenditure increases by the same proportion between 2018/19 and 2019/20 as it did between 2017/18 and 2018/19 (2.7%) then, even with the uplift to £12million, the Children's Hospice Grant will only contribute 9.2% to children's hospice charities' charitable expenditure during 2019/20.
- Crucially, no commitment has been made by NHS England or the Department for Health and Social Care to maintain and protect the value of the children's hospice grant beyond 2019/20. This commitment is essential to ensure the sustainability of children's hospice charities.

3. Funding is patchy and varies widely across local areas. 15% of children's hospice charities receive nothing at all from their local NHS organisations and local councils.

- There is huge variation in the level of funding children's hospice charities receive from CCGs, local authorities and the children's hospice grant. When all sources of statutory funding are taken into account, we found that one children's hospice charity respondent received 48% of its charitable expenditure from the state. The lowest contribution was 7%.
- 15% of children's hospice charities receive nothing at all from their local CCGs.

4. In order to mitigate the impact of changes in statutory funding, children's hospice charities are cutting short breaks and using cash from reserves

- Nearly one in five (19%) respondents reported that they had had to cut their short breaks for respite.
- Current levels of statutory funding have also meant that, while children's hospice charities have been able to protect some services for now, they have also been unable to expand them to meet the growing demand. Of the 27 children's hospice charities that responded to our survey:
 - 74% have neither expanded nor cut the end of life care they offer.
 - 70% have neither expanded nor cut the care they offer to manage children's symptoms
 - 63% have neither expanded nor cut their hospice at home services.
- Where they have experienced falls in statutory funding, 10 (36%) children's hospice charities said that they have been forced to find more money from charitable sources to fund their services. 11 (39%) are using funds from reserves. Worryingly, three children's hospice charities (11%) have had to stop some of their services entirely.

- Additionally, four children's hospice charities (14%) told us that they are employing fewer whole time equivalent (WTE) staff in care roles to mitigate the impact of lower statutory funding. This raises serious concerns about how sustainable children's hospice care is in the long-term.

5. The public think children's hospice charities should receive more funding from the state

- A YouGov survey¹, carried out on behalf of UK charity Together for Short Lives in 2019, has found that the public think that children's hospice charities receive 81% more of the charitable costs they incur from the state than they actually do (38% compared to the real figure of 21%). When asked what percentage they thought children's hospice charities should receive from the state, respondents said that children's hospice charities should receive two and a half times (252%) more than they currently do (74% compared to 21%).

6. What we want to happen as a result of our findings

- We call on NHS England to protect and increase the children's hospice grant to £25million. Without an increase, services provided by children's hospice charities will continue to be cut.
- In December 2018, Simon Stevens, Chief Executive of NHS England, was quoted in an NHS England statement which committed NHS England to match fund increases in children's hospice charity funding made by CCGs by up to £7million per year, in addition to the Children's Hospice Grant.
- However, in the Long Term Plan, published a few weeks later, NHS England changed the wording of the commitment to include other palliative care services
- We call on NHS England to honour its commitment and protect and increase the crucial children's hospice grant.
- We call on the government to fill the local authority funding gap. The Disabled Children's Partnership (DCP), of which Together for Short Lives is a member, has identified a £434million gap in local authority funding for social care for disabled children. The gap includes local authority funding for short breaks for respite provided by children's hospice charities and other children's palliative care charities, including Rainbow Trust Children's Charity.
- We call on the government to provide parity of funding between children's and adult hospice services in England. Adult hospices receive around 33% of their expenditure from statutory sources, while children's hospice charities only receive 21% on average.
- We call on the government to develop a funded children's palliative care strategy. This strategy should make sure that 24/7 children's palliative care support can be accessed

¹ All figures, unless otherwise stated, are from YouGov Plc. Total sample size was 2019 GB adults. Fieldwork was undertaken between 11th - 12th March 2019. The survey was carried out online. The figures have been weighted and are representative of all GB adults (aged 18+). The Fieldwork was carried out by YouGov for Together for Short Lives 11-12 March 2019.

by seriously ill children and families when and where they need it, across the statutory and voluntary sectors, in hospitals, children's hospice charities and the community.

How we conducted our survey

1. Together for Short Lives regularly surveys the statutory funding received and services provided by its children's hospice charity members in England. No survey was carried out in 2018, but our most recent survey, carried out during spring 2019, collected data on activity and funding in both 2017/18 and 2018/19.
2. We have carried out the same survey with these charities for 11 years; as a result, we can understand funding trends and their impact on services for children with life-limiting or life-threatening conditions. We surveyed those hospices which provide health and /or social care to children and young people, including those which provide hospice care to both children and adults.
3. 27 children's hospice charities responded to our survey. Of these, all 27 provide healthcare to children and young people with life-limiting or life-threatening conditions and could reasonably expect to be commissioned and funded by CCGs. All 27 of the charities also provide social care to this group of children and young people and could reasonably expect to be commissioned and funded by local authorities.
4. Together for Short Lives has 34 children's hospice charity members which provide healthcare to babies, children and young people in England with life-limiting and life-threatening conditions. Some of these organisations operate multiple services, across multiple children's hospice sites. The response rate to this survey from children's hospice charities is 79%.

Rainbow Trust Children's Charity and The Children's Trust

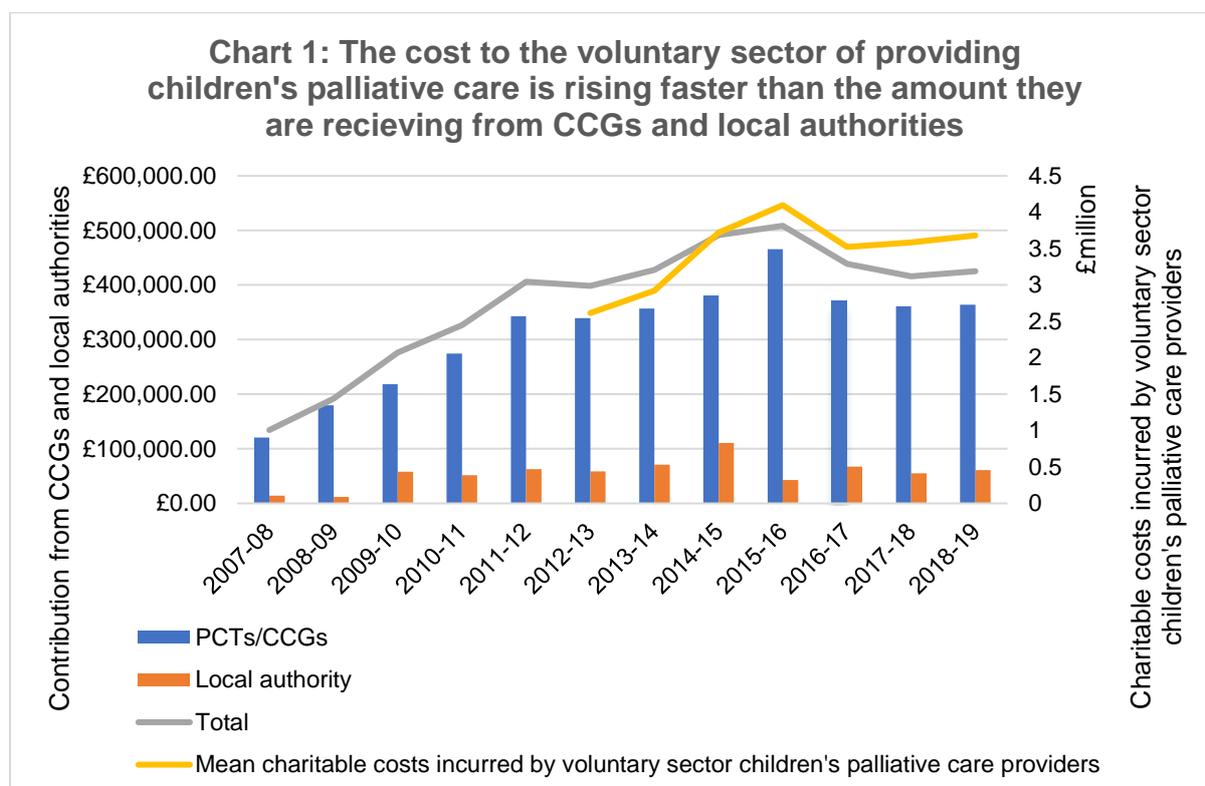
5. The overall analysis that we set out in this report omits two of our voluntary sector provider members, Rainbow Trust Children's Charity and The Children's Trust. Both provide Care Quality Commission-regulated care and support for children with life-limiting and life-threatening conditions and currently receive some degree of statutory funding. However, they do so through different models of care to those used by children's hospice charities. Rainbow Trust provides social care that supports families who have a child aged 0-18 years with a life threatening or terminal illness. They provide sibling support, home support, hospital support and bereavement support. The Children's Trust is the UK's leading charity for children with brain injury. It delivers rehabilitation, education and community services through skilled teams who work with children and young people, and their families.
6. Together for Short Lives echoes and supports Rainbow Trust's call for a greater financial contribution from the state towards the care and support it provides. In 2018, for example, Rainbow Trust reported that it helped more than 1,230 siblings in various ways including:
 - staying with them while parents take a much-needed rest
 - taking them to nursery and school

- talking to them about their brother or sister's diagnosis
 - taking them on breaks or trips for some precious time out of their home
 - spending time with bereaved siblings to help them cope if their brother or sister has died.
7. For Rainbow Trust Children's Charity, years of sustained cuts to local government funding means it now needs to fundraise more than 97% of its income in a challenging economic environment, with no central government funding.

Our findings

The amount children's hospice charities are spending on providing palliative care is increasing

8. The mean charitable expenditure incurred by children's hospice charities in 2018/19 was £3,681,442.04 per children's hospice charity. In 2017/18 the mean was £3,584,774.07 per children's hospice charity. This represents an increase of 2.7%. The mean for both years is based on a response from 27 (79%) of 34 children's hospice charities.
9. This is an above-inflation increase in costs of 4.5% since 2016/17 when mean charitable expenditure incurred by children's hospice charities was £3,523,631.81.
10. In 2018/19 children's hospice charities spent an estimated £125,169,029.26 on providing children's palliative care. They spent £121,882,318.52 in 2017/18 (2.7% increase). These estimated totals are based on the average expenditure of 27 children's hospice charities (£3,681,442.04), multiplied by the total number of children's hospice charities (34).
11. In March 2019, the Consumer Prices Index measure of inflation was 1.8%. In March 2018 it was 2.3%, which meant that prices increased by 4.1% between March 2017 and March 2019.



The volume of activity being undertaken by children's hospice charities

12. For the first time we have an impression of how many children in total children's hospice charities are providing support to over a year. We estimate that, in 2018/19,

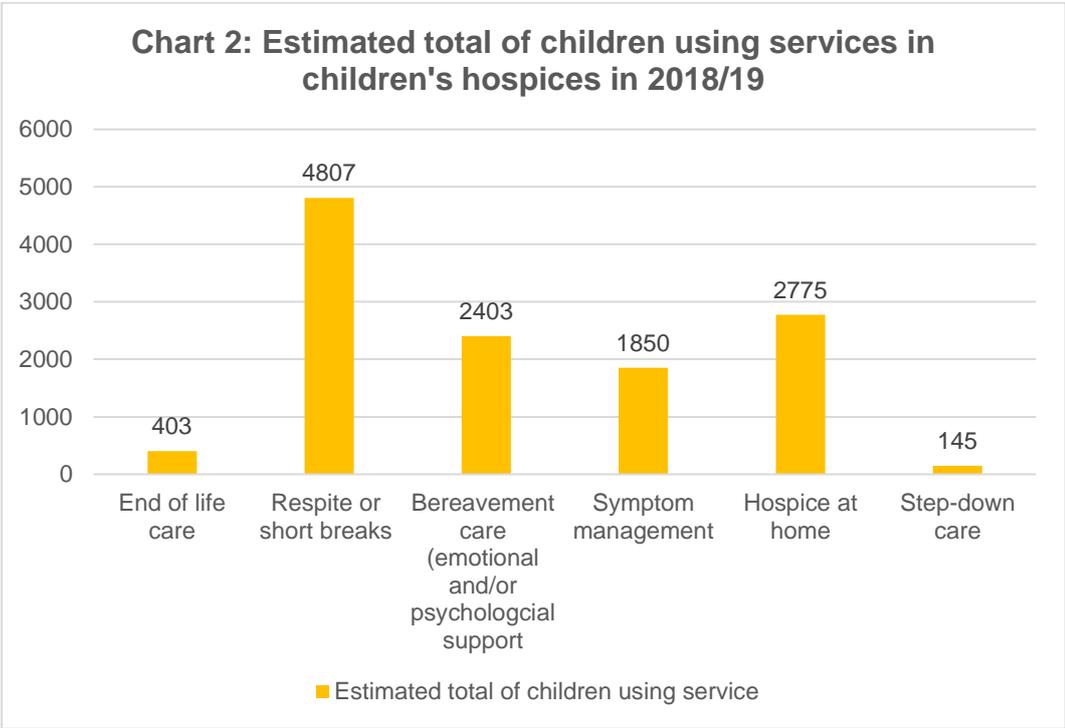
children’s hospice charities had a total of 10,509 children with life-limiting or life-threatening conditions on their caseloads. This is based on an average of 309 children per hospice charity, which we calculated from 27 responses.

- 13. Of these 10,509 children, an estimated 8,159 (78%) received active clinical care from a children’s hospice charity in England in 2018/19. This is based on an average of 240 children per hospice charity, which we calculated from 27 responses.

“We have an increasing caseload of children aged under 5, who tend to be more vulnerable to deterioration and therefore are more likely to require symptom management or end of life care which is charged for via spot purchasing.”

Demelza House Children’s Hospice

- 14. As described by Chart 2, by far the most-accessed support at children’s hospice charities in 2018/19 was respite and short breaks (provided by 23 (85%) of 27 respondents), with an estimated total of 4,807 children accessing these services (based on an average of 141 children per responding children’s hospice charity). An estimated 2,775 children also used hospice at home services in this period (an average of 82 based on numbers from the 19 of 27 respondents that provide this service). An estimated 403 children accessed end of life care support from a children’s hospice charity in 2018/19 (based on an average of 12 per responding hospice).

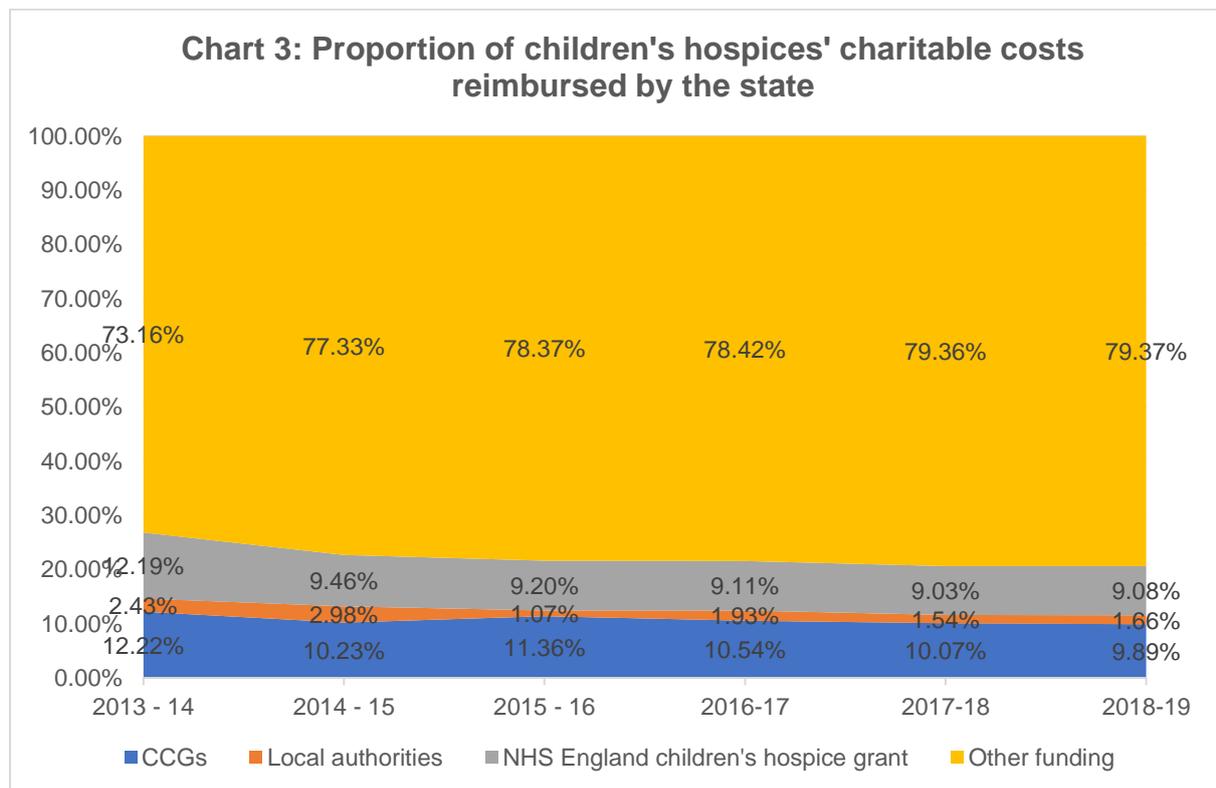


The state is failing to contribute enough to the children’s palliative care provided by children’s hospice charities and other children’s palliative care charities in England - and this shows little sign of improving

- 15. The state’s total contribution to the charitable expenditure incurred by all of our 27 respondents combined dropped to 21% in 2017/18 and has remained at that level in 2018/19. This is the lowest level of statutory funding since Together for Short Lives began gathering data on statutory funding levels in 2013/14 (see chart 3). This represents a slight drop from 22% in both 2015/16 and 2016/17, but is particularly significant when compared to levels of 23% in 2014/5 and 27% in 2013/14.

“The amount of children we care for increases year on year but our statutory funding is not increasing. The cost per child has increased too inline with inflation but this is not recognised by statutory funding either.”

James Hopkins Trust



Funding from CCGs is contributing a lower proportion towards children’s hospices’ charitable expenditure

- 16. The 21% contribution from the state (based on responses from 27 (79%) of children’s hospice charities) comprises contributions from CCGs, local authorities and NHS England (through the Children’s Hospice Grant). On average, we have found that CCGs contributed 9.9% to the average charitable expenditure incurred by respondents

during 2018/19. Each year this has fallen slightly since a level of 11.4% was recorded in 2015/16.

17. Since our last survey in 2017, CCGs are contributing less in cash terms. In 2018/19, each charity received a mean of £364,075.96 from their local CCGs, a decrease from £371,303.30 in 2016/17, but an increase of 0.8% from an average of £361,133.96 in 2017/18.
18. This means that, between 2016/17 and 2018/19, the average funding each children's hospice charity received from local NHS clinical commissioning groups (CCGs) fell by 2%.
19. The percentage contribution that CCGs provides towards charitable expenditure is decreasing (9.9% in 2018/19, compared to 10.1% in 2017/18 and 10.5% in 2017/18).

“Demelza has set our charges for CCG's for spot purchasing of in-hospice care. This depends on negotiation with each individual CCG (17 in our area) for each admission.”

Demelza House Children's Hospice

Local authority funding still does not reflect the social care provided by children's hospice charities and levels are erratic

20. Overall, local authorities contributed an average of just 1.7% to the charitable expenditure of children's hospice charities in 2018/19, less than was recorded during our last survey in 2017 when it was 1.9%, but an increase on the 1.5% recorded for 2017/18.
21. The average value of funding from local authorities has been erratic over the past five years. In 2014/15 the average value of local authority funding was £110,909.09. The next year (2015/16) this dropped by over 60% to £43,095.24. In 2016/17 this jumped 57% to £67,653.71, and then dropped 19% to £55,050.15 in 2017/18. In 2018/19, the figure rose 11% to £61,092, although overall this still represented an 11% fall compared to 2016/17.
22. These erratic changes in the value of funding present a challenge for children's hospice charities who will plan and scope activity based on the statutory funding they receive.
23. Currently, local authority funding for children's hospice charities and other children's palliative care charities does not adequately reflect the amount of local care and support provided to children with life-limiting conditions. It is shocking that 11 of the 27 (41%) of the children's hospice charities we heard from report receiving no money whatsoever from their local authorities in 2018/19.
24. Local authorities are responsible for planning and funding services like short breaks for respite, bereavement care and counselling. Without the services provided by charities, seriously ill children and their families would be forced to rely on other overstretched services, having a greater negative impact on the public purse.

Statutory funding for children’s hospice charities and other children’s palliative care charities in England remains patchy

25. Overall England-wide data about the way in which the state funds children’s hospice charities masks a wide variation in different local approaches (see variation shown in Chart 5). Calculating the standard deviation of all the percentage contributions that CCGs make to different children’s hospice charities is a way of summarising the amount by which every contribution varies from the mean.
26. However, the range of contributions is large: one charity received 22% of its charitable expenditure from its local CCGs in 2018/19, while four (15% of respondents) received nothing at all. 12 children’s hospice charities and other children’s palliative care charities (44%) received between 1% and 10% and another six (22%) received between 11% and 20%. Two children’s hospice charities (7%) received between 21% and 30% (see Chart 4).

“We have no funding for our Children’s Hospice from them [CCGs and local authorities]. We are in one of the most deprived areas of the country where we can improve the lives of the children who need us - if we have the resources to help them.”

Brian House (Trinity Hospice)

“We are not being funded as part of the local health and social care economy either by local authorities or CCG’s. We are charging them on an ad hoc basis for care and have no contracts with them to deliver this care”

Shooting Star Children’s Hospice

“[We] deliver services across three CCG’s and only receive funding from one”

The Jessie May Trust

“There appears to be an expectation that hospices should only receive a small proportion of their funding from statutory sources. As this trend continues and activity increases the funding per patient has decreased”

Keech Hospice Care

Chart 4: CCG % contribution to charitable costs

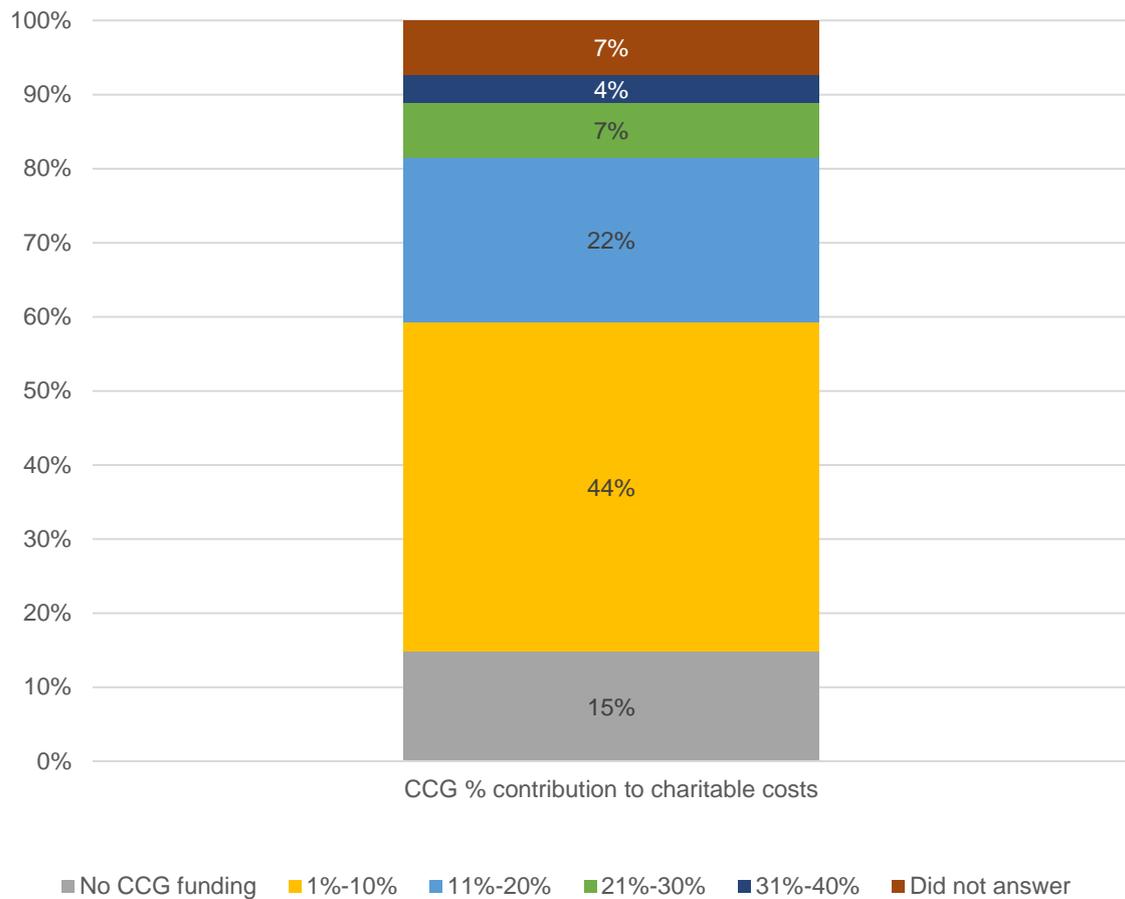
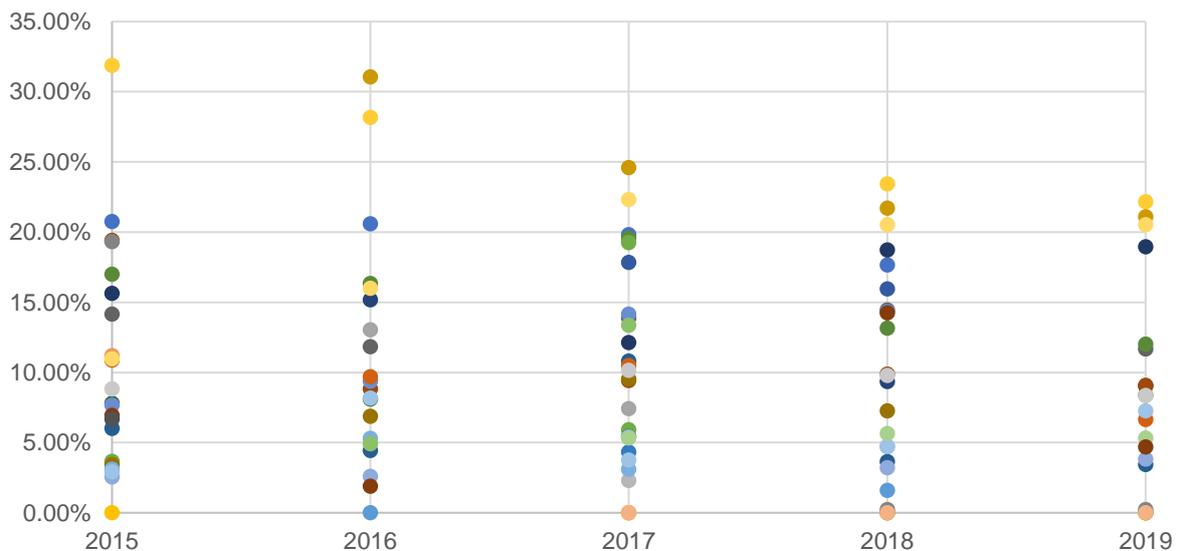
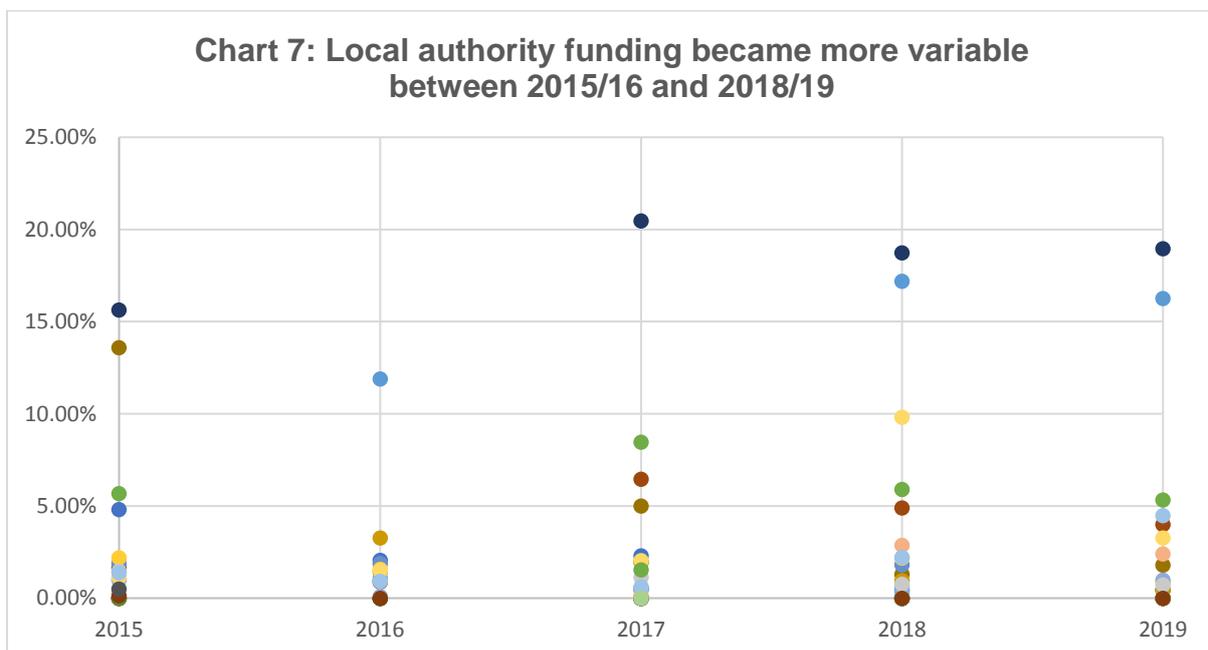
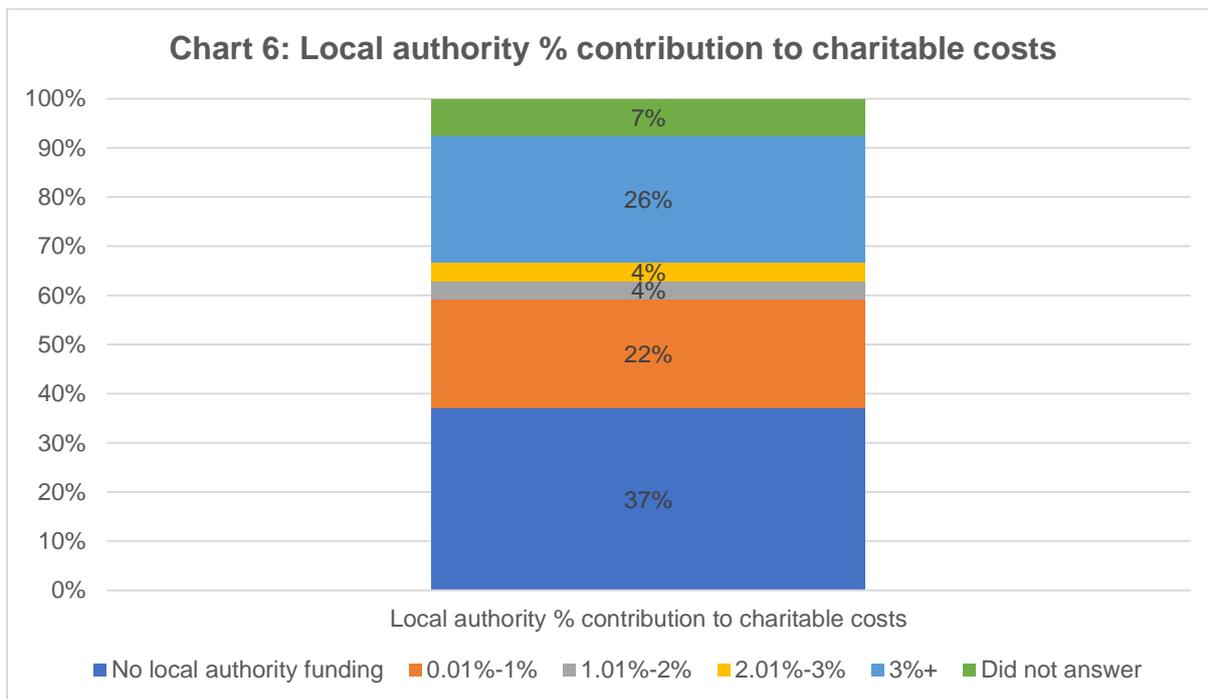


Chart 5: % contribution made by CCGs to children's hospices' charitable costs in 2018/19



27. 11 respondents (41%) received nothing from their local authorities, while one (4%) received 19% of their charitable expenditure. See Chart 6 and 7 for variation between funding levels.



28. When the Children’s Hospice Grant is taken into account, one children’s hospice charity respondent received 48% of its charitable expenditure from the state. Yet, the lowest contribution was 7%. The most common range of contributions from the state was between 11% and 20%, which was reported by eight children’s hospice charities (30%). Six children’s hospice charities (22%) received between 21% and 30%. Charts 8 and 9 show the variation in levels of overall statutory funding received by children’s hospice charities.

Chart 8: State % contribution to charitable costs in 2018/19

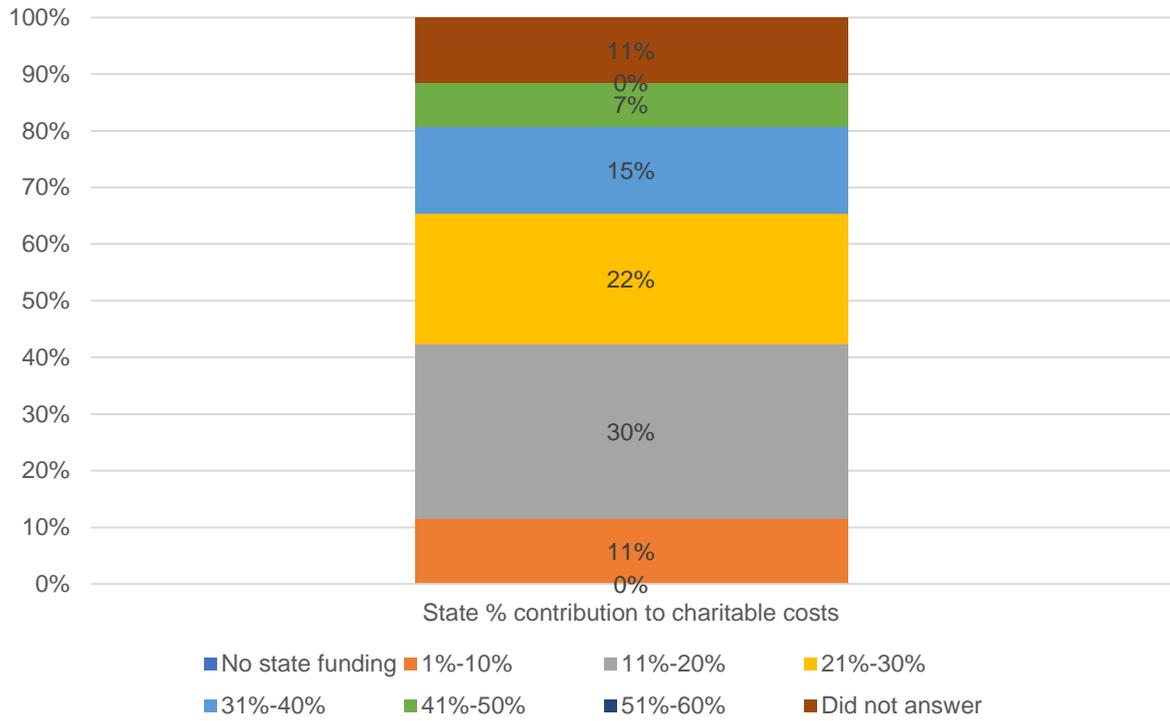
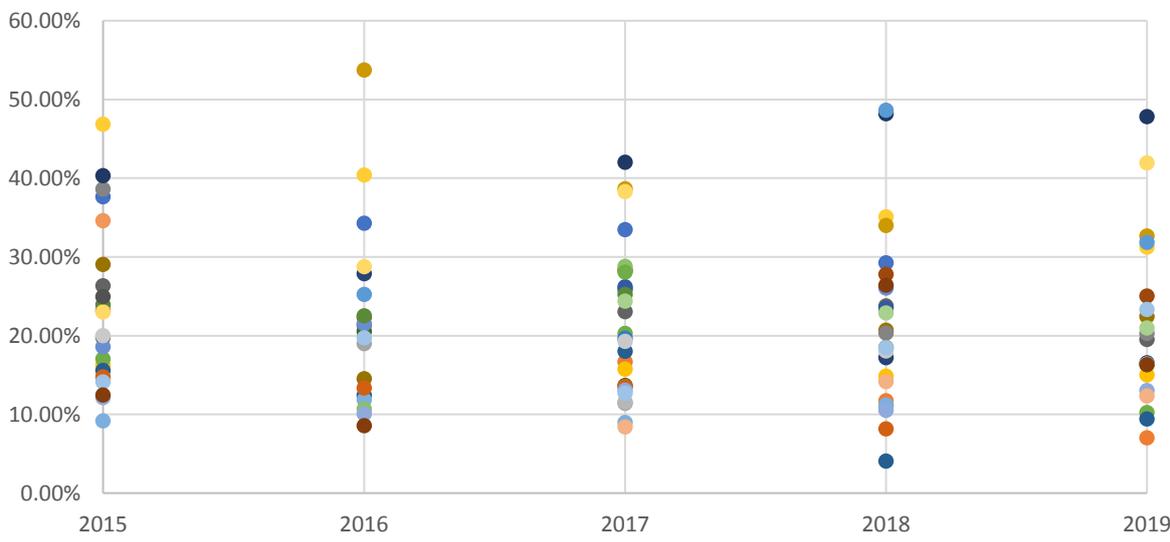


Chart 9: The contribution made by the state to the money charities need to spend on providing children's palliative care was more variable in 2015/16 compared to 2018/19



Changes in statutory funding is having a negative impact on children with life-limiting conditions and their families

“Although our income has increased, we have reduced the number of charitable bednights that are available to families without funding from statutory agencies.”

Shooting Star Children’s Hospice

29. Chart 10 shows how changes in statutory funding have had an impact on the services provided by children’s hospice charities.
30. Nearly one in five (19%) respondents reported that they had had to cut their short breaks for respite, compared to one (4%) which reported that they had been able to expand this offering. This is particularly worrying in the context of research conducted by [Julia’s House Children’s Hospice and Bournemouth University](#), which found that 64% of divorced or separated parents cited having a child with complex needs as a reason for the breakdown of their relationship. Of those couples, 75% had no access to short breaks at that time.
31. Short breaks offer respite and prevent families having to rely on costly and distressing emergency services when they reach crisis. However, decreasing funding from local authorities and the impact that this has on the support children’s hospice charities can offer is leaving many families with no access to these lifeline services.

“We are currently budgeting a £600k+ operating deficit and will have to consider cutting services at Board meetings if we cannot raise any more charitable income over the next three to five years.”

Brian House (Trinity Hospice)

“Cuts to local authorities in particular have led to families being made to use their charitable allocation of "Short Breaks" nights for other purposes such as step-down (where this is for family confidence rather than clinical need), building works to the home and family crisis. This then impacts on the family's ability to get a meaningful short break.”

Demelza House Children’s Hospice

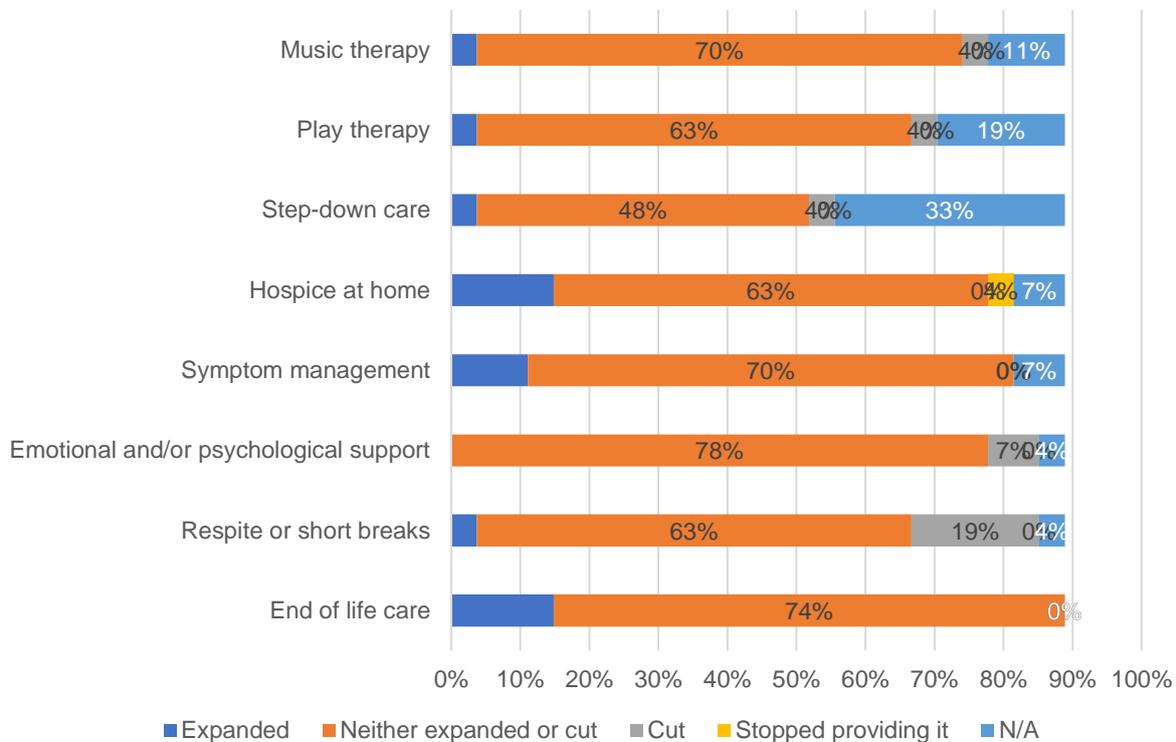
32. Other cuts include emotional and/or psychological support (cut by two hospices (7%)), music therapy, play therapy and step-down care (each cut by one hospice (4%)).
33. The largest increases in service provision were found in end of life care and hospice at home services, with four (15%) of responding children’s hospice charities saying they had expanded these services.
34. Current levels of statutory funding have also meant that, while children’s hospice charities have been able to protect some services for now, they have also been unable to expand them to meet the growing demand. Of the 27 children’s hospice charities that responded to our survey:
 - 74% (20) have neither expanded nor cut the end of life care they offer.

- 70% (19) have neither expanded nor cut the care they offer to manage children’s symptoms
- 63% (17) have neither expanded nor cut their hospice at home services.

“[We] cannot see all the children who need us - we are at capacity and are unable to provide additional important support for families in their homes. Our initial findings show we are only seeing about half the local children that we could help”

Brian House (Trinity Hospice)

Chart 10: Have changes in statutory funding levels had an impact on the services your organisation provides?



“We are changing our care model in November 2019 to tier our service so that around half our families are no longer eligible for overnight or community respite care, unless it is funded by a local authority. We are not able to increase our services so we need to tailor them to those that need it most.”

Shooting Star Children’s Hospice

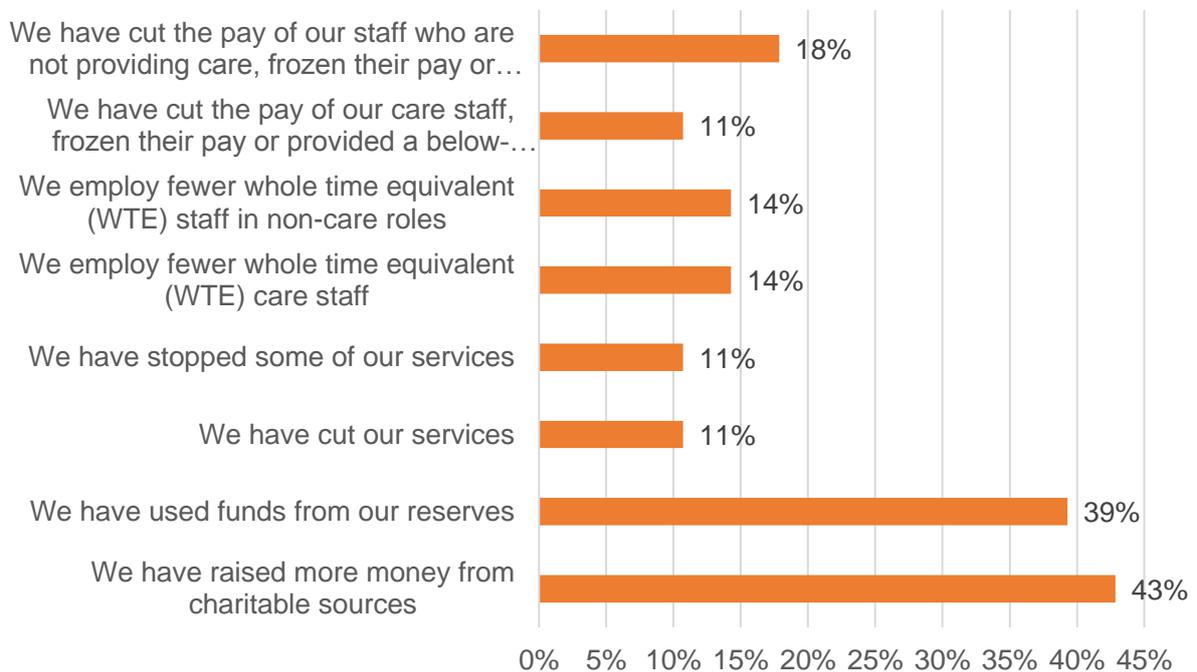
Where statutory funding has decreased, children’s hospice charities and other children’s palliative care charities are being forced to use money from reserves and find more money from local communities

35. We asked children’s hospice charities that have seen a decrease in their statutory funding to tell us the range of actions and measures they have implemented to mitigate the impact of the drop in income. Chart 11 shows that, where children’s hospice charities and other children’s palliative care charities have experienced falls in statutory funding, ten (36%) report that they have been forced to find more money from charitable sources to fund their services. 11 (39%) are using funds from reserves. Worryingly, three hospices (11%) have had to stop some of their services entirely. Five (18%) also report that they have frozen staff salaries or offered pay rises below the rate of inflation.

“Statutory organisations rely on our hospice services being available whenever they wish to refer children and young people to it, but only wish to pay for the hours of care purchased and the exact service provided (eg was the nurse in the room with the child for 24 hours, otherwise arguing it is not 1 to 1 provision). Only one Local Authority (out of 10) and no CCGs (out of 17) contribute towards the service being available. There is little recognition of the wider context and costs incurred in making this service available, and the fact that the hospice has to be staffed to be flexible enough to respond to emergency admissions, deterioration etc.”

Demelza House Children’s Hospice

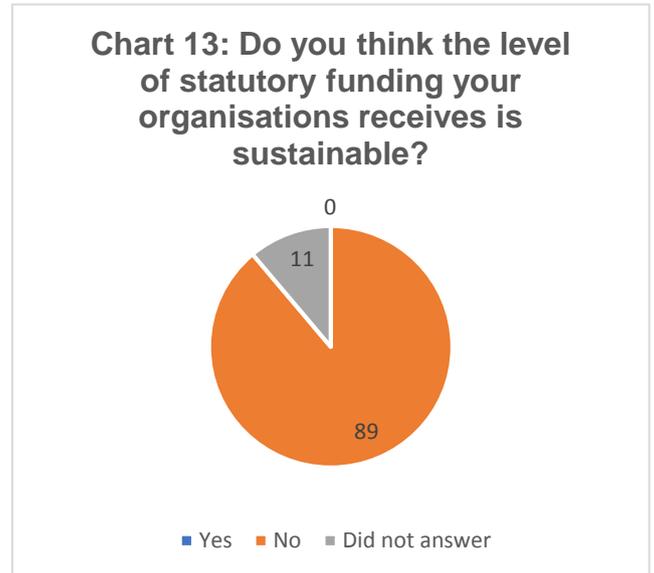
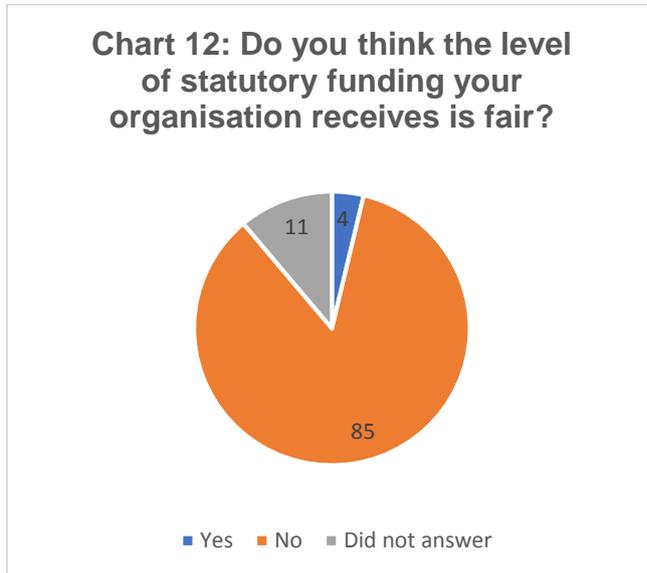
Chart 11: If your funding has decreased, or any increase was limited to inflationary uplift, how have you tried to mitigate negative impact on your services?



36. Additionally, four hospices (14%) told us that they are employing fewer WTE staff in care roles to mitigate the impact of lower statutory funding. This raises serious concerns about the level of care accessible to children with life-limiting and life-threatening conditions and their families. The loss of services and care staff reduces the reach and impact of children’s hospice charities, meaning many children could face long waits for support or a diminished range of available services.

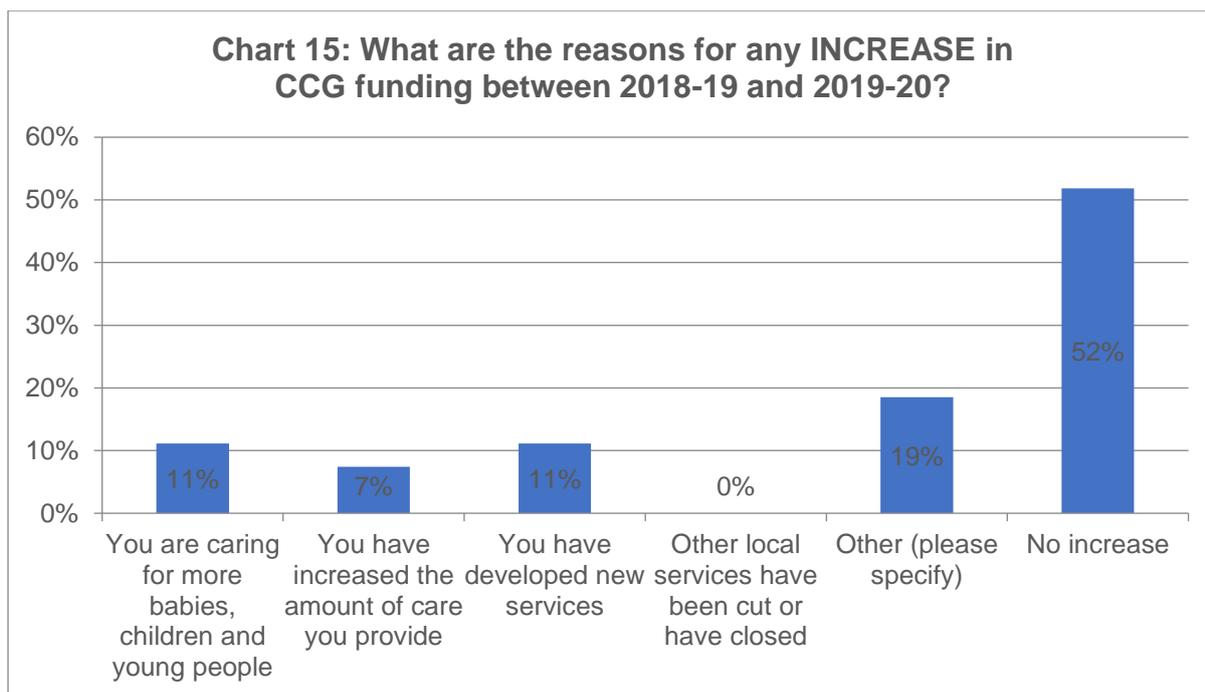
The vast majority of children’s hospice charities believe that they are being funded neither fairly or sustainably by the state

37. 23 of 27 respondents (85%) do not believe that their services are being funded fairly by the state (Chart 12). 24 of 27 (89%) do not believe that their services are being funded sustainably (Chart 13).

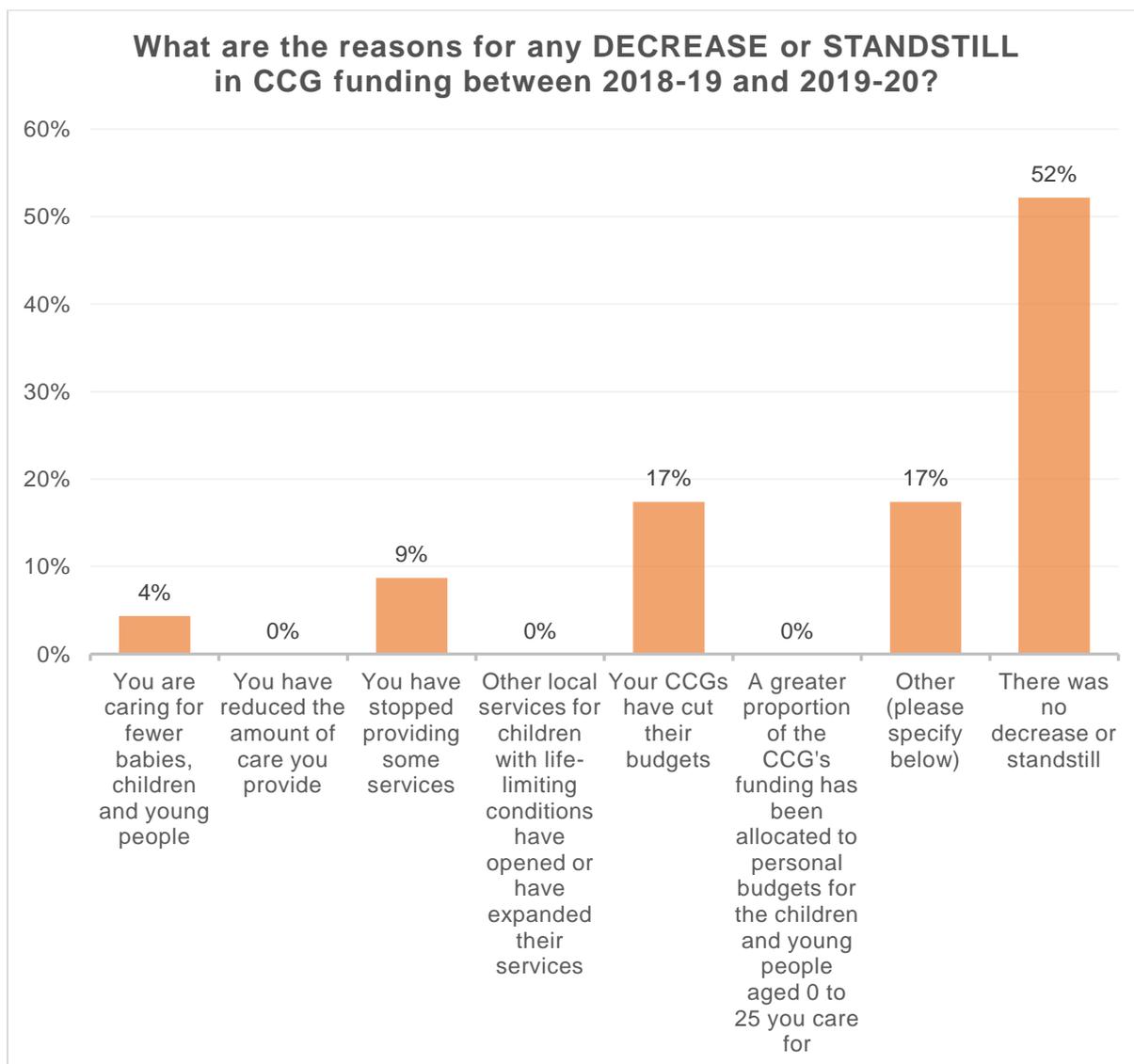


Why has statutory funding for children’s hospice charities and other children’s palliative care charities changed?

38. As shown in Chart 15, over half (58%) of the 27 respondents stated that their CCG funding either decreased or stayed the same between 2017/18 and 2018/19. Of those which did report an increase (11, 41%), three (11%) stated that this was due to caring for more babies, children and young people, while two (7%) stated that the rise was due to increasing the amount of care they provide. Three (11%) also said funding from CCGs had increased as a result of them developing new services.
39. In terms of other reasons, two (7%) children’s hospice charities cited inflationary uplifts as the reason for CCG funding increases.

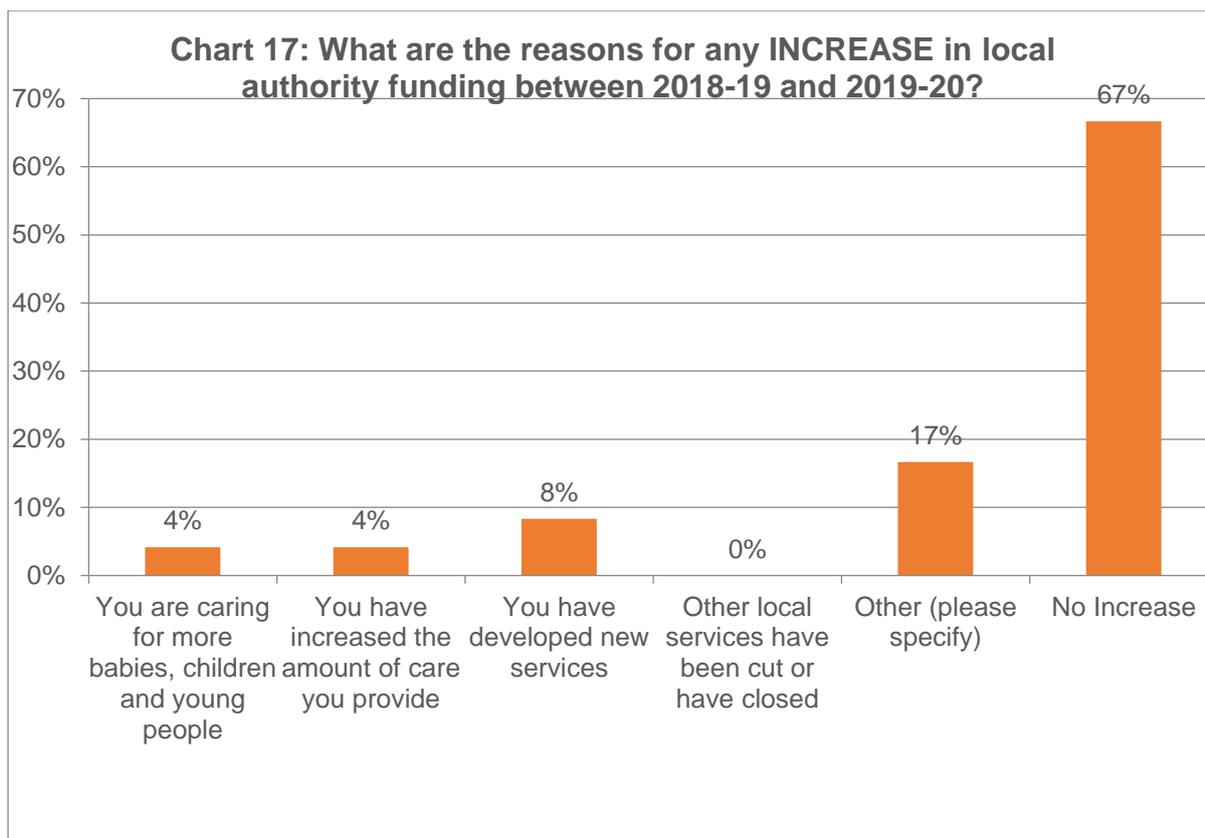


40. The most widely reported reason for CCGs decreasing or freezing their contributions to children's hospice charities was that CCGs had cut their budgets (four of 23 respondents, 17%) or organisations had stopped providing certain services (two hospices, 9%). One hospice (4%) had their funding decreased when one child they cared for died (Chart 16 provides a breakdown of responses). Other reasons included:
- One hospice said CCGs don't recognise the work of hospices and therefore only provide a token funding amount.
 - Funding from CCGs has been ad-hoc for some services, meaning they're unable to predict the level of funding they'll receive.



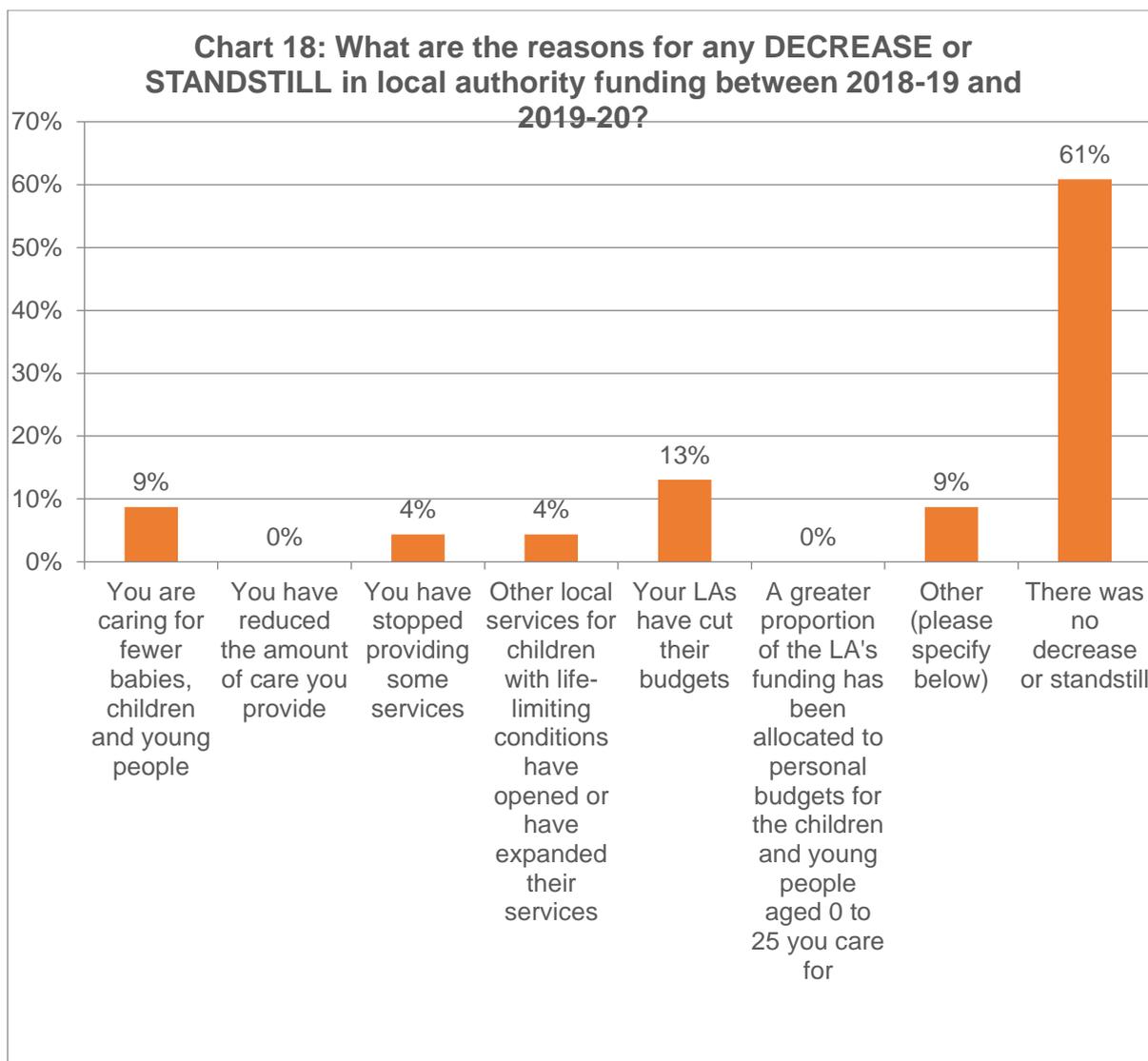
41. Those children's hospice charities which will receive more money from local authorities in 2019/20 (five of 27 respondents) will do so as a result of a range of factors (see Chart 17). These reasons included the delivery of new services (8%) while others have increased the amount of care they're providing (4%) or are caring for more children (4%). Other reasons include:

- One hospice (4%) has started 'selling' bed nights – this change in structure has led to more funding from local authorities.
- One hospice has reached a funding agreement with local authorities following a discussion about workforce or funding requirement.



42. Of the children's hospice charities that experienced a cut in their funding from local authorities (six hospices), 13% owed this to local authority budgets being cut, while one hospice (4%) said they had stopped providing certain services. Two (9%) said that funding was reduced following the death of a child (see Chart 18). Other reasons include:

- local authorities reluctant to pay the price for overnight specialist palliative care
- increasing difficulty in securing individual funding agreements for young adults and for other new patients
- local authorities reducing allocations and funded entitlements to children and young people for social short breaks for respite.



Children’s hospice grant continues to be a vital source of funding, but isn’t making enough impact, despite uplift

43. This year’s survey again emphasised how important the NHS England Children’s Hospice Grant is to children’s hospice charities; among the 27 who answered this question, the grant, on average, contributed 9.1% of their charitable expenditure in 2018/19.
44. The Children’ Hospice Grant, which is allocated to all children’s hospice charities by NHS England, is now worth a total of £12million per year in 2019/20 following an increase of £1million (9%) announced in 2018/19. This has grown incrementally from £8.8million in 2006/07, when the grant was introduced as a £27million award over three years.
45. In 2006/07, the grant contributed an average of 14% towards the cost of providing clinical care in children’s hospice charities. In 2018/19 this contribution was just 9.1%.
46. If charitable expenditure increases by the same proportion between 2018/19 and 2019/20 as it did between 2017/18 and 2018/19 (2.7%) then, even with the uplift in its

value, the children's hospice grant will only contribute 9.2% towards expenditure, well below the 14% it did when the grant was established.

47. Furthermore, no commitment has been made by NHS England or the Department for Health and Social Care to maintain and protect the value of the children's hospice grant beyond 2019/20. This commitment is essential to ensure the sustainability of children's hospice charities.

Commissioners are relying on historical precedent when deciding funding levels

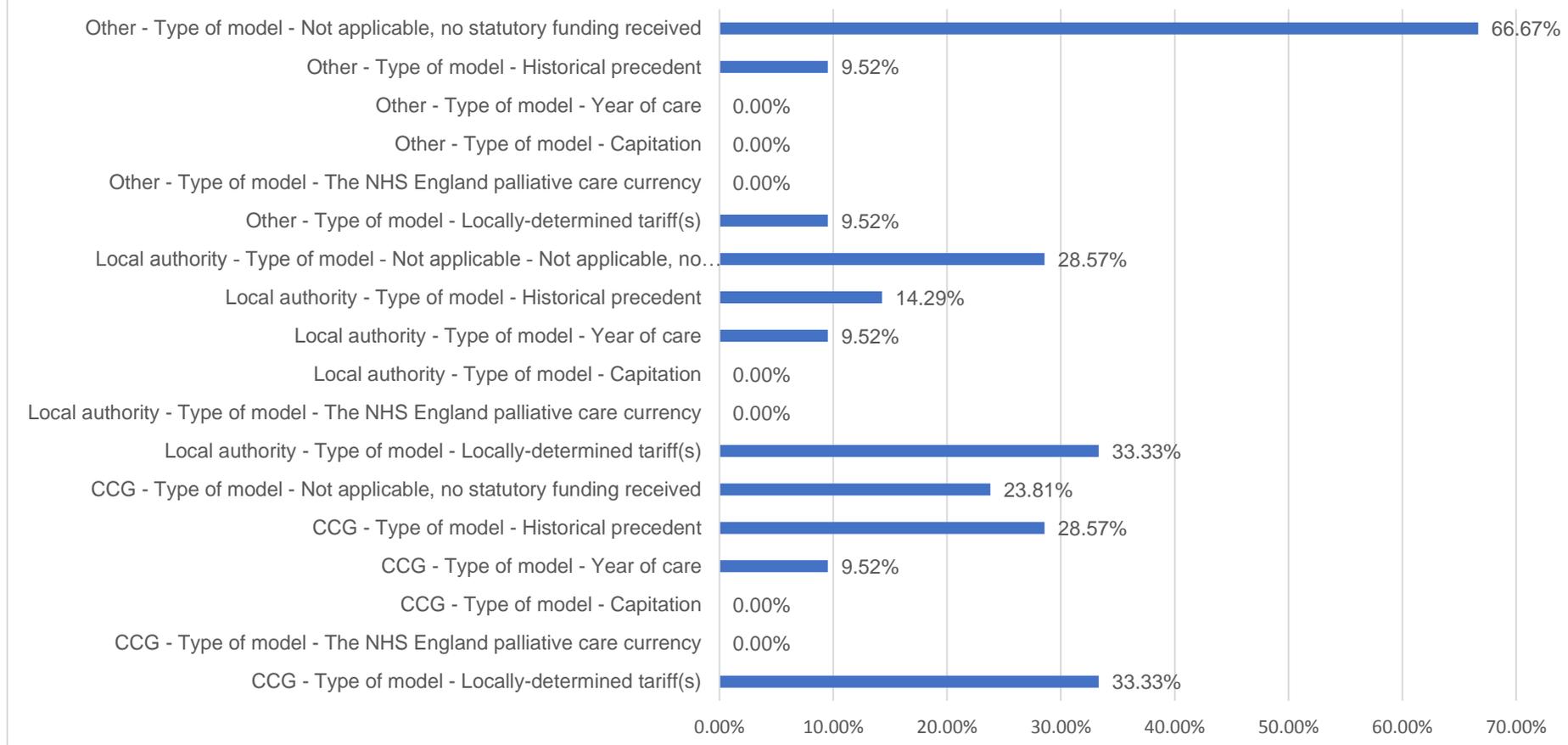
48. There is little evidence so far to suggest that the NHS children's palliative care funding currency², published in 2017, is having an impact on statutory funding. Indeed, no children's charities report that their CCGs are using it. This was also the case in 2017.
49. As Chart 19 demonstrates, across funding from CCGs, local authorities and other statutory sources, the majority of children's hospice charities report that funding levels are based upon historic levels. 29% (six) of hospices told us that CCGs and/or local authorities are determining funding levels in this way, with 10% (two) of other statutory funders doing the same. Respondents were able to cite a number of different methods for determining funding in the response.
50. This is opposed to CCGs and local authorities using other funding models such as currencies (like the palliative care currency), capitation³ or year of care⁴ approaches. Relying on funding precedent suggests that commissioners therefore aren't adapting funding depending on levels of need within a region and have little idea of the adequacy of certain funding levels.

² NHS England. 2017. Palliative Care Currency. Available to download from: <https://www.england.nhs.uk/resources/pay-syst/development/palliative-care-development-currency/>

³ HM Government. 2015. Capitation: An Introduction. Available to download from: <https://www.gov.uk/guidance/capitation>

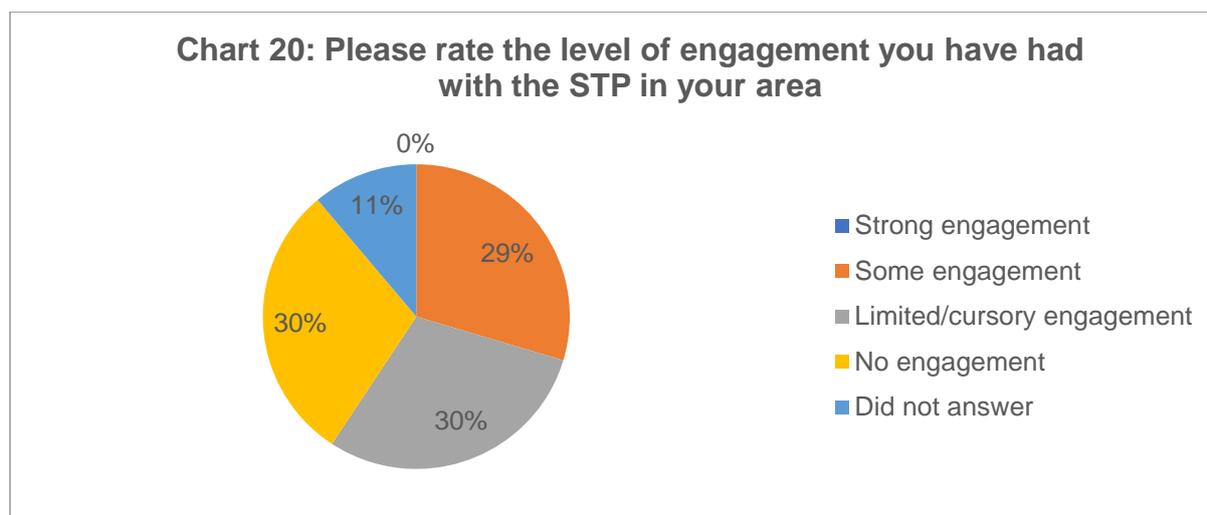
⁴ NHS Year of Care Partnerships. Available to download from: <https://www.yearofcare.co.uk/>

Chart 19: How levels of statutory funding from CCGs and local authorities were determined for 2019/20



Most children’s hospice charities have engaged with their local sustainability and transformation partnerships (STPs) – however, the quality of the engagement is largely poor

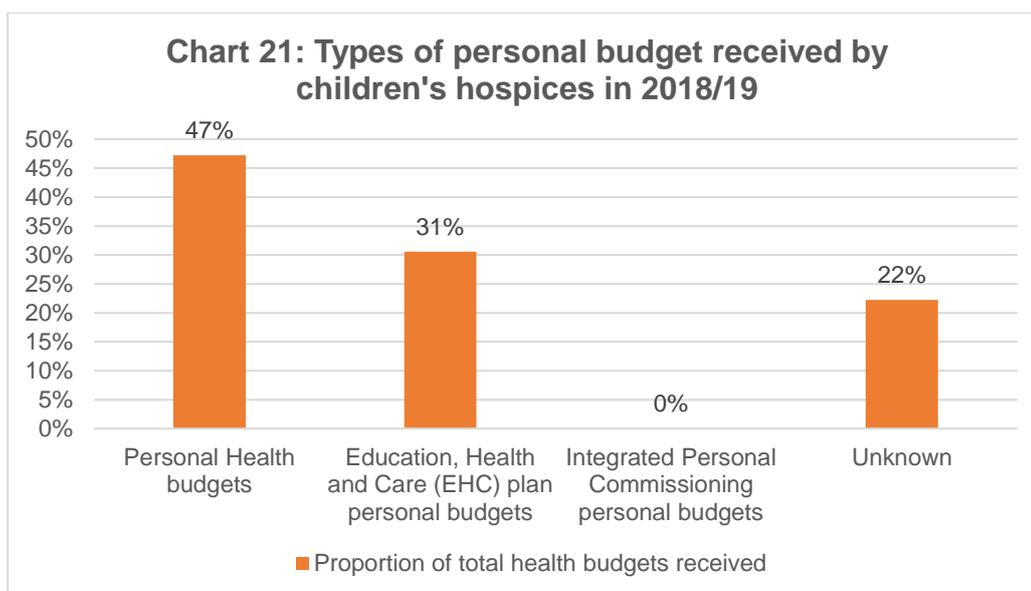
51. Unlike our 2017 survey, no respondents to our 2019 survey reported having a strong engagement with their local STP or ICS (Chart 20). Eight hospices (30%) reported having no engagement at all, while the same number reported ‘limited/cursory engagement’ and a further eight reported ‘some engagement’.



Personal budgets reimburse less than 2% of the average charitable expenditure incurred by our respondents

- 52. Only 10 of the 27 (37%) children’s hospice charities that responded to the survey said they had received funding through personal budgets in 2018/19. Of those receiving personal budget income in 2018/19, the average number of personal budgets per hospice was 3.6. The highest managed by any one hospice was 24.
- 53. With an average caseload of 309 babies, children and young people per children’s hospice charity, this suggests that only 1.2% of children receiving support and care from a children’s hospice charity are using personal budgets. The NHS Long Term Plan⁵ includes a commitment to have 200,000 people using personal health budgets by 2023/24.
- 54. Nine hospices responded with a total value of the personal budgets received. The average amount received by these nine hospices was £67,780. This represents just 1.8% of the average charitable expenditure incurred by children’s hospice charities.
- 55. As shown in Chart 21, of the 36 health budgets reported, 17 (47%) were personal health budgets. No income was recorded through Integrated Personal Commissioning personal budgets.

⁵ NHS England. 2019. Long Term Plan. Available to download from: <https://www.longtermplan.nhs.uk/wp-content/uploads/2019/01/nhs-long-term-plan.pdf>



The public believe children’s hospice charities should receive much more funding than they do

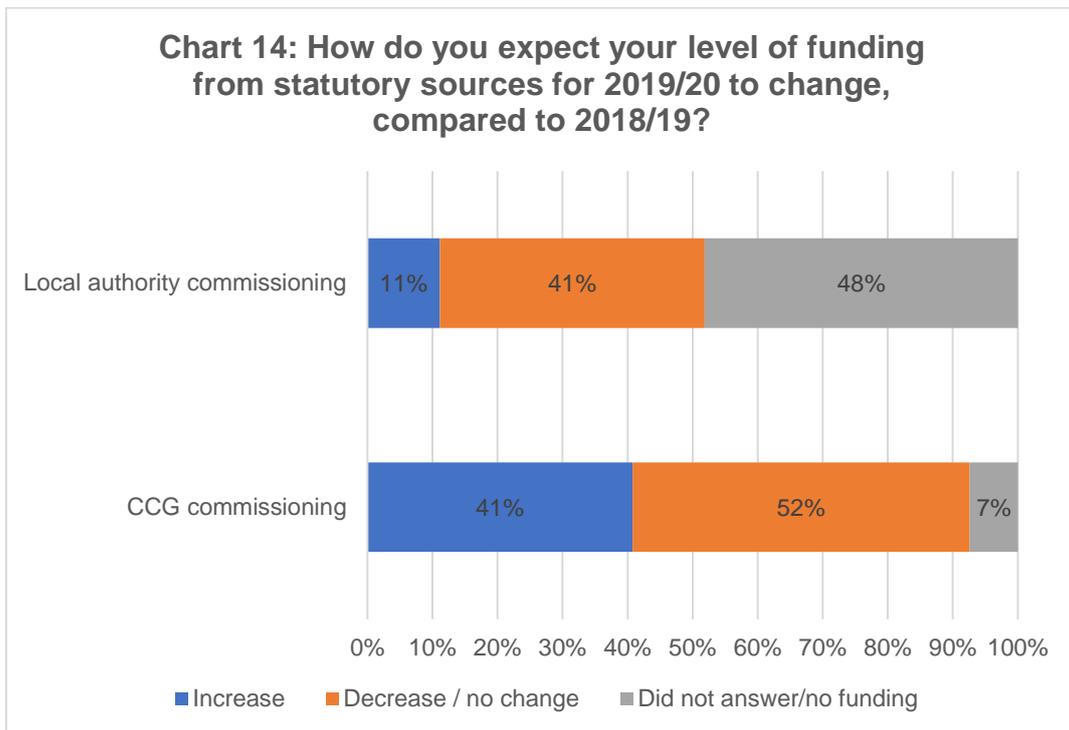
- 56. A new YouGov survey⁶, carried out on behalf of UK charity Together for Short Lives, has found that the public think that children’s hospice charities receive 81% more of the charitable costs they incur from the state than they actually do (38% compared to the real figure of 21%). This answer is based on a response from 2019 GB adults. Together for Short Lives carried out the same survey in 2016.
- 57. When asked what percentage they thought children’s hospice charities should receive from the state, respondents said that children’s hospice charities should receive two and a half times (252%) more than they currently do (74% compared to 21%).
- 58. When they were told how much children’s hospice charities actually receive, nearly four fifths (78%) of respondents thought children’s hospice charities receive too little from the state, which is very similar to the 81% who thought this in 2016. 7% think that the funding level is about right, compared to 8% in 2016. 2% think it is too much, compared to 1% in 2016. 13% do not know, compared to 10% in 2016.

Future funding for children’s hospice charities and other children’s palliative care charities shows little sign of improving

- 59. Children’s hospice charities report that they do not expect their statutory funding to improve significantly over the course of 2019/20. Mean funding per respondent from CCGs in 2017/18 was expected to increase by 0.8% to £366,957.04 compared to the £364,075.96 recorded in 2018/19, based on responses from 27 children’s hospice charities.

⁶ All figures, unless otherwise stated, are from YouGov Plc. Total sample size was 2019 GB adults. Fieldwork was undertaken between 11th - 12th March 2019. The survey was carried out online. The figures have been weighted and are representative of all GB adults (aged 18+). The Fieldwork was carried out by YouGov for Together for Short Lives 11-12 March 2019.

- 60. Mean funding per respondent from local authorities was expected to decrease by 0.1% from the £61,091.85 recorded in 2018/19 to £57,840.58 in 2019/20.
- 61. 41% of 27 respondents expect that funding levels from local authorities will either decrease or stay the same. Over half (52%) of respondents expect the same from CCGs (See Chart 14).
- 62. If average charitable costs increase by the same proportion from 2018/19 to 2019/20 as they did from 2017/18 to 2018/19 (2.7%) the average will increase to £3,780,840.97. With the level of funding expected by children’s hospice charities in 2019/20 – including the £1million uplift in the children’s hospice grant from £11million to £12million – the statutory funding contribution will continue on its downward trend, dropping to 20.4%



What we recommend

1. We call on NHS England to protect and increase the children's hospice grant to £25million. Without an increase, services and care provided by children's hospice charities will be cut.

- In December 2018, Simon Stevens, Chief Executive of NHS England, was quoted in an NHS England statement which committed NHS England to match fund increases in children's hospice charity funding made by CCGs by up to £7million per year, in addition to the Children's Hospice Grant.
- However, in the Long Term Plan, published a few weeks later, NHS England changed the wording of the commitment to include other palliative care services too.
- Together for Short Lives welcomes NHS England's focus on children's palliative care in the Long Term Plan and its commitment to match fund increases in CCG investment by up to £7million per year. We also welcome NHS England's recognition that other, non-hospice services also need equitable and sustainably NHS funding.
- We are, however, now concerned that the Children's Hospice Grant will no longer continue to be paid exclusively to children's hospice charities. When pressed, ministers continue to decline to commit to this, saying they "expect hospices will be significant beneficiaries of the additional funding."
- Crucially the future of the Children's Hospice Grant, which comes directly from NHS England, is material to the sustainability of children's hospice charities in England. It is insecure beyond 2020. This financial uncertainty is putting pressure on children's hospice charity care.

2. We call on the government to fill the local authority funding gap. The Disabled Children's Partnership (DCP), of which Together for Short Lives is a member, has identified a £434million gap in local authority funding for social care for disabled children. The gap includes local authority funding for short breaks for respite provided by children's hospice charities and other children's palliative care charities, including Rainbow Trust Children's Charity.

3. We call on the government to provide parity of funding between children's and adult hospice services in England. Adult hospices receive around 33% of their expenditure from statutory sources, while children's hospice charities only receive 21% on average. In 2016, the Scottish Government committed £30million over five years to Children's Hospices Across Scotland; this amounts to approximately 50% of their charitable costs.

4. We call on the government to develop a funded children's palliative care strategy. This strategy should make sure that 24/7 children's palliative care support can be accessed by seriously ill children and families when and where they need it, across the statutory and voluntary sectors, in hospitals, children's hospice charities and the community.