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.

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Welsh NHS Confederation
Health and Wellbeing Alliance

Inquiry – Improving access to support for unpaid carers

Welsh NHS Confederation social care sub-group response

September 2025

The Welsh NHS Confederation Health and Wellbeing Alliance have over 80 members with representatives from the NHS, local government, healthcare, social care, patient organisations and the professions. The Health and Wellbeing Alliance aim to be a collaborative independent voice, able to identify and seeking to address issues affecting the health, social care, wellbeing and the integration agenda, and its impact on people across Wales.

This response has been developed by the Health and Wellbeing Alliance subgroup on social care. Membership includes ADSS Cymru, Age Cymru, Alzheimer's Association, Care and Repair Wales, Carers Wales, Carers Trust Wales, Community Housing Cymru, Learning Disability Wales, Life Science Hub Wales, Marie Curie, Mencap Cymru, Motor Neuron Disease Association, Office of the Older People's Commissioner, Royal College of GPs, Royal College of Nursing, Royal College of Occupational Therapists, Royal College of Physicians, RNIB, and Stroke Association.

Overview of carers in Wales

The Office for National Statistics analysis of 2021 census data shows that in Wales has a higher proportion of carers providing 50 or more hours of care a week and carers providing 35-49 hours of care a week than in England. In Wales the highest percentage of unpaid carers was in people aged 55-59 for women and 55 and 64 for men.

There is a higher percentage of unpaid carers in the more deprived communities across Wales - 11.5% in the most deprived areas compared to 9.7% in the least.

Females are more likely to be carers than males until the age of 74-79. Women carers between 55 and 59 and 60 to 64 years old provide the highest amounts of care. From the age of 80 onwards, men are more likely to provide unpaid care.[1]

Rural areas account for 82% of the land area of Wales and are home to 32% of the Welsh population.[2] Rurality can be an additional challenge for carers due to barriers such physical access, staff recruitment and retention, and increased service delivery costs.[3]

Findings from Carers UK and the University of Sheffield show that unpaid carers in Wales contribute £10.6 billion to the Welsh economy every year.[4] This has increased by almost a fifth (17%) since 2011.

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. [5] People from black, Asian, and minority ethnic cultures faced increased financial struggles over white carers.[6]

Older carers are more likely to be living with poor health and multiple health conditions, sensory loss, digital exclusion and co-caring.[7]

People with a learning disability, their families and carers often have to pay more for essential disability-related specialist products, equipment, and services.[8]

Carers are under increasing pressure to provide increasing levels of care as the health and social care sector struggle to recruit, retain and train staff. With urgent and crisis needs in social care taking priority, a consequence is that carers are left further down waiting lists for care and support until their needs become urgent.

An investment in carers is an investment in prevention. The projected population changes for Wales mean more people will be living longer with ill health, so more

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[1] https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/socialcare/articles/unpaidcarebyagesexanddeprivationenglandandwales/census2021

[2] https://phwwhocc.co.uk/wp-content/uploads/2023/07/P6.5-Rural-Communities-Eng-final.pdf

[3] https://impact.bham.ac.uk/delivery-models/networks/rural-social-care/

[4] https://www.carersuk.org/press-releases/unpaid-care-in-wales-valued-at-10-6-billion-per-year-gwerth-gofal-di-d%C3%A2l-yng-nghymru-yw-10-6-biliwn-y-flwyddyn

[5] https://www.carersuk.org/media/bvdg2fvh/poverty-and-financial-hardship-of-unpaid-carers-in-wales_web.pdf

[6] https://raceequalityfoundation.org.uk/wp-content/uploads/2024/02/updated-briefing-on-ethnic-minority-carers-v2.docx.pdf

[7] www.agecymru.wales/carers

[8] https://www.mencap.org.uk/sites/default/files/2025-05/Extra%20costs%20of%20learning%20disability_Final.pdf

unpaid care will inevitably be needed in the future. Getting the range of support services carers need now would help keep carers and the cared for healthier.

Our main calls for this inquiry are

- Carer identification needs a renewed and increased focus. Far too many carers are caring alone without the help they often do not know is there to help them.
- There needs be a sustainable focus on increasing staff knowledge on carers.
- Without an increase in dedicated resourcing for carers support, the aims of the Act will not be achieved. Competing priorities at local, regional and national level are leaving carers needs sidelined with what appears to be short term decisions made on what is a long term and increasing need.
- It is vital that at national level it is fully understood how investing in carers is investing in the future health of the nation and reducing earlier dependency on services funded through the public purse.
- Without improved data on carers, accountability on what is provided and how well it is working is lacking.

1. **<u>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.</u>**

Identification

Identification remains a significant barrier, despite Welsh Government’s support through grant funding, campaigns and through funded projects. The Social Services and Wellbeing Act (Wales) 2014 enshrines in Welsh law the legal right to information, advice and assistance, but a carer needs to know these exist before they can access them.

Carers time is precious, so it’s important that places carers already go are focussed on to increase identification levels. The Track the Act report shows only 39% of carers of all ages were identified within the first year of caring, 25% of carers took between one and three years to be identified, and 36% took more than three years.[9] It found only 12% of carers were identified in medical settings and only 9% by local authority officials. Health services are an important place for identification. When asked their preference for where they should be identified, 72% said hospital and GP settings.

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[9] https://www.carersuk.org/wales/policy-and-research/track-the-act/track-the-act-home-page/

Age Cymru's analysis of responses 2025 What Matters to You? 2025 annual survey with older people across Wales shows that only three quarters of older people who asked social care for help for someone else self-identified as a carer. Of those that did, many of these voiced their frustrations on how help was not there when they needed it after many years of caring alone.[10] Increasing resourcing for earlier identification can reduce the incidences of carers reaching crisis point and the devastating impact this has on them, as well as the high cost to the public purse of a multi-agency crisis intervention.

Not all carers want external help early in their caring journey, but many are left without earlier information and advice that could help them stay safe and well whilst caring. Carer feedback is often 'you don't know what you don't know,' so increasing opportunities to get that vital information out makes a large impact. Peer support groups offering local support and activities can help carers prepare for future changes in their caring journey.[11]

There are good examples of national initiatives supported by Welsh Government that are providing the resources for increasing carer identification, such as the Older Carers Project delivered in partnership between Carers Trust Wales and Age Cymru. The 2024-2025 project had a focus on increasing older carer identification rates and older carer's specific challenges in health and settings.[12]

Many such projects rely on short term funding, which can often mean only a short-term focus in specific areas from year to year. It is important that there continues to be a national focus on carer identification, with an additional focus on increasing identification rates in groups for whom identification rates are low. This needs to be sustainably resourced.

Getting early information and advice

The Track the Act report details the differences in likelihood of seeing information on caring, depending on the relationship with the person needing care and the situation of the carer. More than half of carers caring for a child had seen information (51%), while only 42% of those caring for partner had seen information. For those who care for a parent, this reduces to 39%. The report found only 37% of carers in employment saw any information that helped them in their caring role.[13]

Of those who had seen information, the majority saw this from a national carers' organisation like Carers Wales (51%) or from a local carers' charity or group (28%). This indicates members of the public are more likely to approach a local group for help before they ask for help from statutory agencies.

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[10] www.agecymru.org.uk/annualsurvey

[11] Examples include Carers Wales 'Me time' - https://www.carersuk.org/wales/help-and-advice/your-health-and-wellbeing/me-time-sessions/metime-sessions/ and other community led social groups

[12] www.agecymru.wales/carers

[13] https://www.carersuk.org/media/x5odnlk5/track-the-act-6-english-compressed.pdf

Additional efforts are needed to target carers who are less likely to be identified early. To increase self-identification in carers it is vital that information and advice is accessible and available in places carers routinely turn to for help.

It is vital that resourcing is focussed on ensuring that opportunities to identify early are available through community groups and health settings.

Inconsistencies across Wales

How carers are identified and the care pathways that then follow vary across Wales. This includes the language used in carer identification and care pathway planning (see below section). Knowing where to go, the variation of availability of services in different parts of Wales differences in information provided and what support is available in different parts of Wales is a barrier. Reducing those differences in what is available and where is vital.

There are variations in how information, advice, peer group support and care arrangements are advertised and delivered across Wales. Some local authorities fund third sector organisations to provide information, advice and support to carers, whilst others have these in-house.[14] Some areas have been looking at different ways of providing this this.[15] It is important that where changes are made and when services are reviewed that this includes a focus on increasing consistency across Wales.

As included above, carers preference is for information via a health setting, and their first port of call when they need help is often a community group/charity. An added focus on consistency of the care offer in health settings would be a good short-term action to reducing inconsistencies.

Language and terminology

Using the right language and preferred communication choice of carers can increase carer identification and improve care planning.

The Older People's Commissioner for Wales 2018 report on dementia and respite care highlighted how the language used around respite care can be a hindrance to getting meaningful respite options for the carer and the cared for.[16]

The Track the Act report details the differences in terminology used across Wales and how earlier 'what matters' conversations are being had at different times in the identification and care planning journey. It details how carers simply don't know whether they have had an assessment or not.

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[14] https://www.carersuk.org/media/x5odnlk5/track-the-act-6-english-compressed.pdf

[15] www.agecymru.wales/why-are-we-waiting

[16] https://olderpeople.wales/wp-content/uploads/2022/05/Rethinking-Respite-for-People-Affected-by-Dementia.pdf

These differences inhibit a clear picture emerging of how many carers are being identified, how early, what is offered at each stage and whether that response was effective. Standardising terminology used across Wales reduces confusion and improves data collection quality.

Additional efforts are needed nationally, regionally and locally to reduce variations in terminology used. The agreed upon terminology must be co-produced with carers.

Workforce capacity and carer awareness

The care workforce across Wales (social care, health and wider care agencies and third sector services) is struggling. Recruitment and retention are issues, and this means additional, resource effective methods are needed to quickly upskill newer staff on understanding carer pressures and needs so that identification increases, and earlier information, advice and support is offered. There are a range of resources available through carers organisations, patient interest groups both on and offline that assist in increasing awareness of carers needs and circumstances.

Every health board and every local authority have arrangements for carer identification and support, for both staff and the public. It is vital that arrangements ensure that there is an ongoing focus on carer identification to ensure that newer staff are able to increase their skill levels early.

As included above, project funding supported by Welsh Government has produced a range of carer training modules and resources and these have increased staff awareness and understanding of carers pressures and needs. Modules and materials have variously involved carers in their design and delivery, including carers' lived experience. [17]

It is important that resourcing is available to regularly update and disseminate resources to maintain and increase staff awareness of carers.

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

Respite should be a way to support families in maintaining important relationships, maintaining and developing new skills, and should underpin and sustain the overall wellbeing of both individuals and families. Carer service engagement shows large numbers of carers not getting the help they need, and not getting enough help when they really need it.[18]

It is difficult to quantify the volume of respite offered across Wales, or to show the difference that respite offered is making to carers from current data collection methods and reporting. The variations in what is available, the funding streams they

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[17] https://carers.org/carer-aware-project/what-is-carer-aware

[18] Age Cymru Why are we still waiting

are provided through, and the differing reporting requirements mean no clear picture is available.

Some positive data is available from the evaluation of the Short Breaks scheme. The evaluation shows the positive impact that the scheme is having on carer wellbeing and how its flexibility gives increased choice and tailored respite options. It also demonstrates how the community and business connections made through the scheme are helping support community groups to be more resilient.[19]

This evaluation also shows only 14% of adult carers had accessed a short break from elsewhere in the last year and 80.5% of carers taking short breaks were caring for at least 50 hours a week.

Age Cymru's campaigns in 2022, 2023 and 2024 highlighted the delays in getting older people including older carers access to care for the person they provide care for and themselves, as well stalling in some local authority areas on carer service developments. Their 2024 report found that of carer developments discussed in their 2023 report, some were still in progress, at least one had stalled from an apparent lack of buy-in at decision maker level.[20] Unless carers needs are further prioritised, development that can help them in their caring role will continue to stall.

A reduction in service provision, for example day services for people with a learning disability, not only impacts the person accessing this service but also their families. Mencap Cymru's Future of Day Services Report found that 73% of respondents experienced some form of cut to day service support hours as a result of the COVID pandemic, which impacted on the well-being of both the individual and their family carer.[21] Family members may be left with no choice but to quit their jobs.

There needs to be increased accountability on local authorities, health services and regional partnership boards on how much is spent on carer services and whether that funding is making a difference. This should include the wider landscape of provision – including the availability of peer group support and community groups.

Welsh Government must provide long term, sustainable funding for carer services to increase stability and quality of carer support. To ensure professional knowledge is maintained, a proportion of the funding should be assigned to increasing and maintaining staff knowledge on what support exists.

Improved monitoring of carer support provision is vital to ensure the Social Services and Wellbeing (Wales) Act 2014 aim of allowing people to live at home for longer is met so that plans can be made to meet the levels of carers needs.

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[19] https://www.shortbreaksscheme.wales/downloads/evaluation-of-short-breaks-scheme-interim-report.pdf

[20] www.agecymru.wales/why-are-we-waiting

[21] https://wales.mencap.org.uk/sites/default/files/2023-07/Future%20of%20Day%20Services%20Mencap%20Cymru.pdf

3. The extent to which the demand for carers support services is being assessed and addressed, and current levels of unmet needs

The various funding streams that support carer needs, the ways in which services are commissioned and tendered for and the variety in reporting outcomes makes it difficult to see an accurate picture of the extent of unmet need for carers' support.

Though unpaid carers have a right to a standalone assessment of their own needs, Carers Wales Track the Act information requests found that some local authorities often combine a Carers Needs Assessment with an assessment of the person with care needs, while some councils will operate a two stage process whereby carers will have an initial conversation with a professional, such as a social worker, before potentially being offered a Carers Needs Assessment.

Unless needs are holistically assessed, the true volume of need remain unknown. The Public Service Ombudsman's report, 'Are we caring for our carers?' found only 2.8% of the carer population had their needs assessed and this led to only 1.5% having a support plan.[22] The Track the Act report shows only a quarter of carers did not want a carers assessment, and three quarters were open to having one.[23] This shows there is a large gap between those that are open to having an assessment, and those that are getting one.

The evaluation of the short breaks scheme highlights just how many carers accessing that respite support did not get any other breaks and how a large proportion are providing high hours of care each week, which indicates a high level of unmet need.[24]

Not having sufficient services and support to offer disincentivises staff on making an offer of a care assessment if they know the offer is unlikely to result in positive outcomes for the carer. If an assessment is completed and there are long delays in getting the help needed, trust in the system is lost. Care assessors need to be confident that the care planning they offer has the services behind it to meet carers needs. Without an increase in levels of carers support services, this disincentive continues.

Local authorities need to commit to long term, sustainable funding for carers services at a level suitable to meet their needs.

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

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[22] Are we caring for our carers? Ombudsman Wales https://www.ombudsman.wales/wp-content/uploads/2024/11/OI-report.pdf

[23] https://www.carersuk.org/wales/policy-and-research/track-the-act/track-the-act-home-page/

[24] https://dsdc.bangor.ac.uk/news/evaluation-of-the-national-short-breaks-scheme-20682

To meet the holistic needs of carers requires a multi-agency and well-coordinated response. Making sure Regional Partnership Boards (RPBs) embed the needs of carers across all their work is vital.

The Social Services and Wellbeing Act (Wales) 2014 recognises the key role played by carers. The Act places a duty on RPBs to improve the efficiency and effectiveness of service delivery, including delivering support to carers. Each RPB dedicates a proportion of funding to carer needs primarily through Regional Integration Funding. As included above, it is difficult to quantify and compare the volume of resourcing in each area and the efficacy of what that funding achieves. Increased transparency on this is needed.

There are variations in how well carers voices are heard at regional partnership boards across Wales. It is important that prioritisation at regional board level is based on good quality evidence and projections for the future and that partners all understand how well supporting carers contributes to prevention work.

The Charter for Unpaid Carers includes a requirement that RPB membership must include at least one person to represent people with needs for care and support, at least one person to represent carers, at least two persons to represent the interests of third sector organisations, and at least one person who represents the interests of care providers.[25] This means that in effect the legal requirement is only one carers voice. While this very basic requirement is being met by each RPB, how well that carer voice is heard and understood varies. If carer voices are not well embedded, it is unlikely their needs are understood and sufficiently prioritised.

In Age Cymru’s report on delays in access to social care for older people, difficulties local authorities faced in getting funding from RPBs for carers services were highlighted. These included difficulties in aligning reporting requirements between various funding strands and the resourcing required to tender for regional funding. The reports also highlight how funding pressures on local authorities meant ‘edge of care’ grant funding that helped with earlier identification and prevention were reducing or not being renewed.[26]

With competing pressures on RPBs, prioritising resourcing for carer support does not always happen, despite evidence of need. As such it is vital funding is ringfenced. This funding should be provided on a level sufficient to meet carers’ needs on a long term, sustainable basis.

To support accountability and good use of public resources, RPB reporting requirements should include financial accountability for funding spent on carers that measures the positive impact on carers’ lives.

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[25] https://www.gov.wales/regional-partnership-boards-charter-service-user-carer-third-sector-and-provider-members-html-0

[26] www.agecymru.wales/why-are-we-waiting

5. 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).

Above we have called for funding for carers services to be provided at a suitable level to meet their needs. While above we have focussed on this at RPB level, this call equally applies to local and national bodies to provide increased stability for the carer service workforce. This contributes to resources being better directed towards improving services rather than repeated tendering for commissioning services and agencies constantly ‘chasing’ limited funding opportunities which could be better used. It is vital that it is understood at all levels just how much carers contribute to the prevention agenda.

It is vital that additional sustainable resourcing is directed to increase identification and staff understanding of carers needs and care planning. This would be a change from the current short-term measures that miss many staff in roles where turnover is higher, despite efforts to provide continuity of projects through resources.

Data collection needs significant improvement before it is possible to increase accountability of how public funding is spent on carers and the difference that investment makes. What is collected should be based on carer’s views and they should be involved in these developments. Linked with this, variations in terminology used in care planning need to be eradicated to increase consistency across Wales.

Increased accountability is needed on the range and quality of carer services to hold those accountable who are not sufficiently prioritising the commissioning of carer support services.