**Cyflwynwyd yr ymateb i ymgynghoriad y Pwyllgor Iechyd a Gofal Cymdeithasol ar Gwella mynediad at gymorth i ofalwyr di-dâl**

**This response was submitted to the Health and Social Care Committee consultation on Improving access to support for unpaid carers.**

**UC09 : Ymateb gan: Ty Hafan | Response from: Ty Hafan**

---

Tŷ Hafan
CHILDREN'S HOSPICE
HOSBIS I BLANT
Hayes Road, Sully CF64 5XX
Heol Hayes, Sili CF64 5XX
Tel | Ffôn: 029 2053 2199
info@tyhafan.org
www.tyhafan.org

Dear Chair,

I am writing to you to provide an evidential response to your Committee's current inquiry into Improving access to support for unpaid carers. At Tŷ Hafan, we feel strongly that unpaid carers are a vital part of the caring ecosystem in Wales, providing necessary support to loved ones, relieving the pressure on statutory services and ensuring that no-one gets left behind. We therefore believe that improving access to support for unpaid carers is essential to ensure that they are enabled to care to the best of their abilities, not only for the people they love, but for themselves also.

## Background

Tŷ Hafan Children's Hospice has been a primary provider of respite and family centred short break care provision for children with profound disabilities and complex medical needs for over 25 years. Over this period there has been a creeping reduction in the services provided to families from statutory health and social care providers, often leaving families with very little practical support from the burden of their 24/7 caring responsibilities. This leaves families facing extreme exhaustion and often finding themselves at breaking point; it is no wonder families have described the support provided by children's hospices as a 'lifeline'. Our survey Family Voices, conducted jointly with Tŷ Gobaith, the children's hospice in North Wales, in 2019/20 identified that for over 90% of the family respondents the hospice was their only or primary source of respite or any break from caring, other than school.

## Statement of evidence

Tŷ Hafan supports families from across 6 of 7 Local Health Board areas and 16 of the 22 Local Authorities in Wales. Whilst there is significant variation regionally in relation to unpaid carer support we are not aware of any Local Authority that has access to enough specialist respite care resource to provide meaningful respite support to families caring for children with complex medical needs.

There is often an assumption that a child with a life-shortening condition, and the associated complex medical care needs, will automatically be supported via a health or Continuing Care (CC) package, but this is not the case. For the families supported by Tŷ Hafan only around 30% of the children meet the eligibility criteria for a Continuing Care package but many of the remaining 70% of children have clinical needs that cannot currently be supported by existing

respite services for disabled children. This leaves many families unable to access appropriate and much needed respite support or having to rely on arranging something themselves via Direct Payments. We are aware of the Welsh Government consultation into Direct Payments that is currently open and have responded to this with our comments.

Despite the children's hospices in Wales having no formal commissioning or funding relationships with Local Authorities, or Regional Partnership Board's, they are often cited in Care & Support plans as the identified service providers for respite care. This can result in Local Authorities not actively considering the statutory service gaps in relation to their local populations.

The provision of appropriate locally based services can be challenging as the numbers of these very complex children are reasonably small and spread across geographically diverse areas. Families can often be disadvantaged in relation to accessing more centrally located service provision both due to the logistics of travelling with a child with complex medical needs and the impact of low incomes and associated fuel poverty. Statutory service providers will need to think creatively when looking for solutions to the lack of respite provision in their local areas.

As highlighted, many parent carers do not have, nor have been actively offered, a Carers Assessment so the level of unmet need is virtually impossible to estimate. We are aware of parent carers who have turned down a Carers Assessment because they have already been advised that there are no appropriate respite services available and this is their primary need. Feedback from families known to Tŷ Hafan indicates a level of reluctance to engage in Direct Payments as a response to an identified need for respite care for a multitude of reasons:

- The logistics of trying to establish, maintain and oversee the employment of carers when balanced against the 24/7 emotionally and physically demanding role of parenting a very fragile, complex child;
- The specific training required to provide care for complex medical needs. Often, the issue is that training is not available for paid carers who are not employed by the Health Board. This means that parents are expected to deliver nursing level interventions unsupervised, but carers cannot be trained to do this;
- Any respite care provided by Direct Payment carers is likely to be in the family home environment, and for short periods of time, not overnight, so for many families this does not feel like an adequate or appropriate break.

For the families who do receive a level of care provision via a Continuing Care package this is often not a package that allows for any meaningful respite or break from caring. The support offered differs across health boards but generally parents still need to be present in the home when their child has Continuing Care staff in. Even for parents receiving large

packages of care and overnight care this is often not a proper break as they still need to be available to give certain medications or perform specific tasks that nurses or carers are not able to do.

In our experience access to appropriate support services for unpaid carers, including routine Carers Assessments has become harder to obtain in the 10 years since the introduction of The Social Services and Well Being Act. With the increased demand on, and tightening budgets of, Local Authorities, the move towards social services being more of an information and signposting service has left families isolated and without appropriate advocacy support to access services they are entitled to. Over this period, Tŷ Hafan has extensively increased the family wellbeing and advocacy support provided to families and in many cases have picked up the role previously provided by social workers supporting these families by virtue of Section 17 of the Childrens Act (1989) - Children in Need.

These factors have resulted in more families reaching breaking point due to exhaustion and lack of appropriate support. We have seen an increase in demand for our crisis respite offer and we are only able to offer a fraction of the support that we know is desperately needed.

To provide a concrete example of this issue. We have around 280 families registered with us at any given time who are eligible for our range of support services including some level of respite provision. Based on the recent Prevalence Study this is approximately 10% of families living with a child with a life-shortening condition. Last year we were able to offer around 1000 nights of respite to approximately 120 of those registered families. This leaves over 50% of the families known to us with no, or very little respite care support to help them sustain their considerable caring responsibilities. Based on the prevalence data it would be a reasonable assumption that the level of unmet need for respite care support to parent carers of medically complex and profoundly disabled children is woefully inadequate.

It is our experience and belief that this situation will continue to deteriorate, placing an extra burden on organisation like ours, who have stepped in to fill the gaps left by a paucity of statutory services. The Prevalence Study, mentioned earlier, shows that the numbers of children with life-shortening conditions is increasing, and is only predicted to continue to rise. These children will need increased levels of support, as complexity is also forecast to rise. It is therefore vital that appropriate, robust support is put in place that is easy to access and meets the needs of unpaid carers across Wales.

Finally, we strongly believe that adults who provide unpaid care for their children, above and beyond their parental responsibilities, are an overlooked group. Their care often falls under the umbrella of parental responsibility, whereas experience tells us otherwise. Too often these parents are performing roles and tasks that fall under the remit of social care, health care or both. We know that this can lead to family stress, family breakdown and increased

Tŷ Hafan
CHILDREN'S HOSPICE
HOSBIS I BLANT

pressures on parents and siblings leading to the start, or exacerbation, of health conditions, including mental health issues. Too often, as has been mentioned already, we are their lifeline, and without us, these families would be reaching a crisis point sooner, and with more ill effects.

It is vital therefore, that this group are included in any work, and any recommendations that come from this inquiry are made them with at the forefront of decision making. Included in this must be further support for Wales's children's hospices – funding 30% of our care costs by 2030 – whilst any Welsh Government continues to build on and improve the availability and suitability of the support available.

Kind Regards,

Irfon Rees
Chief Executive, Tŷ Hafan