

Tŷ Hafan & Tŷ Gobaith Consultation Response: Draft Budget for 2022/23

Tŷ Hafan and Tŷ Gobaith children's hospices welcome the opportunity to comment on the Finance Committee's call for information in relation to the Welsh Government's draft budget for 2022-2023.

Our response focuses around two key areas, covered by questions three (financial preparedness) and six (scrutiny of specific areas of the budget).

Background

It is estimated that there are around 3,600 children in Wales living with a life-limiting condition. Approximately 800 of these children have ongoing palliative care needs which require contact with hospital services, only about half of whom access respite at children's hospices. A recently commissioned incidence and prevalence study will give us more up-to-date figures about the numbers of children with palliative care needs, and it is expected this figure will rise significantly¹. A full breakdown of the children we support by both local health board and local authority can be found in [appendix 1](#).

As Wales' only children's hospices, together our charities Tŷ Hafan and Tŷ Gobaith offer holistic, child-centered care, free at the point of service, for more than 450 families across Wales, providing over 2500 nights of respite care each year – a service not available from the NHS or Local Health Boards. Despite this, the two hospices receive less than 10 percent of our funding from statutory sources in Wales – that is the Welsh Government, Health Boards and Local Authorities. We are dependent on the generosity of the Welsh public to raise over 90 percent of our annual funding (circa £7.5m for both hospices), a situation that is increasingly untenable given our cost base is going up and our income sources compromised by both economic conditions and the pandemic.

Our 'Family Voices' report (found in appendix 2), jointly published by Tŷ Hafan and Tŷ Gobaith in 2020, made clear that the families of children with life-limiting conditions need both more and longer respite, enabling them to have essential breaks from their caring responsibilities. In order to meet this need, we require a sustainable funding solution that will provide us with financial certainty and confidence to extend the depth and breadth of our services. Vitally, this will also reduce the burden of unplanned and crisis NHS admissions at a time when the service is under pressure. It will also offer a greater choice to children and their families, and ultimately, fulfil the government's ambition to create a more compassionate Wales.

To address this situation, we are calling on the Welsh Government to introduce a 'Lifeline fund' - that is sustainable funding for Wales' children's hospices, and the children with life-limiting conditions, above the current levels of less than 10 percent that we receive annually. While we welcome recent commitments to review the funding for hospices, we remain concerned that the different nature of children's hospices is not fully understood. We believe that to achieve true progress for the vulnerable children and their families we support requires a

¹ 1 In August 2020, the All-Wales End of Life Board Core Group approved the research proposal: "Trends in the Prevalence and Complexity of Children with a Life-limiting or Life-threatening condition in Wales". We anticipate this will report later in 2021.

whole-Senedd approach. We would like to see the Finance Committee at the vanguard, scrutinising budget allocations and ensuring that the Welsh Government find and allocate additional statutory funding for third sector children's hospices. Together we must ensure that no child with complex life-limiting conditions, or their families, goes without the support he or she needs - regardless of where they live in Wales. We would welcome opportunities to work with the Committee to develop recommendations for the Government in this area.

Question 3: How financially prepared is your organisation for the 2022-23 financial year, and how can the budget give you more certainty in planning and managing budgets given the ongoing volatility and uncertainty?

Together, Tŷ Hafan and Tŷ Gobaith receive less than 10 percent of their funding from statutory sources, including Welsh Government, Local Health Boards, Local Authorities and Regional Partnership Boards. This is, by some distance, the lowest allocation of any nation in the UK. Our hospices' respective Income Generation teams are left to fundraise for over 90 percent of our funding, relying on the generosity of the Welsh public to ensure provision of vital pediatric palliative care services.

While the hospices have received some support from statutory sources – for example Tŷ Gobaith receives £220,000 from Betsi Cadwaladr Health Board as part of the National Hospice Grant – such funding does not equate to the services provided; nor does it reflect the need for palliative care services across Wales.

Despite providing end of life care and respite to more than 20 families in Powys, Tŷ Gobaith receives only £6,700 each year from Powys Teaching Health Board and has no service level agreement or contract with the Health Board, highlighting the fragility of the existing arrangements.

Similarly, Tŷ Hafan, which supports families from across six of Wales' Health Boards, received £489,370, including commissioned bed income of circa £128k from public funding and the Health Boards in 2019/20. This equates to around 6% of the charity's income and does not reflect the services offered or the support provided to hundreds of children and families across Wales.

This means that the majority of the income generated by both hospices must come through different activities, all of which are vulnerable to economic (and pandemic) conditions, the generation of which involves considerable cost to the hospices:

- One-off or regular donations from individuals
- Charity retail shops across Wales
- Organised fundraising events
- Lottery
- Businesses fundraising or pro-bono service provision
- Legacy gifts, i.e., supporters leaving gifts in their wills
- Fundraising activities by individuals, schools, churches and community groups
- Non-recurring funding, for example Tŷ Hafan has a commissioned bed, which is available to local authorities and local health boards at a cost. This is essentially spot-purchased by LHB's or LA's and is not a sustainable funding solution.

The ongoing Covid-19 pandemic has had a considerable impact on the fundraising efforts of both hospices, with shops closed for extended periods and most public events cancelled on an ongoing basis. This has resulted in a drop in our funding streams and placing significant pressures on our core services and support staff functions.

The financial year 2017/18 saw Ty Hafan raising over £3m in donations (excluding legacies) through over 88,000 donors via organised events. This compares to £1.9m raised in 2020/21 via 84,000 donors, marking a fall in donations of over £1.0m. The impact of this was mitigated to some extent by government covid grants and the furlough scheme, but neither provides ongoing or sustainable funding.

Like most third-sector organisations, the level of uncertainty over future funding facing Tŷ Hafan and Tŷ Gobaith going into 2022/23 is greater than pre-pandemic years. We continue to deal with the loss of revenue from public facing and corporate fundraising, while trying to retain and maintain a clinical workforce that enables us to concentrate on our core clinical work that involves providing the best possible support to children with life-limiting conditions and their families.

The figure of 10 percent annual funding for children's hospices in Wales stands in stark contrast to the other UK nations. Children's hospices in Scotland receive 50% of their funding from statutory sources; in Northern Ireland it is 25% - while the Republic of Ireland recently announced it would fund 30% of running costs for their children's hospice³. In England, the comparable figure for children's hospice funding is circa 21%. A summary of the comparison between the UK nations statutory funding for children's hospices based on pre-pandemic 2019 figures, can be found in [Table 1](#).

A sustainable funding solution for Wales' children's hospices over and above the existing 10% would have a marked impact on the children and families that use our services. A Lifeline fund would:

- **Enable hospices to employ more nurses** and allied health care staff to enable us to serve more families; in addition to addressing the shortfall we are experiencing due to attrition and illness, this would also enable the development of more positive relationships with the family throughout a child's life, establishing trusted partnership working, and a deeper understanding of the child and families' needs. This in turn will lead to more effective end of life care and bereavement support, and better outcomes for the families at the time when they face the inevitable and heart-breaking loss of their child.
- **Secure additional crucial nights of care at children's hospices**, for children with life-limiting conditions in Wales. Family Voices was clear - extra nights of nurse-led respite for each child and family supported by the hospices are essential to the whole family's mental health and relationships. Described by families as 'a lifeline', it saves them from 'breaking'.
- **Reduce unplanned and crisis hospital admissions** for children with life-limiting conditions, in turn reducing the burden on, and financial costs to, the NHS.
- **Ensure our hospices can sustain and expand our care in other areas** such as physiotherapy and other therapeutic support, clinical support and advice; also, as part of the broader ecosystem of NHS providers, end-of-life care and bereavement support.
- **Give the hospices the financial confidence** to plan to expand the breadth and depth of services to reach more children and families, knowing that we can meet their needs without depriving others of essential services.
- **Support local government to meet its statutory requirements** in relation to respite care, which cannot be met without a sustainable children's hospice sector.
- Ultimately, help to ensure that Wales makes a vital step in its national mission to become a **compassionate country**.

The table below outlines the impact of additional statutory funding in terms of additional nights of respite care for the families we support across Wales, relative to the other UK nations⁷.

Table 1: Comparison of children's hospice funding across the UK.

Country	Current statutory funding level	How this translates: equivalent funding level for Wales' children's hospices	Additional funding required to attain parity	Extra nights of specialist respite support this amount would fund in Wales
Scotland	50%	£3.75m	£3,050,000	An additional 7 nights of respite per year, per family.
Republic of Ireland	30%	£2.25m	£1,550,000	An additional 4 nights of respite per year, per family.
Northern Ireland	25%	£1.9m	£1,200,000	An additional 3 nights of respite per year, per family.
England	21%	£1.6m	£900,000	An additional 2 nights of respite per year, per family.
Wales	<10%	£0.7m		Current statutory support funds around 2 nights of respite per year, per family.

The upcoming budget provides opportunity for the Welsh government to address the disparity in state funding for children's hospices in Wales in comparison to the other UK nations. By allocating fair and need-based funding for the two hospices, the Welsh Government can ensure that no child with complex life-limiting conditions goes without in Wales, ensure that paediatric palliative care services are offered in every corner of Wales, reduce unplanned and crisis admissions to NHS hospitals and ultimately create a Wales that is more compassionate and kinder to those families who find themselves facing the unimaginable.

Our policy ask is clear. We want the Welsh government to make a step change, allocating funding for Tŷ Hafan and Tŷ Gobaith – who provide support and care to hundreds of children and their families every year – to create

parity with other UK nations so that our children and families are not neglected because they happen to live in Wales.

Our Ask

- 1. Parity with other UK nations.** Tŷ Hafan and Tŷ Gobaith are calling on the Welsh Government to consider a move to, at a minimum, the English model of funding for children's hospices. By providing a grant at **21%** of our annual care costs, i.e., investing an additional **£900,000** per year, the Welsh Government would support the children's hospices to provide two additional nights of respite care per year to each family of a child with life-limiting conditions². It would also support us in futureproofing our services and allow us to lever our charitable funding to extend our reach across Wales.
- 2. A centrally negotiated and distributed funding model.** We are calling on the Welsh Government to introduce a centrally negotiated and distributed "Lifeline fund" that covers all of Wales. Children's hospices work across multiple Health Boards. If funding continues to be channeled through Health Boards this will require protracted multiple negotiations and result in different interpretations, funding models and levels of funding between Boards. Such arrangements would serve to perpetuate the funding discrepancies we experience today.
- 3. Long-term.** A funding agreement for, at a minimum, the life of the Senedd, so as to give children's hospices confidence to develop services and make longer term investments in staff and infrastructure. Such funding model could, for example, be based on 75% committed and 25% subject to annual review to give some flexibility and control to the government while enabling the hospices to plan services with confidence.
- 4. Funding linked to need.** Any additional funding must be linked to need. This could be based on the calculated or estimated number of children with a life-limiting condition in Wales within the catchment area actively supported by the hospices. For example, In Cardiff and Vale all the funding for these children would go to Tŷ Hafan as they are the only children's hospice supporting children in that area. The same for Tŷ Gobaith in Betsi. In Powys where both hospices provide support, the funding could be split proportionate to the number children supported by each hospice. By funding based on need children's hospices can be held accountable for reaching more children and families and providing services that best meet their needs.
- 5. Proportionate reporting.** All recipients of palliative care funding should provide outcome-based reporting. It is important that any additional funding does not generate onerous reporting requirements that cost either hospice considerable time or money to administer and provide. Reporting should be based on reach and meeting a certain need.
- 6. Recognition of the cross-policy working of hospices.** Unlike other settings which separate health and social care, children's hospices holistic child and family centered care that best meets the needs of children and families. It is important that funding does not make an artificial distinction between health and social care, where only certain services provided by the hospices are funded and others are not. Funding should be in the form of a single sum that hospices use to best effect to address the unique needs of children and families, taking account of their specific circumstances.

² Based on the current level of service users across both hospices, this equates to over 450 children and their families each year in Wales.

- 7. Sustainable minimum commitment of annual funding.** To be forward looking, innovative and sustainable, any additional funding should be agreed and paid in one, or at most two, payments per annum. This will give the hospices the resources to invest in ensuring we can make the biggest difference to the children and families that require our services. Funding that is claimed each month become transactional rather than transformative and does not enable us to address the relatively short but precious futures of life-limited children in Wales.

Question 6: The Committee would like to focus on a number of specific areas in the scrutiny of the budget, do you have any specific comments on any of the areas identified below, particularly in light of the COVID-19 situation and how these should be reflected in the 2022-23 budget?

In relation to this question, we would like to focus on two areas:

Approach to preventative spending and how is this represented in resource allocations (Preventative spending = spending which focuses on preventing problems and eases future demand on services by intervening early).

As noted in detail above, Tŷ Hafan and Tŷ Gobaith children's hospices are urging the Government to fund an uplift in the funding allocation for Wales' children's hospices, to the benefit of the hundreds of children with LLC's and their families in Wales.

The two hospices are best suited to provide specialist palliative and end-of-life care to children in Wales, with the skills, resources and understanding to ensure the highest standards of care for the children and their families. Families have told us that Tŷ Hafan and Tŷ Gobaith go above and beyond to ensure all of their needs are met, particularly during end-of-life care, needs that would simply not have been met by the statutory providers of health and social care in Wales.

By providing an increase in the statutory funding available to both hospices, the Government can reduce unplanned and crisis hospital admissions for children with life-limiting conditions, in turn reducing the burden on, and financial cost to, the NHS. The children that require such services have extremely complex needs which are often very resource demanding, and in turn costly to the NHS and other providers of health and social care.

Families remain at the centre of providing round the clock care to children with life limited conditions. The support provided by children's hospices is vital in helping to keep families together and functioning so this care can continue to be delivered. Research has shown that regular short breaks have a positive impact on the health and wellbeing of all family members and helps to keep siblings, who are often young carers in school, and enables parents to be more economically active. Yet despite all these benefits families report remaining almost entirely dependent on the charitably funded hospices for this respite – despite it being a statutory obligation for local authorities across Wales.

By providing a clear uplift in hospice funding, the Welsh Government can offset this against future crisis admissions for children with LLC's, family breakdowns and poor mental health. Such preventative spending needs to be clearly considered by the Government, as well as joint working with third sector providers of health and social care more generally, in the upcoming budget for 2022/23.

How evidence is driving Welsh Government priority setting and budget allocations.

Tŷ Hafan and Tŷ Gobaith have previously raised the issue regarding the evidence base of children with life-limiting conditions in Wales – and how any funding for the children's hospices is linked to need.

There is simply a lack of understanding of how many children and their families in Wales require the support of a hospice – partly as a result of a lack of a central register, or data set, of those children and young people living with a life-limiting condition or who require palliative care. How can the Welsh Government develop evidence-based policy or make comprehensive budget allocations in relation to children and young people with complex, life-limiting conditions, when there is so little evidence regarding the population that make up this group? What we know from our interactions with our network of professionals and families is that there is unmet need; but the facts need to be more effectively collated and understood.

The 2021 stock-take itself acknowledges that there is currently *no data on the current prevalence of LLC in children or young people in Wales*. It goes further, saying: *there are marked disparities in how easily children in different areas are accessing specialist services. We are not yet able to offer families from some parts of Wales a meaningful choice between home, hospice or hospital as the end-of-life approaches. The hospices that serve children in Wales are still not securely funded and we cannot yet muster the full range of services a specialist children's team should be able to offer to patients.*³

We urge the committee to consider this issue as part of its scrutiny of the upcoming Welsh Government budget – and ensure that the funding for children's hospices is linked to the need for their services across Wales. The Welsh Government commissioned prevalence study should be considered in this work – which provides an indication of the growing numbers that make up this group – as conditions become more complex and technological and scientific advances see many young people living longer and more varied lives.

Thank you for your consideration of the above response. If you would like any further information about our calls for a lifeline fund, a comprehensive briefing document can be found online [here](#).

³ End of Life Implementation Group, Review of Specialist Care Services in Wales 2010-2021, July 2021

Appendices

Appendix 1 – Breakdown of Tŷ Hafan and Tŷ Gobaith Service Users in Wales

Tŷ Hafan & Tŷ Gobaith Service Users by Health Board:

Health Board	Aneurin Bevan	Betsi Cadwaladr	Cardiff & Vale	Cwm Taf	Hywel Dda	Powys Teaching	Swansea Bay	Total
Service Users	66	123	97	54	47	26	51	464

Tŷ Hafan & Tŷ Gobaith Service Users by Local Authority:

Local Authority	Service Users
Blaenau Gwent County Borough Council	2
Bridgend Council Borough Council	16
Caerphilly County Borough Council	19
Cardiff City Council	71
Carmarthenshire County Council	22
Ceredigion County Council	9
Conwy County Borough Council	13
Denbighshire County Council	29
Flintshire County Council	22
Gwynedd Council	17
Isle of Anglesey County Council	10
Merthyr Tydfil County Borough Council	9
Monmouthshire County Council	7
Neath Port Talbot Council	9
Newport City Council	22
Pembrokeshire County Council	19
Powys County Council	24
Rhondda Cynon Taf County Borough Council	29
Swansea City Council	41
Vale of Glamorgan Council	26
Torfaen County Borough Council	14
Wrexham County Borough Council	31
Total	461

Appendix 2 - Family Voices report: What families want more of

In 2020, we completed a vital piece of work focused on understanding what families want and need from us. We called our report 'Family Voices'. The report, based on a survey of views from families using or who have used hospice services, provides an important voice in understanding what these families need.

We had over 133 responses – which told us just how vital our services are, but also how desperate families are for more of what the hospices provide. Respite care is for coping and wellbeing, but they spoke of needing more. We know that our support is more important than ever, and this report is essential in helping us plan for the future.

The full report can be found online here: [English](#) / [Cymraeg](#)

Service	Total
More / Longer Respite	43%
More Availability of Services	15%
Advocacy / Information / Benefits / Housing Etc.	13%
Sitting / Home-based Care	10%
More Access to Counselling / Emotional Support	10%
Better Communication between Services (Hospice and Wider Services)	10%
Easier Access / Admission Process	9%
More Local Services	8%
Increased Age Limit	8%
More Activities / Events	6%
More Sibling Support	5%
More Responsive to Crisis	5%
Better Access to Specialist PPC	4%