Cafodd yr ymateb hwn ei gyflwyno i ymgynghoriad y Pwyllgor Iechyd a Gofal Cymdeithasol ar Flaenoriaethau'r Chweched Senedd

This response was submitted to the Health and Social Care Committee consultation on Sixth Senedd Priorities

HSC PSS 70
Ymateb gan: | Response from: Ymddiriedolaeth Gofalwyr Cymru | Carers Trust Wales

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Blaenoriaethau cychwynnol a nodwyd gan y Pwyllgor
Initial priorities identified by the Committee

Mae'r Pwyllgor wedi nodi nifer o flaenoriaethau posibl ar gyfer ei waith yn ystod y Chweched Senedd, gan gynnwys: iechyd y cyhoedd a gwaith ataliol; y gweithlu iechyd a gofal cymdeithasol, gan gynnwys diwylliant sefydliadol a lles staff; mynediad at wasanaethau iechyd meddwl; arloesi ar sail tystiolaeth ym maes iechyd a gofal cymdeithasol; cymorth a gwasanaethau i ofalwyr di-dâl; mynediad at wasanaethau adsefydlu i'r rhai sydd wedi cael COVID ac i eraill; a mynediad at wasanaethau ar gyfer cyflyrau cronig tymor hir, gan gynnwys cyflyrau cyhyrysgerbydol.

The Committee has identified several potential priorities for work during the Sixth Senedd, including: public health and prevention; the health and social care workforce, including organisational culture and staff wellbeing; access to mental health services; evidence-based innovation in health and social care; support and services for unpaid carers; access to COVID and non-COVID rehabilitation services; and access to services for long-term chronic conditions, including musculoskeletal conditions.

C1. Pa rai o'r materion uchod ydych chi'n credu y dylai'r Pwyllgor roi blaenoriaeth iddynt, a pham?
Q1. Which of the issues listed above do you think should be a priority, and why?

Public health and prevention;

Recent Public Health Wales publications focused on education and mental health strongly demonstrate that there are specific public health considerations that need to be given in planning and delivering support for unpaid carers.

There are clear links between caring and poverty, poorer health outcomes and financial insecurity.

Carers Trust Network Partner services have worked quickly and effectively to develop and deliver support schemes including delivering the Carers Support Fund generated and delivered by Carers Trust Wales on behalf of Welsh Government. Through this program a significant number of carers who are in need of support and were previously unknown to services have been identified. In many cases, more than 50% applicants to emergency grants schemes, who are applying at a point of crisis, were previously unknown to services. Whilst it is positive that we have been able to generate an effective way of connecting with carers who are struggling it is clear that there is a significant unmet demand for support amongst carers who are at breaking point. Network Partners have reported that the needs identified through these grants are concerningly basic with carers mostly needing help to afford food and utility bills. There have also been requests from carers for funding to help purchase equipment to enable them to care safely which had been refused by health and social services.

As COVID19 restrictions hopefully ease there would be value in the Committee exploring how public health policy and research can contribute to better health outcomes for carers with a particular focus on poverty and access to respite / short breaks from their caring role. This could be something usefully considered as part of early work on COVID recovery and ought to involve carers, carers services, third sector organisations, local authorities, local health boards, NHS confederation and Public Health Wales. This issue also relates directly to the mounting challenges facing formal social care services which are adding damaging impacts onto unpaid carers and their families across Wales through the reduction of services.

More widely, it is crucial that health inequalities are considered by the Committee and that key themes picked out in the NHS Confederation's Health and Wellbeing Alliance's recent paper on this issue are addressed. We support the call for an inquiry across all Senedd Committees on tackling health inequalities in Wales. Meaningful progress will require coherent efforts across all sectors to close the gap and an inquiry undertaken by all Senedd Committees will enable Committees to consider what action each Welsh Government department is doing to tackle the root cause of health inequalities and put forward recommendations around where improvements are needed.

The health and social care workforce

We are proud of the services provided across the Carers Trust Wales Network and their impact on carers and those that work with them. However, in order for carers services to have the most impact they need to be funded in sustainable ways that fully appreciate both the importance of innovation and the importance of funding long-term mainstream services. There is a clear and growing need for additional investment in social care across Wales with local authorities having felt the pressure of reducing budgets over many years.

Within our Network, we have recent examples of closures, mergers and the cessation of services as a result of the increasing local financial pressures. The particular challenges that have been faced are often as a result of commissioning processes that don't sufficiently prioritise achieving the wellbeing outcomes of those they are designed to support. The pandemic has increased pressure with some services reporting blanket reductions in funding despite growing demand.

In some areas Network Partners of Carers Trust have described decreasing levels of collaboration with local authorities and an increasing sense that funds such as ICF are being used to fund existing local authority provided services during the pandemic. Carers representatives, citizen representatives and third sector representatives on several Regional Partnership Boards have expressed concern at their lack of involvement on funding decisions during the pandemic. The reduction of their involvement is a retrograde step. One Network Partner has reported a 3% blanket reduction in their funding to deliver carers services in the next financial year from their local authority. This is despite them operating a waiting list for some services they provide and having clear evidence of the need to expand the service. Another Network Partner reports losing a longstanding contract to provide a carers services as the local authority opted to bring it in house to help support other functions within the local authority. This Network Partner has real concerns about the quality and reach of this approach and early feedback from carers on the negative impact this has had on them. It is important that local authorities, local health boards, the third sector and carers work positively through regional partnership boards to sustain essential and effective carers services based on a clear understanding of local need.

As employers, all of our Network Partners have seen rising salary costs in line with rises to the National Living Wage. Whilst fair and appropriate remuneration is, of course, essential, this increase alongside the costs associated with training and developing the workforce has made the cost of delivering services substantially higher. This increase in cost has not been recognised by all commissioners, with many service providers themselves often facing real-term cuts year on year.

As providers, Network Partners have experienced a range of challenges to being commissioned in a way that enables them to continue to deliver a high-quality service for carers and those they care for in a way that is sustainable.

To develop appropriate and impactful services, it is important that when service specifications are developed the third sector are engaged as equal partners in determining what support is needed and how this can best be delivered to the individual. Many of the additional benefits that can be gained as a result of providing care within the home, such as signposting to other services, providing assurance and support to the family and delivering appropriate and compassionate care are often curtailed by seemingly arbitrary limits on call times.

Within our Network we have had examples where Partners have been commissioned by local authorities to deliver domiciliary care at a rate that is below what it costs to deliver the service. This has resulted in some Network Partners handing contracts back, with others facing significant financial difficulty as a result.

Other examples, in terms of financial disincentives to providing domiciliary care, include the cost of travel between calls in rural areas. This cost is both the pay for the care worker and the actual cost of travel, which can be prohibitive in some rural areas.

As more people with increasingly complex needs are choosing to live at home, the skills required to deliver this type of care are growing. Upskilling the workforce presents challenges, both the time and cost implications of doing so, and the challenge of retaining them within the social care sector once they have been trained. Training and recruitment costs can be significant for care providers and are often not accounted for in commissioning processes.

The regulations under the Regulation and Inspection of Social Care (Wales) Act 2016 are a welcome move towards the creation of a recognised and highly-skilled registered workforce. While our Network supports the professionalisation of the workforce, we are concerned by the potential to add pressure to the ability to recruit and retain the workforce on current terms and conditions. These measures will undoubtedly create additional costs for the sector in terms of training, administration and registration fees.

It would be useful for the committee to consider:

- routes to more effective recruitment and retention of the social care workforce and

- approaches to commissioning integrated service delivery models that work meaningfully with and across public, statutory and third sector organisations is essential to achieving these aims.

Access to mental health services;

We know that the pandemic has had a detrimental impact on the mental health of carers of all ages and those they care for. Our research during the pandemic gave solid evidence that many young carers were struggling with mental health problems and were unable to access appropriate support. Young carer support workers within our network report an increasing number of carers presenting with complex mental health needs including self harm and suicidal ideation. Access to specialist services remains difficult, In the context of COVID19 recovery it will be important for the Committee to consider what steps can and should be taken to both ensure that those in immediate need can access appropriate services and that preventative support is available to help build resilience and mental wellness amongst young carers who are more likely to be in poverty and experience other environmental factors that make them more prone to mental ill health without the right support.

During the pandemic many carers, particularly young carers, have described that they would like to be able to access more help with their emotional and mental health. Our Carers Trust Network Partners, local and regional services that provide direct support to carers, have described a huge demand for counselling services, which they have prioritised investing in. Despite this, support workers within carers services have described that many carers are increasingly showing signs of mental ill health and that referring them onto specialists services is both difficult and often unsuccessful. Many carers remain on waiting lists to access specialist mental health support and support workers within carers services are facing a significant emotional pressure as they work hard to remotely support carers who are struggling.

Despite carers services working at pace to reshape services the move to online has not been positive for many carers. Whilst it is clear that online services have helped to engage specific groups of carers that may have previously not accessed services, for example working carers, many unpaid carers have expressed that online services are not as effective for them. When seeking emotional support, peer support or general opportunities for socialising online alternatives have widely been seen as less effective. It is also important to recognise that those experiencing digital or data poverty, or those who are less comfortable using online platforms, have been largely unable to access support for the vast majority of the pandemic.

The emotional impact of supporting carers who are struggling has been significant for staff working within carers services. Many services have enhanced the emotional support available for staff and put in place approaches to keep staff morale high. However, it is important to recognise that those working withing carers services and the wider third sector have been working in an extremely tiring and emotionally charged environment with ever-changing parameters to and limitations on their work for the last 18 months. Dedicated staff have in many cases gone above and beyond to meet the needs of the carers they support.

There would be significant value in the Committee considering evidence relating to unpaid carers' access to Mental Health services and to appropriate support to build emotional resilience and mental wellbeing.

Services for unpaid carers;

Carers' own health and wellbeing needs are often exacerbated or caused because of their caring role. If a carers' health continues to deteriorate it will have a negative impact on their own wellbeing, and also the wellbeing of the person or people they care for. It may also have an impact on health and social care services as they may be required to provide unplanned, emergency care to the people with care and support needs.

Despite the Social Services and Wellbeing (Wales) Act setting out clear responsibilities in terms of preventative services:

"Part 2, Section 15 places a duty on local authorities to provide or arrange for the provision of a range of preventative services to prevent or delay people's needs for care and support.
"A relevant partner, such as an LHB, must comply with a request to cooperate in relation to the delivery of preventative services, unless to do so is incompatible with their own duties."

There remains a lack of join-up in the commissioning of specialist and generic carers services and an expectation that the third sector will be able to innovate and sustain preventative services, upon which the statutory sector relies, without appropriate public-sector investment. This challenge has undoubtedly been exacerbated by the pandemic.

Unpaid carers have consistently told us that there are a core suite of essential support services that we can predict a need to provide sustainable funding for. The new Strategy for Unpaid Carers and the accompanying Delivery Plan (due to be published this autumn) presents a new opportunity to address the import role of national, regional and local third sector services and to work towards a consistent approach to ensuring that the services carers most rely on are put on a sustainable footing. When planning approaches to service provision as pressures and restrictions caused by Covid-19 hopefully ease, it will be important for there to be clear direction to local authorities and regional partnership boards about the importance of making decisions that support the sustainability of carers services and actively involve local carers in the decision-making process. Decision making at regional partnership board level during the pandemic has served to make carers representatives feel less involved and less able to influence and inform decisions.

As referenced above, COVID19 has had a direct impact on carers and the services they rely on, with opportunities to generate income to deliver key preventative services increasingly limited. The commitment to a preventative approach laid out in the Social Services and Wellbeing (Wales) Act can only be delivered within the context of a vibrant and thriving third sector. Outside of the direct commissioning of services, the value the third sector brings to the delivery of the Act is significant. This must be recognised and supported as without working in a supportive partnership with the third sector there is a very real risk that our most effective preventative services will not survive and certainly will not be able to thrive and develop to meet the needs of more carers before they reach crisis point.

As highlighted in our response to the Health Social Care and Sport Committees' inquiry into the delivery of the Social Services and Wellbeing (Wales) Act for carers, the funding of young carers services remains patchy and in parts insufficient. Many services struggle with year-on-year funding and the delivery of young carer support often relies on third sector generated, funded and delivered programmes. Funding streams used by local authorities can restrict or limit access to much needed support for young carers, particularly where Families First funding is used to fund support as an "Intervention" when in reality support needs are likely to continue for the longterm. The national plan should address the funding of key services for young carers, particularly those that support respite opportunities and build resilience and positive emotional and mental health and wellbeing.

The insecure and sometimes unsustainable funding of carers services can prevent the development of stable, reliable services that the general public can become familiar with. In evidence to the Finance Committee's Inquiry into the cost of caring for an ageing population we provided strong evidence that the way services were commissioned, often undervaluing contracts, has a detrimental impact in the quality and sustainability of services. Since then, we have worked with Welsh Government, local authorities and carers services to develop a guide for commissioners. It would be beneficial for the plan to highlight this guide, and to recommend that commissioners utilise the checklist included within it.

Additionally, Network Partners of Carers Trust have highlighted that monitoring and evaluation of the services they provide is often time consuming and inconsistent based on which body is commissioning the service. There is significant room to improve monitoring and evaluation to improve comparability of data generated and an emphasis of collaborative impact assessment.

Alongside Welsh Government's recent consultation on *Rebalancing Care and Support* the Committee could usefully undertake work focused on how Regional Partnership Boards and other statutory bodies can best approach working collaboratively to commission and deliver integrated preventative services to support unpaid carers.

For all of these areas of work Carers Trust Wales would happily facilitate sessions with our Network Partners which include regulated service providers. We would also be keen to be involved in opportunities that support carers to directly have their views heard, including young carers via our Youth Council and Welsh Youth Parliament Member.

Blaenoriaethau allweddol ar gyfer y Chweched Senedd
Key priorities for the Sixth Senedd

C2. Yn eich barn chi, pa flaenoriaethau allweddol eraill y dylai'r Pwyllgor eu hystyried yn ystod y Chweched Senedd mewn perthynas â:
a) gwasanaethau iechyd;
b) gofal cymdeithasol a gofalwyr;
c) adfer yn dilyn COVID?

Q2. In your view, what other key priorities should the Committee consider during the Sixth Senedd in relation to:
a) health services;
b) social care and carers;
c) COVID recovery?

Gwasanaethau iechyd
Health services

Our flagship partnership project with Carers Wales, Carer Aware, is utilising new ways in engaging health professionals in understanding, informing and supporting unpaid carers. The change away from requiring LHB to identify and deliver targeted support for unpaid carers (with the removal of previous legislation, the Carers Measure) was a retrograde step. LHBs face insecure funding for carer-specific work (these were previously referred to as 'transition' funds and are just £1m across the whole of Wales). An increase in the amount LHBs receive to identify and support unpaid carers is needed.

A priority focus for additional funding would be to support GP services to identify and signpost carers - including relevant requirements on GPs (through the use of QOF points or similar) to drive up identification.

Carers Trust Wales has worked with Age Cymru and generated important evidence that older carers' still rely on GPs for signposting and would most value information about available support from trusted individuals like GPs or GP staff. The collection of data across Wales at GP level is patchy and even LHBs struggle to access reliable information. The struggle in identifying unpaid carers for a COVID vaccine in early 2021 is a good example as to why it is important for carers to be identified formally within the health service.

A short piece of work by the committee to better understand this issue and consider future approaches would be beneficial.

Gofal Cymdeithasol a gofalwyr
Social care and carers

In terms of Information, Advice and Assistance carers continue to tell us that it is difficult to access timely and accurate information. Whilst they value the expertise of local carers services, many carers still struggle to navigate the system without support. Additionally, recognising that a substantial number of carers will not self-identify as such, IAA services are not consistently supporting carers to recognise their role or to signpost them to carers services. It's important that all Single Points of Access have up to date information to ensure that those answering queries from carers have the skills and information they need to understand their legal rights and to signpost them for support effectively. It is important that carers are not expected to negotiate a complex system and that active offers of support are made at every opportunity. There is a particular role for IAA services in delivering the preventative agenda in the act through taking a professional curiosity in individual's wider life circumstances and being proactive in the provision of advice and support.

Carers Trust Network Partners have also highlighted that during the pandemic carers are being offered support at the least effective point in their caring journey and only once they reach crisis point. Opportunities for truly preventative services, support and information as defined by the Social Services and Wellbeing (Wales) Act have been limited. It is clear that more needs to be done to integrate the preventative agenda with approaches used to delivering IAA to ensure carers are prepared for their caring role and have a clear idea of how to access support they may need along the way.

The committee could look at IAA provision, including the training of professionals working within Single Point of Access to ensure that carers receive accurate and timely information enabling them to access all of their rights under the Act.

Adfer yn dilyn COVID
COVID recovery

We have covered aspects of b) social care and carers and c) COVID recovery in this answer:

Access to support, including shortbreaks and respite

Research from Carers Wales has demonstrated that during the pandemic more people have become carers and that many existing carers are caring for more hours a week and for people with more complex needs than they were before the pandemic. Our own research, focused on young carers, found that 58% are now caring for more hours a week and 35% are now caring for more people than they were before the pandemic began. 68% of young carers are caring for 20 hours a week or more with 18% of young adult carers telling us they now care for 90 hours per week or more.

There is a weight of evidence that carers and those they care for are less able to access support and that this is having an impact on their physical, emotional and financial health.

Age Cymru's research has found that unpaid carers have struggled to access primary care services and our own research, through the Welsh Government funded Carer Aware project, has found that many carers are struggling to access routine appointments and treatments in both primary and secondary care. These barriers to maintaining their own health and that of the person they care for has meant that there has been a clear decline in their health and wellbeing in many cases, often concurrently.

Before the pandemic research showed that many carers cancel treatment for themselves, or are slow to address their own health concerns, because of their caring role. Given the anecdotal and formal research evidence collated during the pandemic it is a clear and real concern that carers' current health and longer-term health outcomes may well be negatively impacted.

The lives of carers who rely on day centres or other external support for those they care for have been significantly impacted. For some, the closure of day services has led to them taking on a 24/7 caring role with little to no respite since March 2019. Some carers have reported that they have had to give up paid work because they are unable to juggle work with full time caring, others have had to reduce hours or change roles often having a significant and negative effect on family finances.

For carers caring for someone in a care home the pandemic and restrictions to visiting have been hugely difficult. Many carers have not been able to see those they care for face to face and this has been very distressing for both the carer and the person they care for. Many nursing and residential homes have worked hard to enable visiting in creative ways and to use technology to help carers stay connected. However, carers, particularly of people living with dementia, have struggled to maintain meaningful contact with the person they care for. For some, the person they care for no longer recognises them and the lack of physical contact makes communication and providing reassurance very difficult. This has left many struggling with guilt and enhanced feelings of anticipatory grief. Through a session with Social Workers held by the National Engagement Group for Carers some Social Workers described a significant concern for carers who had chosen to bring the person the care for home at the beginning of the pandemic to avoid the issues presented by limitations to visiting. Social Workers described carers taking on very heavy caring roles which they had previously felt were too significant to manage at home. Social Workers expressed concern that carers in some cases felt they had no other alternative despite knowing that very limited respite would be available to them once they had chosen to take on an enhanced caring role.

We know that before the pandemic many carers described that they struggled to take sufficient breaks from their caring role to do the basics in life like shopping or going to the GP or to do the things that matter to them. The pandemic has amplified these feelings for many carers who have been less able than those without caring responsibilities to maintain a normal day to day life or a social life or other activities. In some cases, this has been as a result of steps taken to protect someone who has been shielding and in others it has been because the demand of their caring role leaves them no time or space to socialise or maintain hobbies. Network Partners of Carers Trust have had a positive response from carers to initiatives where they've sent wellbeing packs to carers homes as a way of encouraging self-care. Many carers have described that they are approaching breaking point and that as the pandemic goes on their resilience has decreased. It is important to recognise the protracted length of time carers have been expected to care without respite and the inevitable high demand for respite services once restrictions are lifted and services can be opened up safely. This spike in demand is predictable and should be proactively planned for.

Carers Trust services mobilised quickly to proactively reach new carers during the pandemic and to provide support to those already known to them. During the early stages of the pandemic there was a significant rise in demand for support with emotional health (including counselling), support accessing benefits and managing finances, food boxes and access to small grants. Initially there was a reduction in demand for domiciliary care as families were cautious about allowing people into their homes and the added risk this might present in terms of transmission of the virus. Within a matter of weeks demand had returned to its pre pandemic normal as many carers found they simply couldn't cope without support. Demand for domiciliary care services remains high, despite many carers still refusing support within the home. It is predictable that as the vaccines are rolled out there will be a backlog of carers likely to come forward to request services once they deem it is safe to do so.

The Committee could play a useful role in exploring access to respite and support for carers to enable them to rest, take care of their own health and do the things that are most important to them. This must include a consideration of current and future demand and the service delivery models that will best meet the needs of a growing number of carers who may be potentially facing burnout