

Finance Committee Consultation Response on behalf of Tŷ Hafan and Tŷ Gobaith

1. What, in your opinion, has been the impact of the Welsh Government's 2022-23 Budget, including funding related to the recovery of the pandemic? Have Welsh Government business support policies been effective as the economic outlook for 2023-24 continues to worsen?

We welcomed the uplift in the funding made available to Welsh children's hospices in the last budget. This was the first such uplift in over a decade, and in addition to the emergency funding made available during the pandemic, this saved the hospices from the worst-case scenario. However, the support available for our sector is not keeping pace with the rapidly changing circumstances. Not only are prevailing conditions and the economic outlook impacting on the charities' ability to raise funds, there has been no recognition of how increasing costs and inflation have essentially swallowed the bulk of funding made available. With nursing resource costs set to increase further, this gap between funding received and impact on service delivery becomes greater.

2. How should/could the Welsh Government support the economy and business following the pandemic, Brexit and inflationary and other economic pressures?

– How financially prepared is your organisation for the 2023-24 financial year, how will inflation impact on your ability to deliver planned objectives, and how robust is your ability to plan for future years?

Both charities face a very difficult year in 2023-24. Inflation, and rising staff costs will hamper our ability to meet the increasing demand for our services. We know that an upcoming prevalence study, sponsored by Welsh Government, will show that a huge number of families with life-limited children, who are among the most vulnerable in our society, are not currently in receipt of hospice support. Without a significant, stable and secure uplift in funding it will be impossible for the hospices to reach those families, even though we will often be the best placed organisations to do so. Although both charities have reserves for worst case scenarios, our ability to plan for future years is severely limited by inflation.

We are committed to the principles embedded in "A Healthier Wales" and recognise that the provision of new and innovative 'care closer to home services' would meet the needs of families. The uncertainty over future sustainable funding makes driving forward new initiatives such as this difficult as we would not want to be in a position of offering such services only to have to remove them.

Research shows that need for the hospice-based services, end of life care, symptom management and increasingly crisis driven respite care is only going to keep growing. Increasing staffing costs, and financial constraints to maintain a competitive employment choice for nurses, mean that at best we can only stand still rather than increase our offer. Neither hospice is currently able to work to full capacity due to resourcing shortfalls.

Staffing shortages have been impacted by Brexit - our inability to easily recruit from the EU means we would have to look to recruit from MEA; an expensive and unproven proposition and one we cannot presently afford to contemplate. As we effectively 'compete' with the NHS for resource, ultimately this puts the on-going delivery of our services in jeopardy.

3. With inflation and costs of living issues continuing to escalate, what action should the Welsh Government take to help households cope with this latest crisis?

In line with the Welsh Government's stated aim to be a compassionate country, we strongly believe that more significant support be directed at Wales's most vulnerable households. As detailed in our [Lifeline Fund Report](#) we know that many families caring for children with life-limiting conditions were close to breaking point – they were already suffering their own cost of living crisis. Sometimes they face a choice between putting food on the table, and spending money on petrol to reach one of the hospices. Such families invariably face the hardest time in the future, and yet they are limited in number, and relatively easy to identify. This means that, with relatively little Government support, many short lives, and the lives of their siblings and families, could be utterly transformed.

– How should the Budget address the needs of people living in urban, post-industrial and rural communities and in supporting economies within those communities?

With only two children's hospices in Wales, located in Sully and Conwy, we know that many families in rural areas find it very difficult to access our services. Both charities do a huge amount of work in the community, but sometimes services, especially respite care can only be accessed in the hospices themselves. Support for families that need to make these essential journeys should be available from Government. Our (pre-Cost-of-Living crisis) research shows that a quarter of families who do access our hospices have to travel for more than an hour. 38% of families say they have trouble with financial hardship relating to petrol, or transport costs. One family said: *"Sometimes we don't go (to the hospice) because we are just so skint and we haven't got money for petrol."*

4. Are Welsh Government plans to build a greener economy clear and sufficiently ambitious? Do you think there is enough investment being targeted at tackling the climate change and nature emergency? Are there any potential skill gaps that need to be addressed to achieve these plans?

N/A

6. Is the Welsh Government using the financial mechanisms available to it around borrowing and taxation?

N/A

7. The Committee would like to focus on a number of other specific areas in the scrutiny of the Budget. Do you have any specific comments on any of the areas identified below?

- – Welsh Government policies to reduce poverty and gender inequality. Is enough support being given to those people living in relative income poverty?

Our Families Voices Report shows that 51% of families we support have an annual income of less than £25,000, with 21% of families relying on less than £12,000. Over half the families who responded incurred debt to cover expenses within the last two years. Again, these are figures from 2020, the situation now is likely to be worse still. We know that it is more likely for mums to have to give up work in order to care for children with life-limiting illnesses. Whilst we do what we can as charities to signpost families to benefits and income support, many of them still find themselves in severe income poverty – due to both the increased costs associated with caring responsibilities and parental choices around giving up work, chances for promotion etc. Inevitably many of these families will now face fuel poverty and food shortages, particularly as they have no choice regarding the maintenance and use of life-saving equipment in their homes. While the charitable sector does its best to plug the gaps, it is incumbent on the Welsh Government to look after this vulnerable population, particularly in these times of crisis.

- – How/whether the approach to preventative spending is represented in resource allocations (Preventative spending = spending which focuses on preventing problems and eases future demand on services by intervening early).

Welsh children's hospices already do a huge amount of heavy lifting in terms of preventative spend. Without the support we offer a huge financial burden would be inflicted on the Welsh NHS and social care providers. Losing our services would be a

catastrophe, not just for vulnerable families, but also for Welsh public sector finances. We know that respite care helps keep families together, and away from (costly) crisis. The specialist support we offer means that placements out of Wales are not necessary for scores of our most vulnerable children. Any genuine shift towards a preventative model would see increased support for children's hospices in Wales which currently save the Welsh taxpayer millions of pounds each year.

- – How resources should be prioritised to tackle NHS waiting lists for planned and non-urgent NHS treatments. Do you think the Welsh Government has a robust plan to address this issue?

We would like to see an action plan to address long standing issues around CAMHS and for access to specialist equipment such as wheelchairs.

- – The sustainability of NHS, social care, further and higher education, local government and other public services more generally. Is the Welsh Government providing adequate support to the public sector to enable it to be innovative and forward looking through things like workforce planning.

There has been a clear and longstanding weakness in developing a sustainable pipeline for nursing staff in Wales, and this is particularly impacting children's and palliative nursing care. This has been exacerbated by the decision not to pursue the training and deployment of Nurse Associates which currently happens in England. The correlation between great care and experienced nurses is well-known, and yet the current shortage of nursing staff in Wales is severely impacting our ability to provide the level of care and support we would like, to as many families as possible. If our current rates of attrition prevail, it is conceivable that we will not be able to operate.

- – Whether there has been adequate investment from the Welsh Government in basic public sector infrastructure.
 - Support for children and young people whose education, development, and mental health and well-being have been affected by the pandemic. Is there enough infrastructure investment targeted at young people?

Children and young people supported by the hospices are already disadvantaged in terms of access to wider wellbeing activities, such as leisure and inclusion in local initiatives. These are generally not structured to cater for additional medical needs. That means these young people can be doubly disadvantaged by both the pandemic and post pandemic recovery initiatives. As disabled young people they are often 'forgotten' in terms of service response. We would like to see genuinely inclusive infrastructure investments in the future.

- – Whether it is clear how evidence and data is driving Welsh Government priority setting and budget allocations.

We believe that a properly evidence-based approach to budget setting would see more resources directed towards preventative services, like respite care, which save families from crisis and saves the public purse millions of pounds.

- – Is support for third sector organisations, which face increased demand for services as a consequence of the cost of living crisis and the pandemic, sufficient?

We believe there is a recognition at Welsh Government as to how bad these crises have been for the third sector, and the support made available has been welcome. However, there is a serious lag in the response time from Government in addressing the worsening situation. That means for example that the uplift provided last year to children's hospices has now essentially been swallowed by crisis costs and inflationary pressures. A response that kept pace with emerging circumstances would ensure we can "keep the lights on", and potentially allow us to work with more families

- – What are the key opportunities for Government investment to support 'building back better' (i.e. supporting an economy and public services that better deliver against the well-being goals in the Well-being of Future Generations Act)?

The pandemic gave us all an opportunity to reassess our priorities and focus support on where it was needed most. It should be an alarm call for everyone in Government that families with life-limited children regard the current cost of living crisis as more terrifying than the pandemic, as they don't see the same level of support, certainty and solidarity. To create our Compassionate Cymru, we must support our most vulnerable families first.