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.

UC32: Ymateb gan: Conffederasiwn GIG Cymru | Response from: Welsh NHS Confederation

Welsh NHS Confederation
Conffederasiwn GIG Cymru

	The Welsh NHS Confederation response to the Health and Social Care Committee's inquiry on improving access to support for unpaid carers.
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Introduction

1. The Welsh NHS Confederation welcomes the opportunity to respond to the to the Health and Social Care Committee's inquiry on improving access to support for unpaid carers.

2. The Welsh NHS Confederation is the only membership body representing all the organisations making up the NHS in Wales: the seven local health boards, three NHS trusts (Velindre University NHS Trust, Welsh Ambulance Services University NHS Trust and Public Health Wales NHS Trust) and two special health authorities (Digital Health and Care Wales and Health Education and Improvement Wales). We also host NHS Wales Employers and are part of the NHS Confederation.

The main barriers faced by unpaid carers in accessing the support they need; including any specific challenges for carers based on factors such as age, ethnicity or where they live.

3. Our members agree that there are several barriers faced by unpaid carers in accessing the support they need, including due to age, ethnicity or where they live.

4. Unpaid carers are fundamental to the sustainability of health and social care and to communities across Wales. Their contribution supports individuals and communities across the nation. However, despite the existence of support services, unpaid carers experience multiple barriers when accessing support they need.

5. Our members stated that though there are engagement events and various sources of information, many unpaid carers remain unaware of support services available to them, including short breaks, direct payments and local initiatives and support networks. Feelings of guilt, reluctance to self-identify as carers, and mental health challenges can prevent carers from seeking support that they need.

6. There are a range of factors that can lead to barriers for unpaid carers. Transport issues, specifically in rural areas, limit access to services and activities. Gaps in local transport infrastructure are a major barrier, especially for young carers, those in rural areas, and those wishing to attend training courses (like the MECS programme) or access community services. Housebound carers or those with mobility challenges face

additional barriers. Additionally, cultural and language barriers faced by Black, Asian and Minority Ethnic (BAME) carers, compounded by a lack of culturally appropriate services, can be a barrier faced by unpaid carers accessing support. Also, there is limited age-appropriate respite for younger adults compared to the better-established services available for older adults and those with complex or behavioural needs.

7. The lack of services also causes challenges. Our members have stated some services suffer from a lack of flexible and short-notice options. Specifically, there is limited overnight provision for children/ young people with Learning Disabilities (LD) and those requiring Child and Adolescent Mental Health Services (CAMHS), even though commissioned beds are available. With the decline in support services and rising demand due to demographic changes such as more people living with chronic conditions, it is leading to multiple reports of carer burnout/crisis. When preventative respite is unavailable, families escalate their need, sometimes requiring long-term placements for the cared-for person.

8. Commissioning approaches need to better reflect the diverse needs of different groups, including young carers, those in rural areas, and carers from ethnic minority backgrounds, who often face additional barriers to accessing support.

The current availability of respite care across Wales, including levels of variation across regions.

9. Our members agree that there are levels of variation across Wales regarding the current availability of respite care. Traditional residential respite is often limited to those in crisis, meaning that preventative, sustainable needs are frequently unmet.

10. Respite care should be a pillar of family support. Its core purpose is to enable families to maintain and strengthen important relationships, develop new skills, and ultimately sustain the overall wellbeing of both the person being cared for and the carers themselves. However, this ideal is being undermined by a widespread failure to provide adequate support.

11. A major obstacle to improving respite provision is the lack of clear, comprehensive data across Wales. The current system makes it difficult to quantify the volume of respite offered and nearly impossible to measure the difference it is making to carers. This is due to a confusing mix of available services, varied funding streams, and differing reporting requirements among providers. This data void prevents effective planning, resource allocation, and, crucially, limits accountability.

12. Amidst the failures, the Short Breaks scheme is presented as a positive model. Its evaluation highlights a positive impact on carer wellbeing, showcasing how a flexible model can increase choice, offer tailored options, and help build resilience in community groups through local connections.

13. One of our members highlighted that the Welsh Government's Short Breaks funding has successfully provided flexible, person-centred respite (like grants, vouchers, and activities) to unpaid carers in North Wales. This approach has led to significant

improvements in unpaid carers wellbeing, including better mental health and reduced stress, which helps them sustain their caring roles. Key takeaways from the scheme emphasise that carer-led design is more effective and cost-efficient, regular, predictable breaks are better than one-off events and holistic support (mental, emotional, social) is crucial. However, challenges still exist, particularly with transportation, carer awareness of the support, and the availability of support for the person being cared for.

14. In addition to the short breaks scheme, the Health and Social Care Regional Integration Fund has been used to provide specialist short breaks. For example, for the provision of appropriate respite support for children with complex needs, ensuring the identified needs of both the young people and their unpaid carers are met. Also, the Dementia Emergency Care scheme has been helpful because it ensures specialist care is available to support the person living with dementia for up to 3 days while a longer-term strategy/plan can be developed.

15. In the Gwent area, one of our members highlighted that the Gwent region offers a diverse range of projects, for example, projects like Bridging the Gap Gwent (BTGG). The BTGG provides direct, carer-chosen respite via up to £400 vouchers for short breaks and the Expanded Carers Small Grants Scheme offers up to £300 for "Carers Time Out." For dementia-specific needs, Shared Lives Dementia and Support for Early Onset Dementia provide flexible, tailored in-home and community respite. This flexible, preventative approach is highly valued by carers as it is less disruptive and more sustainable than traditional residential care. However, despite this range of services, several barriers and gaps remain. Rising demand for flexible respite, particularly for dementia-specific placements and the £400 BTGG vouchers, often exceeds capacity.

16. Services such as Carer Support and Events, Carers Hub & Spoke, and Carers Cafés provide indirect respite through activities, social interaction, and emotional support. Formal assessments are also a core part of the offer within the Carer Support and Events project. Other projects, including BTGG, Carers Hub & Spoke, and the various hospital-based and dementia projects, either conduct partial/needs-based assessments or refer/signpost carers to statutory assessment pathways. The overall approach favours small, highly personalised interventions to prevent burnout, but the sustainability of these innovative, flexible schemes is often dependent on inconsistent annual Welsh Government funding.

17. Additionally, direct support is provided to community groups and organisations to offer activities and events that are fully accessible to people and their unpaid carers. Carers report that they can enjoy time with their loved one together at some events and are able to take a break when they know that the person they care for is engaged in meaningful activities, such as art and nature activities.

18. There is a recognised difficulty in balancing investment between traditional statutory respite care and the need to develop flexible, preventative models that offer timely breaks before a crisis occurs. Inconsistent eligibility criteria and service availability across local authority boundaries can create a "postcode lottery" for carers, undermining equity and access to support.

The role of Regional Partnership Boards in the provision of support for unpaid carers, and the effectiveness of current commissioning practices for services.

19. Our members agree that there are range of services across Regional Partnership Boards (RPBs) in the provision of support for unpaid carers.

20. A critical issue is the variation in how well unpaid carers' voices are heard at the RPB level. While the legal requirement set by the Charter for Unpaid Carers only mandates one person to represent unpaid carers on the RPB, simply meeting this very basic requirement is not enough. If the carer voice is not well embedded, understood, and sufficiently prioritised, it is unlikely their needs will be met. Effective prioritisation at the regional level must be based on good quality evidence and future projections, ensuring all partners understand how supporting carers contributes to prevention work.

21. The provision of support for unpaid carers in North Wales relies on a mixed commissioning model, with some services procured individually by statutory bodies and others jointly commissioned across the country or region. The central mechanism for partnership and collaboration among these commissioning bodies is the North Wales Carers and Young Carers Operational Group (NW(Y)COG). This group is crucial for joint planning and coordinating the use of Welsh Government grant funding. For instance, NW(Y)COG supports the deployment of Carers Officers (employed by the third sector) within hospitals to ensure unpaid carers are identified, involved in discharge planning, and given necessary information. Furthermore, the Health and Social Care Regional Integration Fund explicitly ensures that the needs of carers are considered within all models of care.

22. Moreover, despite the Regional Partnership Board’s strategic function, several significant challenges impede the consistent and effective commissioning of services. Much of the innovative, preventative respite (such as the 'Bridging the Gap' model) relies on short-term grant funding. This precarious environment restricts the ability to scale successful initiatives, build workforce capacity, and maintain continuity of support.

23. Ultimately, our members state securing multi-year, sustainable investment in preventative services is critical to enabling the Regional Partnership Boards to develop a balanced and sustainable carers portfolio, reduce crises and burnout, and enhance workforce development for flexible, community-based respite.

The actions required to improve the implementation of the Social Services and Well-being (Wales) Act 2014 provisions for unpaid carers (including Carers Assessments and support plans).

24. Our members agree that there are actions required to improve the implementation of the Social Services and Well-being (Wales) Act 2014 provisions for unpaid carers (including Carers Assessments and support plans).

25. Despite the Social Services and Well-being (Wales) Act 2014 placing a clear statutory duty on Local Authorities to assess and support unpaid carers, emphasising a person-centred "what matters" approach, implementation remains inconsistent across Wales.

26. A primary issue is the confusion among both unpaid carers and professionals regarding the difference between a full Carer's Needs Assessment and more informal support conversations, leading to variability in assessment quality and thoroughness.

27. Our members have stated that to improve the implementation of the Social Services and Well-being (Wales) Act 2014 provisions for unpaid carers, including Carer Assessments and support plans, there is a clear need for further work on early identification of carers and ensuring they recognise their role and are aware of available support.

28. Despite wider challenges in implementing statutory support across Wales, North Wales offers a model of local and community-based support for carers. This system is distinguished by its innovative and comprehensive approach, frequently co-produced with carers and their representative organisations. The region provides a wide spectrum of support, starting with information and advice made accessible through local authority websites, specialist groups, the Dewis Cymru platform, and crucial in-hospital facilitator posts that assist with discharge planning.

29. The support system also addresses the practical and financial needs of carers. This includes providing vital money and benefits advice through both local authorities and third-sector groups, as well as access to carer grants and flexible financial mechanisms like direct payments or support budgets. In terms of formal support, while local authorities conduct Carers Needs Assessments, third-sector organisations play a crucial role by providing informal assessments that help manage overall demand.

30. However, a significant and recurring issue is the failure to fully integrate carers' voices and perspectives into the assessment and care planning process. Carers frequently report feeling that their views are not adequately heard or considered during official assessments, undermining the person-centred approach required for effective support.

31. Compounding this, a lack of transparency often leaves carers in the dark. They are sometimes not provided with care plans of meetings and are not properly informed about the specific health professionals and service providers involved in their care arrangement. This lack of clear communication and involvement erodes trust and makes it difficult for carers to actively participate in or challenge decisions affecting the person they support and their own wellbeing.

32. Additionally, there are advocacy deficiencies. Carers are not consistently offered the option of advocacy support, limiting their ability to engage effectively and advocate for their needs. There is sometimes a lack of communication and information sharing between formal respite care providers and the carers themselves.

33. While the legislative framework is strong, the rising demand for support services highlights the need for more proactive, early intervention approaches. To address the

current inconsistencies, our members suggest improvements are needed in the following areas:

- Improving training and support for professionals undertaking assessments.
- Ensuring greater transparency and involvement of carers throughout the entire assessment and planning process.
- Enhancing advocacy support to empower carers to engage effectively with services.
- Committing to ongoing investment in both statutory services and flexible, personalised respite and support options to meet the rising demand.
- In terms of Assessment and Information, recommendations include ensuring consistent, timely, and comprehensive Carer's Needs Assessments focused on carers' priorities, providing better guidelines to distinguish between informal 'what matters' conversations and formal assessments.

34. Ultimately, the authorities should explore guaranteeing an active offer of accessible information, advice, and assistance, including in Welsh and culturally appropriate formats, and streamlining access to direct payments to grant carers greater control over their support.

Further Comments

35. Carers provide a significant contribution to society, the economy and the health and social care sector. Findings in 2023 from Carers UK and the University of Sheffield show that unpaid carers in Wales contribute £10.6 billion to the Welsh economy every year. This has increased by almost a fifth (17%) since 2011.

36. Austerity and budget cuts have led to a decrease in respite care and flexible breaks, which are essential for maintaining a carer's ability to cope. Unpaid carers are significantly more likely to live in poverty (26%) compared with non-carers (20%). The Poverty and Financial Hardship of Unpaid Carers in Wales report highlights some drivers of poverty for carers are difficulties staying in paid work, high housing costs, lack of support and access to formal support and the inadequacy of social security. People from black, Asian, and minority ethnic cultures faced increased financial struggles over white carers.

37. A primary barrier to support is the failure to identify carers early and effectively. Despite legal rights under the Social Services and Wellbeing Act (Wales) 2014, a significant number of carers are left unrecognised: 36% of carers took more than three years to be identified. Critical identification points, such as medical settings (hospitals and GPs), which 72% of carers prefer, only identify 12% of carers. This lack of early identification means carers miss out on information and advice that could prevent them from reaching a crisis point.

38. Also, this failure to engage is compounded by a massive gap in formal assessment: only 2.8% of the carer population had their needs assessed, leading to only 1.5% having a support plan, despite three-quarters of carers being open to an assessment. Staff are often disincentivised to offer assessments when they know services are insufficient to meet the resulting needs.

39. Ultimately, the challenges facing unpaid carers in Wales are systemic, multifaceted, and rooted in a disconnect between strong legislative intent and inconsistent practical delivery. Unpaid carers are being pushed into poverty and crisis due to a failure to commit to multi-year, sustainable investment in flexible, preventative services and a lack of consistent, high-quality statutory support.

40. To rectify this, our members suggest improving professional training, guaranteeing transparency and advocacy in the assessment process, and securing long-term, flexible funding for community-based support to move from a crisis-led system to a truly preventative one.

41. Finally, dedicated, sustainable funding is essential for long-term planning, and funds for prevention and carer support must be ringfenced against competing demands. This must be coupled with improved accountability and better data collection to quantify needs and measure service outcomes.