



Pushed to the limits



**The impact of COVID-19 on children's hospice funding
2019/20-2021/22**



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Introduction

In April and May 2021, Together for Short Lives asked children's hospices across the UK how their funding has changed as a result of the COVID pandemic. We asked what impact this has had on the services they have been able to provide to seriously ill children and their families. We also asked them how they expected this to change in 2021/22.

29 of the UK's 37 children's hospice organisations responded to our survey. Where the term children's hospice is used in this paper, it means children's hospice organisation. Averages have been calculated as a mean of the total responses to a particular question.

Executive summary

1. In 2020/21, average income increased, largely as a result of support from government and the wider state, but behind this, charitable sources of income were badly affected:

- On average, children's hospices reported an income of £6,954,324.79 for financial year 2020/21. This was 6 per cent greater than the £6,576,501.24 income they reported for 2019/20.
- On average, children's hospices each received £1,330,050.72 in emergency funding for hospices in England from HM Treasury or from the equivalent schemes in the other UK nations and regions in 2020/21. Other forms of funding, including the UK Government's Coronavirus Job Retention Scheme and local authority retail grants, provided an average of £1,051,432.50 per children's hospice in 2020/21.
- Yet two fifths (40 per cent) of children's hospices reported that their income had decreased between 2019/20 and 2020/21.
- Unsurprisingly, income sources which depend on face-to-face contact fell dramatically between 2019/20 and 2020/21. On average, income from trading activities fell by over half (57 per cent) from £1,447,822.72 in 2019/20 to £620,436.50 in 2021/22.
- Average income from challenge events fell by over half (58 per cent) from £199,647.56 in 2019/20 to £83,653.50 in 2021/22.
- Income from community fundraising fell by a third (33 per cent) from £549,254.19 in 2019/20 to £367,566.92 in 2021/22.
- Other forms of income generation were also affected: average individual donations fell by 8 per cent from £1,093,993.68 in 2019/20 to £1,009,733.86 in 2020/21.

2. The funding landscape in 2021/22 could push children's hospices to the limits:

- A combination of COVID-related statutory funding schemes coming to an end and the uncertain economic outlook mean that 2021/22 is likely to be much more challenging for children's hospice income.
- On average, children's hospices expect their income to decrease to £5,805,250.72 in 2021/22, a fall of 17 per cent. Over three quarters (77 per cent) expect their income to fall.
- On average, children's hospices expect to report a net deficit of £324,307.97 in 2021/22.
- Individually, over four fifths (83 per cent) children's hospices expect to report a deficit in 2021/22. Only four (14 per cent) expect to report a surplus.
- Children's hospices expect average income from trading activities to increase by 126 per cent to £1,399,619.60, although this would still be 3 per cent below the 2019/20 figure.
- Children's hospices expect average income from challenge events to increase by 89 per cent to £158,020.31, although this would still be 21 per cent below the 2019/20 figure.
- Children's hospices expect average income from community fundraising to increase by 19 per cent to £437,728.68, although this would still be 20 per cent below the 2019/20 figure.
- Worryingly, other forms of fundraising are likely to generate even less income in 2021/22 compared to 2020/21; children's hospices expect average income from individual donations to fall by nearly a fifth (18 per cent) to £824,779.93 in 2021/22, an overall fall of a quarter (25 per cent) compared to 2019/20.

3. Local authority funding for children’s hospices in England is not enough to make sure all seriously ill children and their families can access the breaks they desperately need

- Despite the welcome 29 per cent increase in local authority funding for children’s hospices between 2019/20 and 2020/21, it was still a small proportion (4 per cent) of the charitable costs incurred by children’s hospices in 2020/21. It is also small considering the proportion of children’s hospice activity that short breaks for respite represents – and the fact that local authorities have a legal duty to ensure disabled children can access short breaks.
- Despite the average increase in local authority funding across England, funding varies widely between children’s hospices. Three quarters (74 per cent) of children’s hospices reported a cut or freeze in their local authority funding between 2019/20 and 2020/21.
- 63 per cent of children’s hospices expect their local authority funding to be cut or frozen between 2020/21 and 2021/22.
- Children’s hospices in England benefited from the larger Children’s Hospice Grant, which totalled £15 million across the sector in 2020/21. Average funding from NHS clinical commissioning groups (CCGs) in England increased by 3 per cent between 2019/20 and 2020/21. On average, CCG funding represented 16 per cent of their charitable expenditure. However, as with local authorities, funding varies between children’s hospices. As many (13) children’s hospices (48 per cent) reported that their CCG funding fell between 2019/20 and 2020/21 as reported an increase.
- 11 (41 per cent) of children’s hospices expect their CCG funding to fall between 2020/21 and 2021/22 compared to 12 (44 per cent) who expect their CCG funding to increase.

4. We are calling on the public to help children’s hospices to be there for families, today and long into the future, by pushing themselves to their limits this Children’s Hospice Week and raising vital funds – so children’s hospices aren’t pushed to theirs

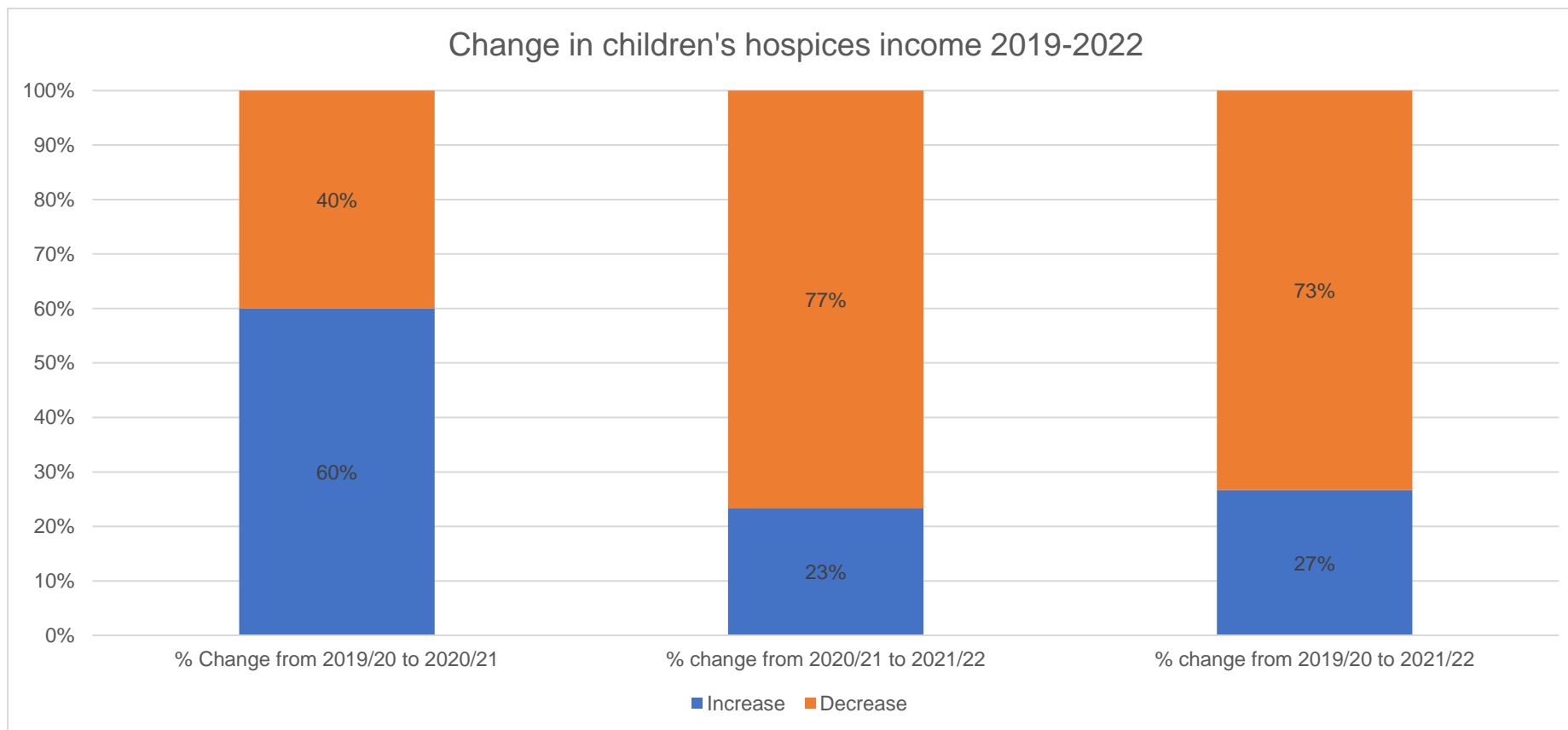
- 2020/21 saw a fantastic response across society, including government, corporate partners and the public, to make sure our children’s hospices could continue to offer vital care to seriously ill children and families. But, without some of these funding streams in 2021/22, children’s hospices will be pushed to the limits.
- We are asking everyone to push themselves to their limits – so children’s hospices aren’t pushed to theirs.

- In particular, we are calling on HM Treasury to fill the £434 million disabled children's social care funding gap in England by creating an annual ring-fenced disabled children's grant. From this, local authorities would be able to make an equitable and sustainable funding contribution to short breaks for seriously ill children.
- The government should also establish a £41 million Disabled Children's Innovation Fund in England. This would provide financial backing to organisations delivering ground-breaking support and approaches in early intervention, such as short breaks for respite.
- The growth in the Children's Hospice Grant is helping to make NHS funding for children's hospices more equitable and sustainable. But we call on the government and NHS England and NHS Improvement to hold NHS CCGs, local authorities and integrated care systems (ICSs) to greater account for the way in which they fund children's palliative care services, including children's hospices.

Our detailed findings

Income

1. On average, children's hospices reported an income of £6,954,324.79 for financial year 2020/21. This was 6 per cent greater than the £6,576,501.24 income they reported for 2019/20.
2. On average, children's hospices expect their income to decrease to £5,805,250.72 in 2021/22, a fall of 17 per cent.
3. This means that in the period 2019/20-2021/22, children's hospices expect their income to have fallen by 12 per cent.
4. Individually, 18 (60 per cent) children's hospice organisations reported that their income increased between 2019/20 and 2020/21. 12 (40 per cent) reported that it decreased.
5. Seven (23 per cent) children's hospices expect their income to increase between 2020/21 and 2021/22. 23 (77 per cent) expect their income to fall.
6. This means that in the period 2019/20-2021/22, eight (27 per cent) children's hospices expect their income to have increased. 22 (73 per cent) expect their income to have fallen.

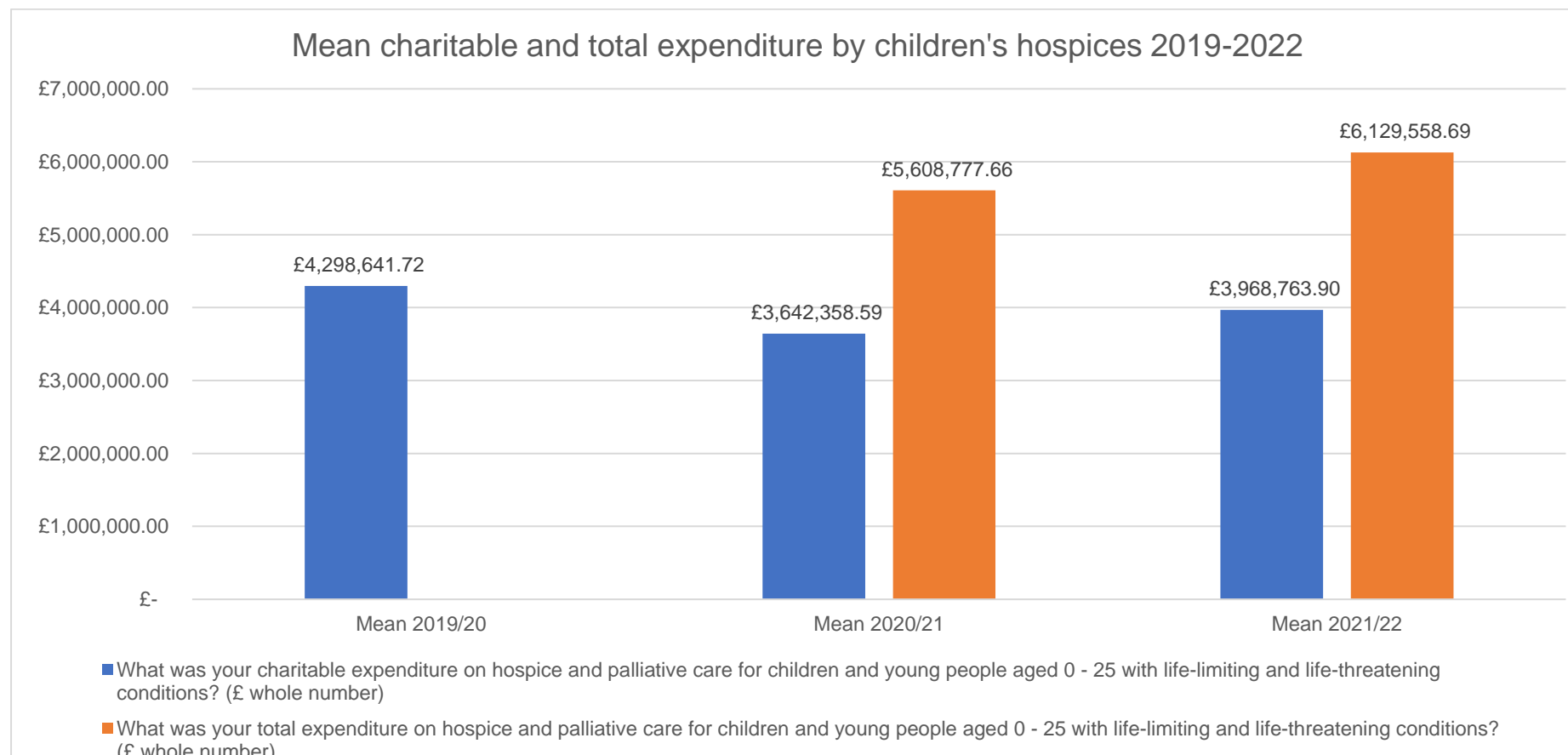


Charitable expenditure

7. On average, children's hospices reported that their charitable expenditure fell 15 per cent from £4,298,641.72 in 2019/20 to £3,642,358.59 in 2020/21.
8. On average, they expect their charitable expenditure to rise to £3,968,763.90 in 2021/22. This represents an increase of 9 per cent compared to 2020.21. However, it is an overall 8 per cent decrease compared to 2019/20.

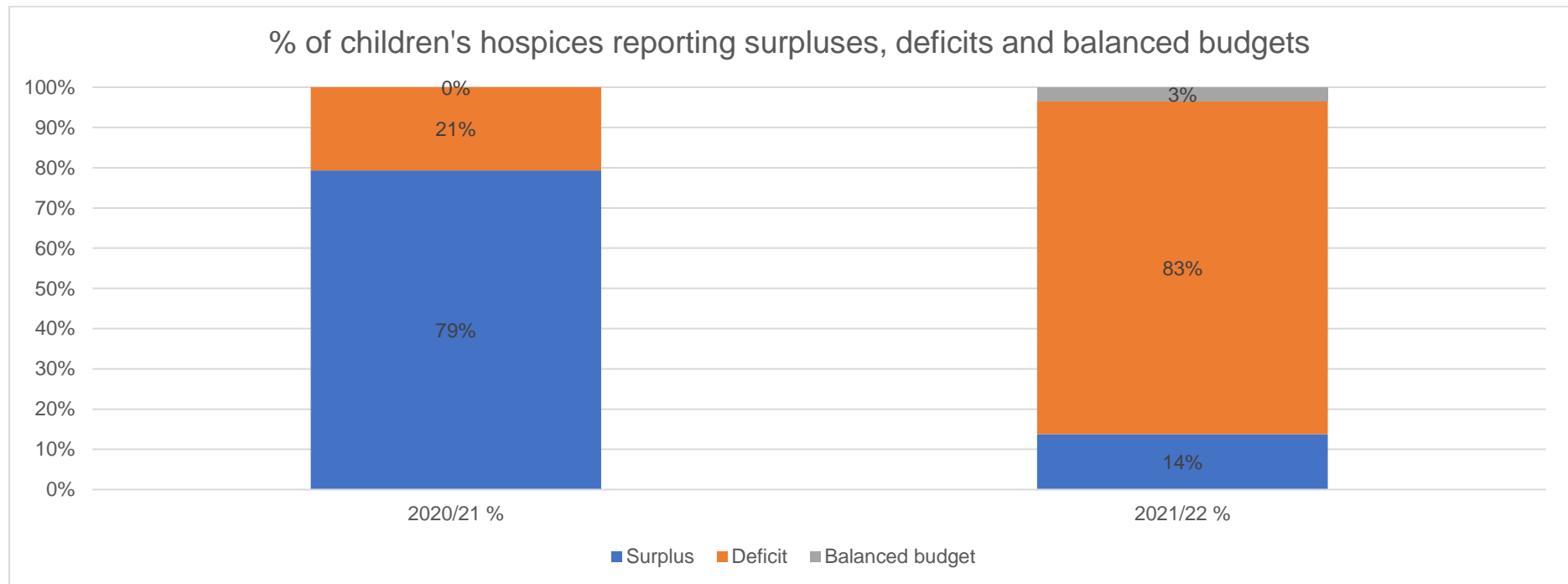
Total expenditure

9. On average, children's hospices reported a total expenditure of £5,608,777.66 in 2020/21. On average, they expect this to increase by 9 per cent to £6,129,558.69 in 2021/22.



Net income/expenditure

10. On average, children's hospices reported a net surplus of £1,345,547.14 in 2020/21, calculated by subtracting total expenditure from total income.
11. Individually, 23 (79 per cent) children's hospices reported a net surplus in 2020/21. Six (21 per cent) reported a net deficit.
12. On average children's hospices expect to report a net deficit of £324,307.97 in 2021/22.
13. Individually 24 (83 per cent) children's hospices expect to report a deficit in 2021/22. Only four (14 per cent) expect to report a surplus. One children's hospice (3 per cent) expects to achieve a balanced budget.



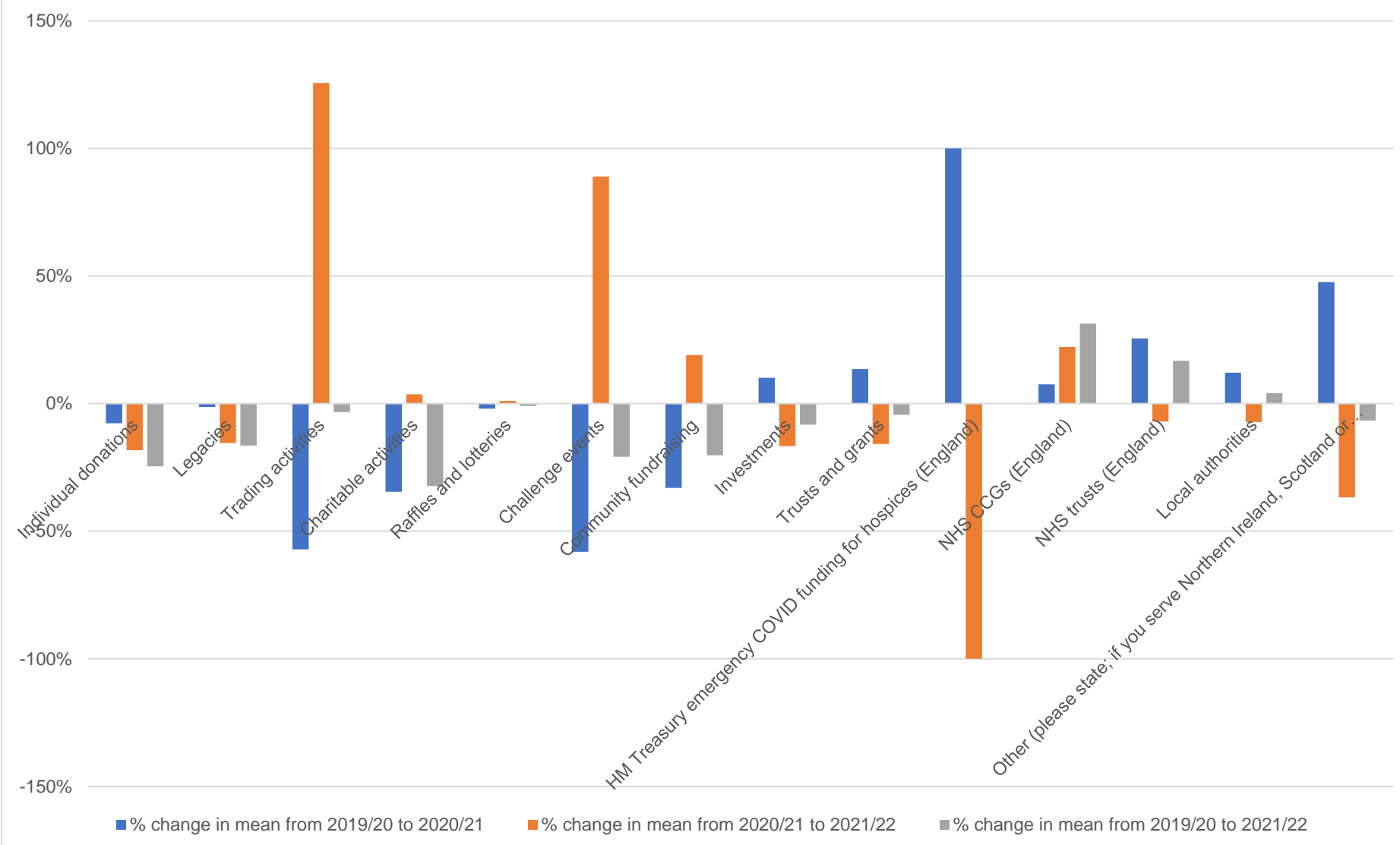
Income by source

14. Unsurprisingly, income sources which depend on face-to-face contact fell dramatically between 2019/20 and 2020/21. On average, income from trading activities fell by 57 per cent from £1,447,822.72 in 2019/20 to £620,436.50 in 2021/22.
15. Average income from challenge events fell by 58 per cent from £199,647.56 in 2019/20 to £83,653.50 in 2021/22.
16. Income from community fundraising fell by 33 per cent from £549,254.19 in 2019/20 to £367,566.92 in 2021/22.
17. Other forms of income generation were also affected: average individual donations fell by 8 per cent from £1,093,993.68 in 2019/20 to £1,009,733.86 in 2020/21.
18. These cuts were offset by support from the four UK governments, the NHS and local authorities. On average, children's hospices each received £1,330,050.72 in emergency funding for hospices in England from HM Treasury or from the equivalent schemes in the other UK nations and regions in 2020/21. Other forms of funding, including the UK Government's Coronavirus Job Retention Scheme and local authority retail grants, provided an average of £1,051,432.50 per children's hospice in 2020/21.
19. However, a combination of COVID-related statutory funding schemes coming to an end and the uncertain economic outlook mean that 2021/22 is likely to be much more challenging for children's hospice income.
20. Children's hospices expect average income from trading activities to increase by 126 per cent to £1,399,619.60, although this would still be 3 per cent below the 2019/20 figure.
21. Children's hospices expect average income from challenge events to increase by 89 per cent to £158,020.31, although this would still be 21 per cent below the 2019/20 figure.
22. Children's hospices expect average income from community fundraising to increase by 19 per cent to £437,728.68, although this would still be 20 per cent below the 2019/20 figure.
23. Worryingly, other forms of fundraising are likely to generate even less income in 2021/22 compared to 2020/21.
24. Children's hospices expect average income from individual donations to fall 18 per cent to £824,779.93 in 2021/22, an overall fall of 25 per cent compared to 2019/20.

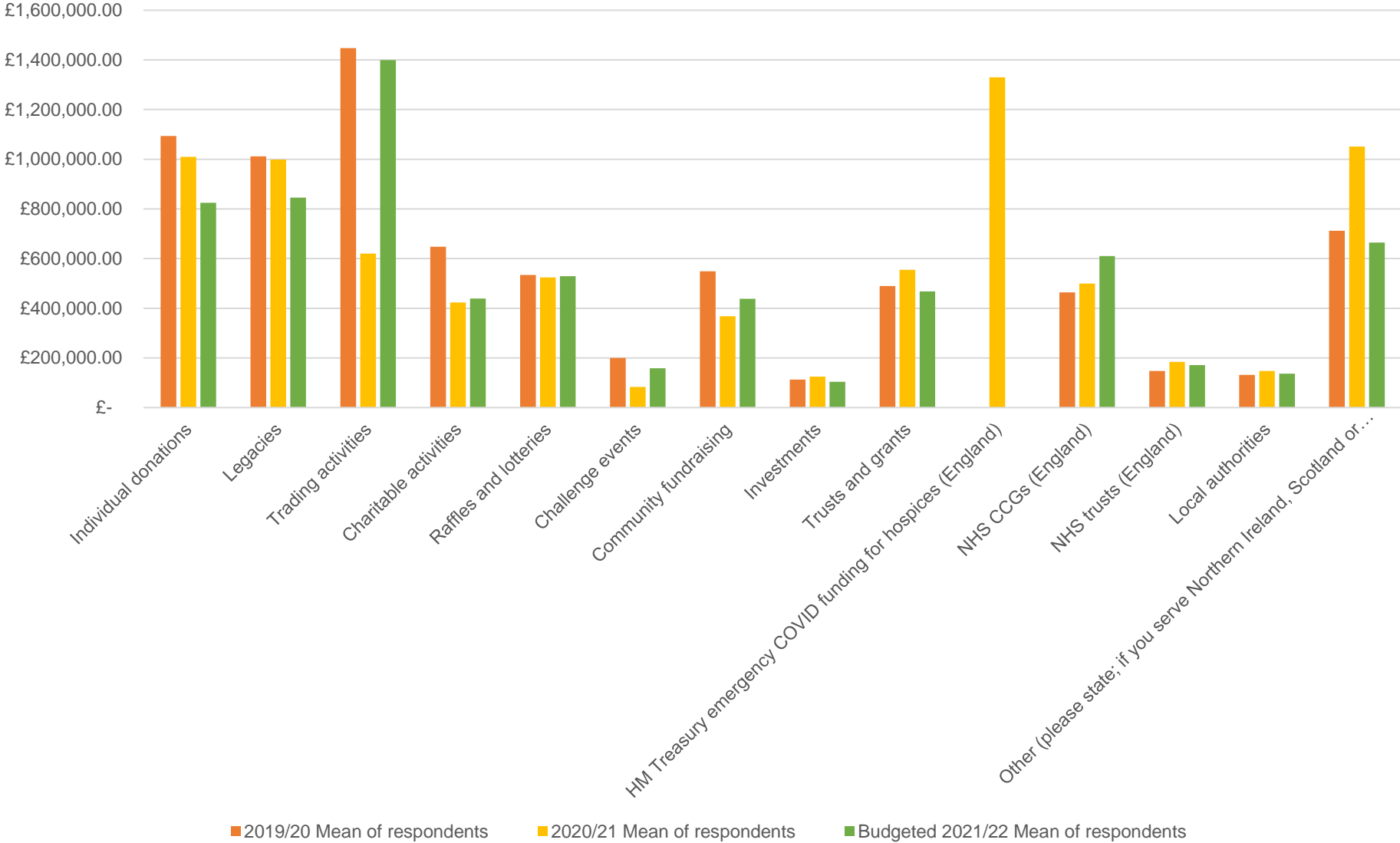
25. Children's hospices expect average income from legacies to fall 15 per cent to £845,304.75 in 2021/22, an overall fall of 16 per cent compared to 2019/20.

26. Children's hospices expect average income from trusts and grants to fall 16 per cent to £467,606.18 in 2021/22, an overall fall of 4 per cent compared to 2019/20.

% change in mean children's hospice income by source 2019-2022



Mean children's hospice income by source 2019-2022



Impact of funding changes on services

27. Changes in funding have had the most profound impact on the short breaks for respite, therapies and emotional and/or psychological support that children's hospices are able to offer to seriously ill children and their families:

- 10 (33 per cent) of children's hospices report that they have cut their short breaks.
- Six (20 per cent) have cut their play therapy services.
- Five (17 per cent) have cut their music therapy services.
- Four (13 per cent) have cut their emotional and/or psychological support services.

28. Two (7 per cent) children's hospices have stopped providing their hospice at home services completely, while one (3 per cent) has stopped providing set-down care.

29. In contrast, in response to efforts to discharge as many seriously ill children as possible from hospital settings during the pandemic, four (13 per cent) of children's hospices have expanded the end of life care they offer. Four (13 per cent) have expanded their symptom management services, while four (13 per cent) have expanded their emotional and/or psychological support services.

What children's hospices have told us about their funding and the impact this has had

"A priority focus has been placed on the preservation of services. This has included finding new and flexible ways of delivering care, such as embracing technology to maintain connectivity and extend reach."

Ty Hafan Children's Hospice

"Although there has been a loss of some income sources mainly in fundraising and retail, we have been able to continue to provide services to children and families. As a result of the pandemic we have had to diversify parts of our offer to deliver some services in a different way."

Acorns Children's Hospice

“Decisions were based on infection control and covid restrictions and the needs of the service at the time. Anticipated reductions in funding meant we were planning cutbacks to services. These would have been short breaks, hospice at home, emotional and psychological support and possibly therapies. However, the announcement of government Covid funding provided assurance which enabled us to continue to provide these services without the planned cutbacks.”

Demelza Hospice Care for Children

“We had to make 40 per cent workforce redundant due to drop in income.”

Zoe’s Place Trust

“Regular respite breaks by nurses and carers played a vital part in the whole family's wellbeing during the pandemic. This was only possible with the emergency Hospice grant.”

Julia’s House Children’s Hospice

“Redundancies were made in the complementary therapy, wellbeing and play therapy teams. Play therapy has been completely stopped and staff redundant or in suitable alternative employment. Psychological services now only working with high risk interventions and specialist counselling. Early intervention work was cut and staff made redundant... Several income streams were severely affected with the lock-downs and the Charity relied on the various Government assistance schemes including the Hospices grant. This enabled Julia's House to maintain the essential nursing and care services so desperately needed by the families.”

“Short term NHS COVID funding enabled us to support the NHS with COVID response but services were stopped when the funding ceased. We have very little notice – eg on week to step down a pan Essex bereavement crisis support line. This was not ethical and would have put patients at risk so we continued to provide a planned and phased discharge on to other services which has cost the charity financially.”

Havens Hospices

“The CCG match funding has enabled us to expand our hospice at home service and facilitate more BCYP to die at home. We reduced our music therapy offer due to the pandemic rather than funding. We saw increased step down referrals which was funded via NHSE/I Covid fund.”

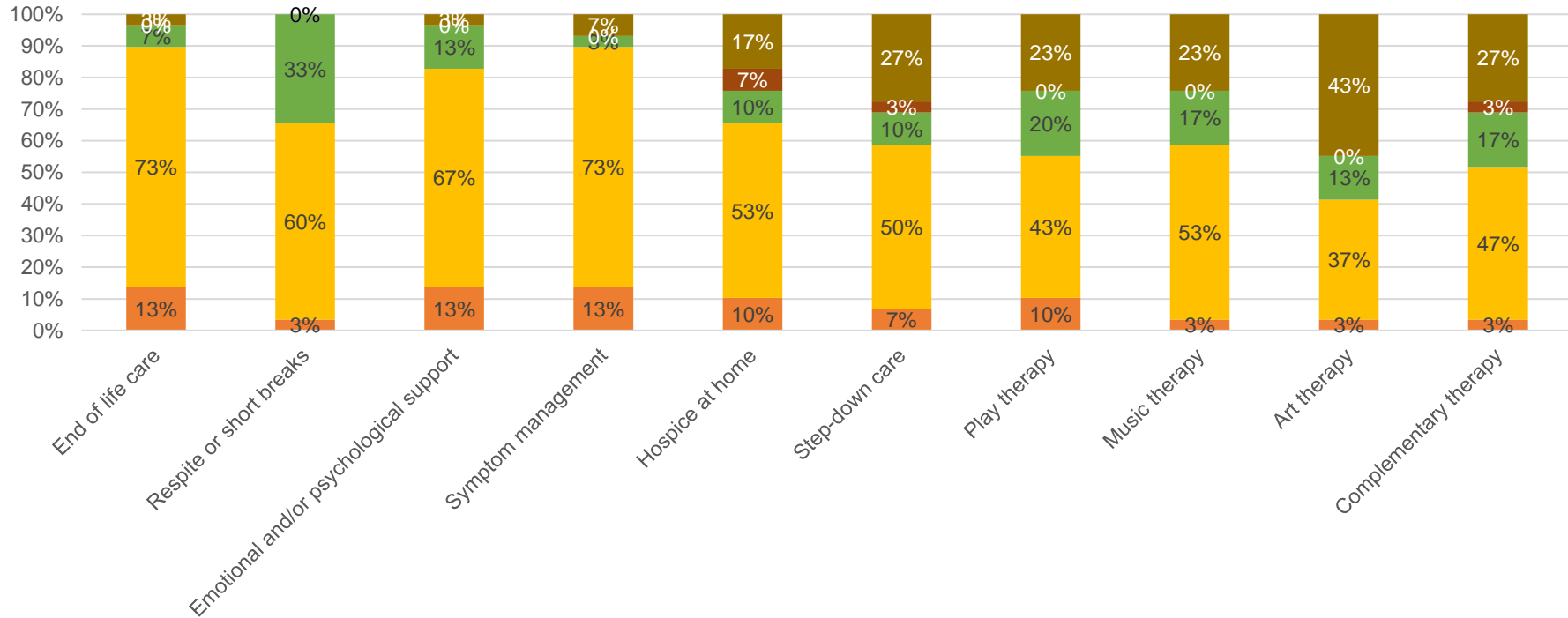
“(We have a) closer working relationship with our NHS integrated care system (ICS). Match funding has enabled us to explore integrated nursing posts with NHS.

Haven House Children’s Hospice

“Launched a COVID appeal, sourced all government retail grants, utilised furlough scheme, redeployed care staff, raised funds through continuing care packages.”

Forget Me Not Children’s Hospice

What impact has any change in funding had on the services you provide to children and young with life-limiting and life-threatening conditions aged 0 – 25? (Please select one for each type of care)?

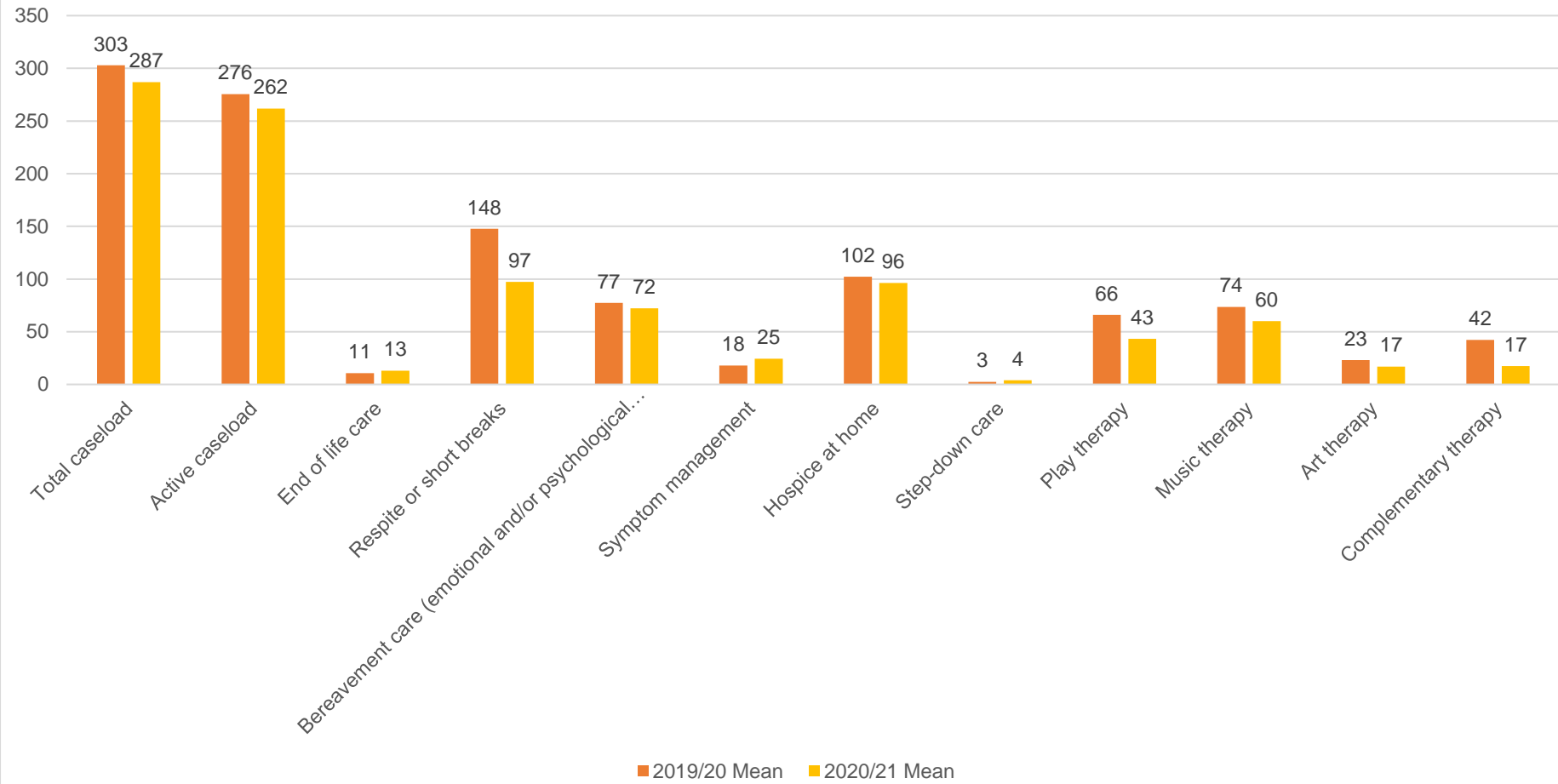


- What impact has any change in funding had on the services you provide to children and young with life-limiting and life-threatening conditions aged 0 – 25? (Please select one for each type of care)? Not applicable - we do not provide it %
- What impact has any change in funding had on the services you provide to children and young with life-limiting and life-threatening conditions aged 0 – 25? (Please select one for each type of care)? Stopped providing it %
- What impact has any change in funding had on the services you provide to children and young with life-limiting and life-threatening conditions aged 0 – 25? (Please select one for each type of care)? Cut %
- What impact has any change in funding had on the services you provide to children and young with life-limiting and life-threatening conditions aged 0 – 25? (Please select one for each type of care)? No impact %
- What impact has any change in funding had on the services you provide to children and young with life-limiting and life-threatening conditions aged 0 – 25? (Please select one for each type of care)? Expanded %

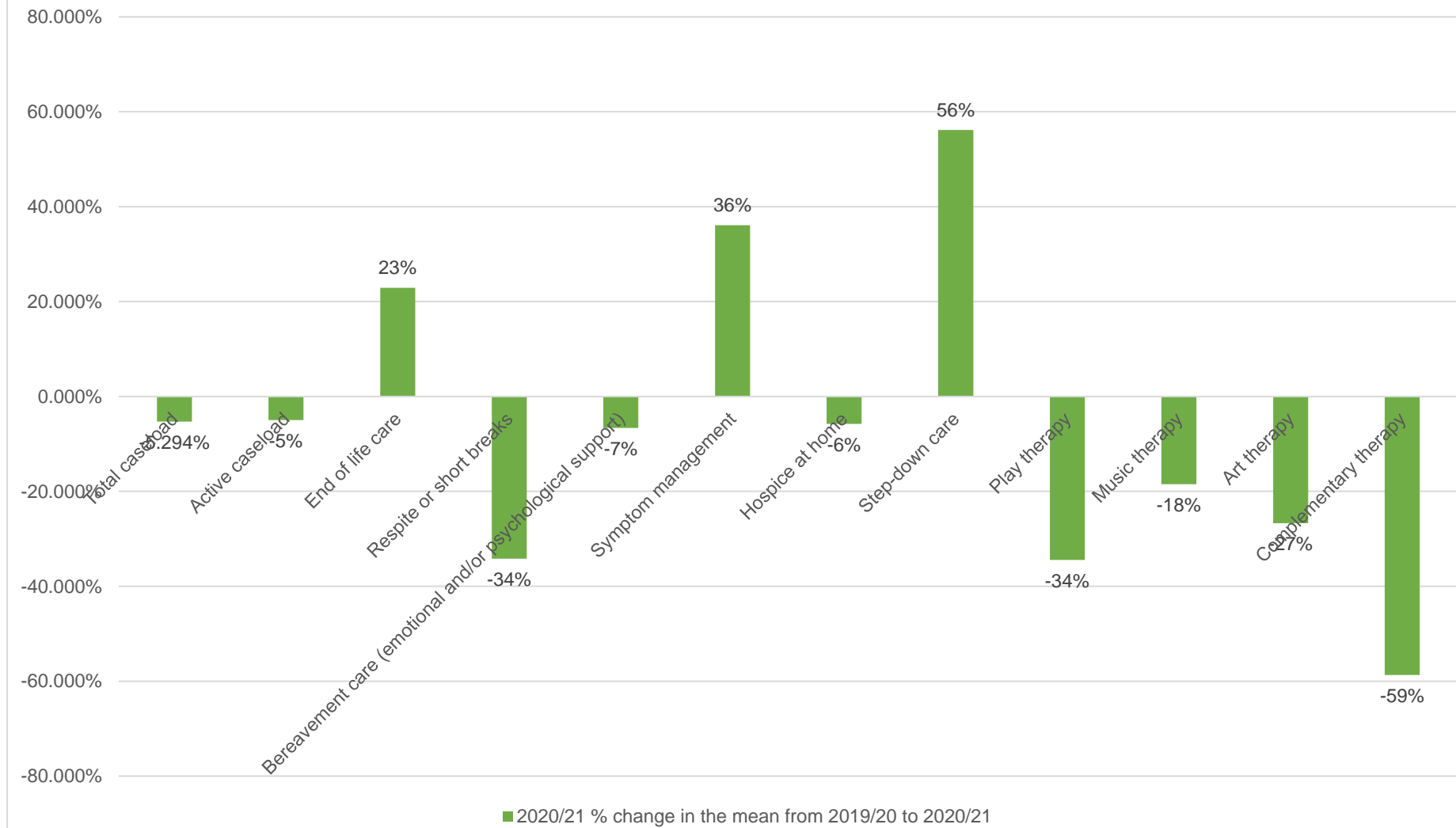
Active caseloads

30. The trends in services expanding and contracting are reflected in changes in the numbers of seriously ill children and families that children's hospices have been caring for.
31. Among the 29 children's hospices that responded to our survey, the total active caseload of seriously ill children across the UK was 7,991 in 2019/20, an average of 276 children per children's hospice. This fell by 5 per cent to 7,593 in 2020/21, an average of 262 children per children's hospice. This perhaps reflects the number of families who chose not to access children's hospice services in 2020/21 because they were shielding and/or were keen to minimise face-to-face contact with professionals.
32. Of this active caseload, the average number of children receiving end of life care increased by 23 per cent from 11 to 13 between 2019/20 and 2020/21. The average number receiving symptom management services increased by 36 per cent from 18 in 2019/20 to 25 in 2020/21. The average number receiving step-down care increased by 56 per cent from 3 in 2019/20 to 4 in 2020/21.
33. The average number of children receiving short breaks for respite fell 34 per cent from 148 in 2019/20 to 97 in 2020/21. The average number receiving play therapy fell by 34 per cent from 66 in 2019/20 to 43 in 2020/21. The average number receiving complementary therapy fell 59 per cent from 42 in 2019/20 to 17 in 2020/21.

Mean caseloads 2019/20 and 2020/21



% change in mean caseloads from 2019/20 to 2020/21



Mitigating the impact of changes in funding

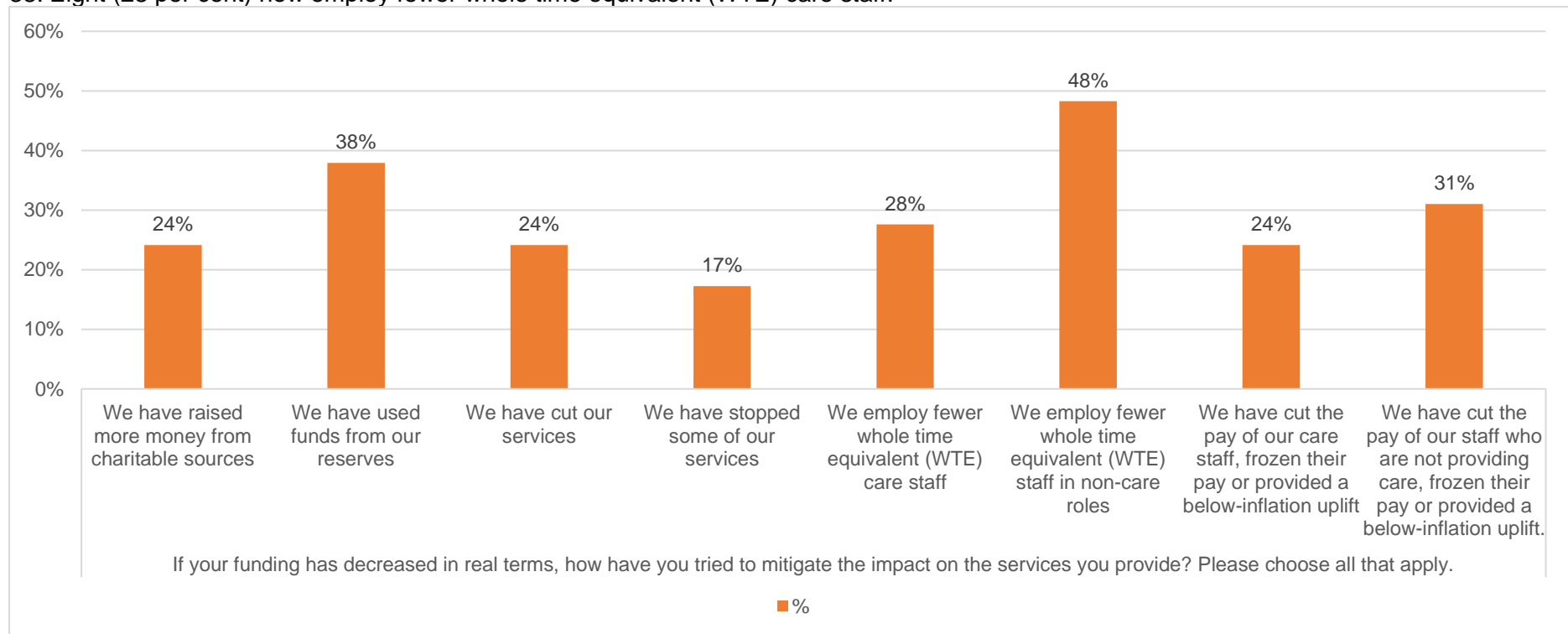
34. Where children’s hospices have experienced real terms cuts to their funding (where funding has increased in cash terms but below the rate of inflation, not changed or fallen), they have most commonly cut staff numbers, cut or frozen pay or used funds from their reserves.

35. 14 (48 per cent) have been forced to employ fewer whole time equivalent (WTE) staff in non-care roles.

36. 11 (38 per cent) have used funds from their reserves.

37. Nine (31 per cent) have cut the pay of our staff who are not providing care, frozen their pay or provided a below-inflation uplift.

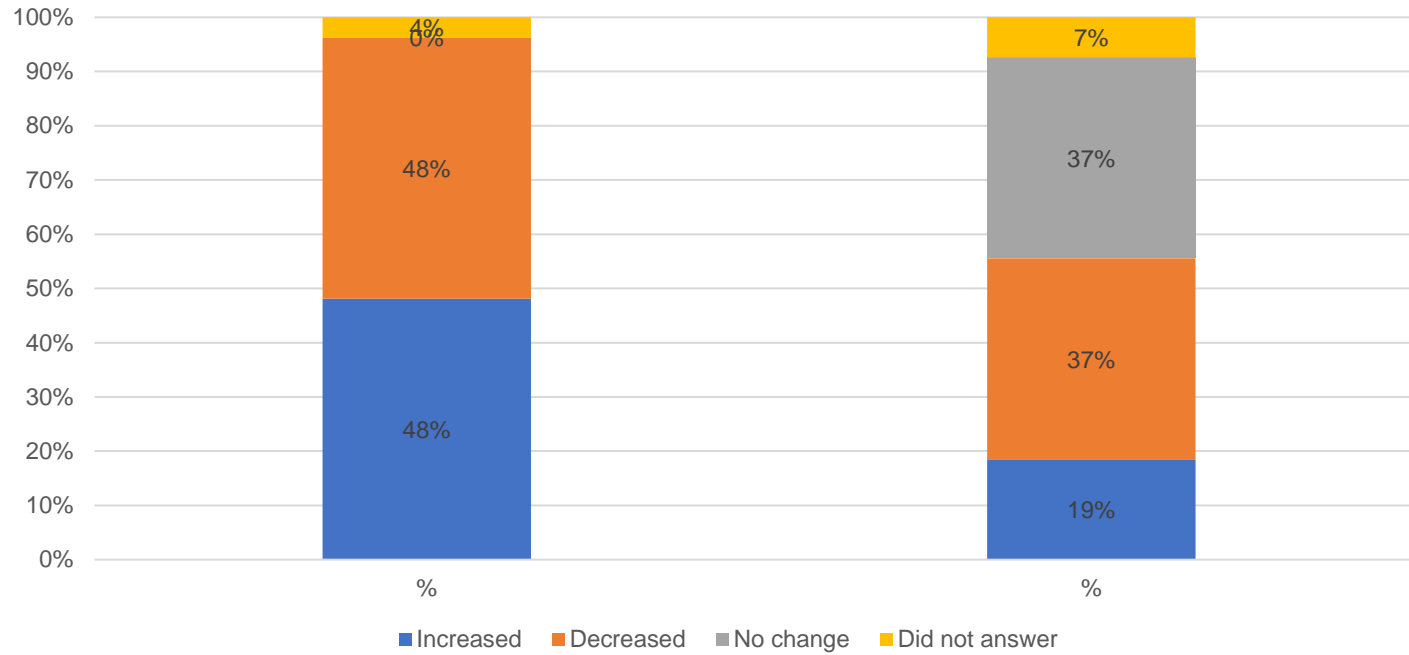
38. Eight (28 per cent) now employ fewer whole time equivalent (WTE) care staff.

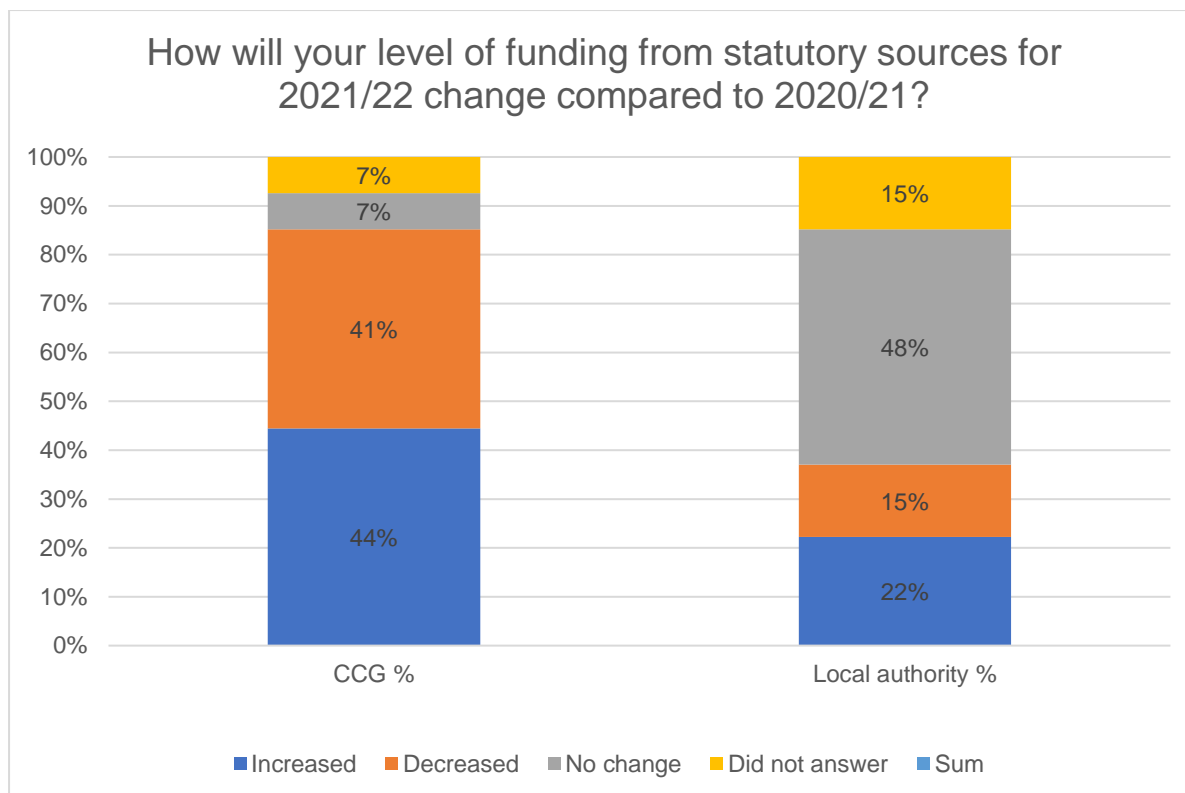


Local authority funding in England

39. Of the 26 children's hospices in England that told us how much they received from their local authorities for providing care to seriously ill children, they received an average of £126,587.65 each. This represented a welcome 29 per cent increase on the £98,003.97 reported in 2019/20, although is still a small proportion (4 per cent) of the charitable costs incurred by children's hospices in 2020/21. It is also small considering the proportion of children's hospice activity that short breaks for respite represents – and the fact that local authorities have a legal duty to ensure disabled children can access short breaks.
40. Despite the average increase in local authority funding across England, funding varies widely between children's hospices. More (10) children's hospices (37 per cent) reported a cut in local authority funding between 2019/20 and 2020/21 than the five (19 per cent) that reported an increase. 10 (37 per cent) reported that their local authority funding did not change. This means that three quarters (74 per cent) of children's hospices reported a cut or freeze in their local authority funding between 2019/20 and 2020/21.
41. A majority of children's hospices also expect their local authority funding to be cut or not to change between 2020/21 and 2021/22. 4 (15 per cent) expect funding to decrease compared to 13 (48 per cent) who expect it not to change. Only six (22 per cent) expect it to increase.

How has your level of funding from statutory sources for 2020/21 changed compared to 2019/20





Local NHS funding in England

42. Of the 27 children’s hospices in England that told us how much they received from their local NHS clinical commissioning groups (CCGs), average funding increased by 3 per cent between 2019/20 and 2020/21. On average, this represented 16 per cent of their charitable expenditure. Where increases have occurred, it is perhaps due to CCGs providing additional funding to help mitigate the impact of the pandemic, in addition to the NHS Long Term plan children’s palliative care match funding.

43. However, as with local authorities, funding varies between children’s hospices. As many (13) children’s hospices (48 per cent) reported that their CCG funding fell between 2019/20 and 2020/21 as reported an increase.

44. 11 (41 per cent) of children's hospices expect their CCG funding to fall between 2020/21 and 2021/22 compared to 12 (44 per cent) who expect their CCG funding to increase. Two (7 per cent) children's hospices expect their CCG funding not to change, which means that a greater proportion (48 per cent) of children's hospices expect a freeze or a cut in funding as opposed to an increase (44 per cent).

What children's hospices have told us about their statutory funding

"Funding caps do not allow for service expansion and flexibility to support those families who need more than the annual allocation of respite nights. Annual statutory income is not sufficient to cover staffing costs in line with NHS agenda for change."

Richard House Children's Hospice

"The amount of statutory funding we receive is very low as a per cent of the charitable activities spend annually, c16-17 per cent. This means we rely on our income generation team to fund the remaining costs. The recent increased NHSE annual childrens grant is welcomed but as yet we do not know what our allocations are for this year or the next two. It will reduce the reliance on our fundraising team to a small extent but the lion's share of the service we provide is paid for by supporters. To be able to substantially reduce that reliance would remove the perpetual need to fundraise for vast sums in order to exist, in order to do what we do. It would provide a greater level of comfort and reassurance to know that a substantial element of our service had much higher guaranteed levels of funding year on year with the fundraising burden at a more manageable, realistic level. The uncertainty and variability about the fundraising income year to year is constant worry and challenge for the organisation."

Helen and Douglas House

"Demand is high and the cost of providing care far out-weighs the funding from statutory services and given the pandemic it is much more difficult to raise funds. However we are incredibly grateful for the government support schemes that have been in place and that we were able to access during the height of the pandemic."

Butterwick Hospice Care

"Regrettably many of our CCGs did not apply for the match funding from government. This was generally due to a gap in communication between the recipients of the notification about the funding (to finance officers) and commissioners for children's palliative care and the short

timescale in which to apply. This has meant palliative care for children and young people has not benefited from the initiative which was designed to support them. We look forward to improved joint working between Local Authorities and CCG's in the form of ICS's so that the needs of the child can be at the centre of decision-making and disagreements between local authorities and CCG's about who should pay for care can be reduced, as this has a negative impact on service delivery and often leads to the charity picking up the cost."

Demelza Hospice Care for Children

"Discussions are starting across the ICS with regards to a sustainable funding solution in future years. There is a lack of clarity for this current financial year and so we still only have one very small recurrent CCG grant. As with other years, we will seek handouts later on in the year which are then non recurrent, helpful from a cash flow perspective, but do not allow us to plan effectively."

Forget Me Not Children's Hospice

"We receive an annual grant from most CCG's in our catchment area, but these are not representative of the work/ number of children in the CCG i.e. a CCG with small numbers of children allocate a larger grant than a CCG with the highest number of children. there is no recognition of the differing services in each CCG and therefore the impact to the service we deliver e.g some CCG provide 6 day community nursing service, another CCG provides no community nursing service."

Bluebell Wood Children's Hospice

"We remain almost entirely reliant on charitable donations to fund our services, the costs of which increase yearly with inflation and the increased complexity of the children for whom we are caring. If costs continue to increase above the rate we can increase our charitable donations we will need to reduce services to bring income and expenditure into line."

Hope House Children's Hospice

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