

	The Welsh NHS Confederation response to the Health, Social Care and Sport Committee's inquiry into the impact of the Social Services and Well-being (Wales) Act 2014 in relation to carers.
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Introduction

1. The Welsh NHS Confederation welcomes the opportunity to respond to the Health, Social Care and Sport Committee's inquiry into the impact of the Social Services and Well-being (Wales) Act 2014 in relation to carers.
2. The Welsh NHS Confederation represents the seven Local Health Boards and three NHS Trusts in Wales. We support our members to improve health and wellbeing by working with them to deliver high standards of care for patients and best value for taxpayers' money. We act as a driving force for positive change through strong representation and our policy, influencing and engagement work.
3. In addition to our response on behalf of our members, the Welsh NHS Confederation Policy Forum has also drafted a briefing highlighting the key priorities for carers, endorsed by over 20 organisations.

Overview

4. There are 370,000 carers in Wales.ⁱ The Welsh Government defines a carer as "*anyone of any age, who provides unpaid care and support to a relative, friend or neighbour who is disabled, physically or mentally ill, or affected by substance misuse*". Carers can be involved in a whole range of practical, physical, personal and administrative tasks. Examples could include: cooking; housework; lifting, washing and dressing the person cared for; helping with toileting needs; administering medication; and providing emotional support.
5. Carers provide a significant contribution to society, the economy and the health and social care sector. The care provided by unpaid carers in Wales is worth an estimated £8.1 billion a year.ⁱⁱ Health and social care services rely on the support provided by carers' and their ability and willingness to provide unpaid care. It is recognised by the NHS that without carers' support the health and social care system would collapse. Health Boards and NHS Trusts recognise unpaid carers as key partners in the delivery of services and for maintaining the health and wellbeing of the population.
6. While three in five of us will become a carer at some point in our lives, a significant number of carers still do not identify themselves as carers but see the support they provide as a natural part of their relationship with the cared-for person. When carers do not conceptualise or identify themselves as carers, they may be reluctant to access the

support they require to maintain their health and wellbeing, as well as the person that they are caring for, or the benefits they are entitled to.

7. Prior to the introduction of the Social Services and Well-being (Wales) Act 2014 (SSWB Act), the Carers Strategies (Wales) Measure 2010 placed a legislative duty on Local Authorities, Local Health Boards and NHS Trusts to produce a joint information and consultation strategy for family/unpaid carers. In many Health Board areas, multi-agency Programme Boards were established to steer, implement and monitor necessary progress.
8. The Carers Measure, and the other carer-specific legislation, was repealed in April 2016 when the SSWB Act 2014 came into force. The SSWB Act recognises the key role played by carers, giving them the rights to support which are equivalent to the rights of those they care for. Section 14 of the Act places a joint requirement on Local Authorities and Health Boards to work together to assess:
 - The extent of the care and support needs of the local population;
 - The extent of support needs for carers;
 - The extent to which those needs are being met;
 - The range & level of services needed to meet the care and support needs identified; and
 - The range and level of preventative services needed.
9. As a result of Section 14 of the SSWB Act 2014 some Health Boards have worked with Local Authorities to produce collaborative carer strategies which streamline service provision by ensuring there is just one strategy in place for carers that work across the Health Board area (rather than one or more Local Authorities having individual/separate strategies of their own).
10. Section 24 of the SSWB Act 2014 requires that carers must be fully involved in their assessments and the Act makes it clear that the duty to assess applies regardless of the Local Authorities view of the level of the carer's needs for support, or their financial situation. Carers can also have a joint assessment with the person they care for.
11. Finally, the SSWB Act 2014 put onto a statutory footing seven Regional Partnership Boards (RPBs), bringing together Health Boards, Local Authorities and third sector partners to improve the efficiency and effectiveness of service delivery, including delivering support to carers. We welcome the central role that RPBs will play in delivering seamless health and social care services, as emphasised in the recently published Welsh Government long-term plan *A Healthier Wales*.ⁱⁱⁱ
12. This response will address the terms of reference of the inquiry in turn. While the SSWB Act 2014 includes a number of duties on Local Authorities, Health Boards and NHS Trusts are a key partner in delivering support for carers across Wales.

The number of carers' assessments undertaken in Wales and how this has changed as a result of the Social Services and Well-being (Wales) Act 2014 and whether there is variation between local authorities;

13. The SSWB Act 2014 places legal duties on Local Authorities to meet a carer's eligible needs following a needs assessment. Health Boards are under a duty to work collaboratively with Local Authorities to assess the extent of the need and the level of supportive and preventative services that are required.
14. Carers Wales' "Track the Act"^{iv} programme found that 19% of carers in Wales received a carer's needs assessment during the first six months of the SSWB Act's 2014 implementation (April – October 2016), however there were significant improvements in the following six months (October 2016 – April 2017) when the number of carer's needs assessments increased to 44%. However, the "Track the Act" programme is informed by people who identify themselves simply as carers, no further information is gathered about how many people they care for, the nature or extent of their caring duties, or how many hours per average week they devote to their caring commitments.

The number of carers receiving support following a local authority assessment, including respite care, how this has changed since the Act came into force, and whether there is variation between local authorities;

15. Our members have highlighted that the number of carers who are known to health and social care services is likely to be considerably less than the true figure. The ambiguity around the number of carers in Wales, and the nature/extent of their caring responsibilities, means that it is difficult to arrive at a reliable picture of how many carers are receiving a Local Authority assessment and how this has changed since the introduction of the SSWB Act 2014.
16. For example, the 2011 Census^v identified that within the West Wales population of 348,000, there are approximately 47,000 carers. However, only around 9,000 carers have been identified either through GP surgeries and/or social services across the Hywel Dda University Health Board (UHB) area. This demonstrates that whilst many carers are being identified as a result of their own health or care needs, there remains a significant number who are not known to statutory services and therefore not receiving the information and support that they require and are entitled to. In relation to young carers, there are over 400 young carers who are known to health services in West Wales. These are people under the age of 18 who care for siblings or parents. As highlighted within our Policy Forum document,^{vi} *"the first step in delivering appropriate support will always start with individuals and professionals being equipped with the information and tools they need to identify carers and to understand the barriers they face"*.
17. Our members inform us that carers really value flexible breaks and respite care because they help them to remain well and able to continue to provide care. The SSWB Act 2014 places carers on the same legal footing as those they care for and places a duty on Local Authorities to promote and provide preventative services. However, due to austerity and cuts to Local Authority budgets, services across Wales providing quality breaks and respite for carers have been cut and there has been a significant decrease in people accessing day

services or respite care since 2012. Some carers who responded to the Carers Wales^{vii} survey in 2017 said that they had not had a break or day off in 17 years; had been on a waiting list for three years for overnight respite; and that the only break some carers received was when they continued to provide 24-hour care but had non-caring responsibilities ease up.

18. Respite care for carers and high quality and accessible information and support services is key to maintaining their own health and wellbeing and to ensure that they have an equal opportunity to stay well and active alongside their caring responsibilities. A deterioration in a carer's health and wellbeing tends to have a negative impact on the health and wellbeing of the person they care for. The result of this could be greater demand on unplanned and emergency NHS and social care services not only for the person they care for, but also the carer themselves. WAST, through its partnerships and Carers Plan, is working with Local Authorities across Wales to offer opportunities for health and wellbeing support and respite for carers.
19. Issues with carers' own health and wellbeing are often exacerbated or caused by their caring role. Carers Wales^{viii} say that full-time carers are more than twice as likely to be in poor health as non-carers, 59% of carers report worsened physical health since they became carers and 70% said they had suffered mental ill health. Three quarters of those providing care to a child with a disability said that they had suffered mental ill health, particularly stress and/or anxiety as a result of their caring responsibilities.
20. This evidence is consistent with the GP Patient Survey of 2015-16,^{ix} which highlighted the impact of caring on carer health. While 52% of non-carers had a long-standing health condition, this rose to 61% for carers and 83% of carers aged 65 and over. The survey also found higher levels of arthritis, long-term back problems, high blood pressure, diabetes, mobility problems, anxiety and depression among carers when compared to non-carers.
21. Feedback from carers has demonstrated that they often feel overlooked and excluded by the system. The Welsh Ambulance Service NHS Trust (WAST) say that feedback from engaging with carers has identified that carers are often hesitant to contact the ambulance service or be conveyed to hospital for fear of the impact it would have on the person they care for. WAST also say that carers have fed back that they often find the current Health & Social Care system to access advice and care complex and difficult to navigate. Services are not always joined up, leaving the carer trying to make sense and synchronise advice and guidance from all the various organisations/authorities involved, with little information about who the first point of contact should be.

The extent to which local authorities are fulfilling their duties under the Act to provide information, advice and assistance to carers;

22. NHS services are well-placed to support Local Authorities to provide high quality and accessible information and advice to carers. Examples include the NHS Direct Wales, 111 and DEWIS.

23. NHS Direct Wales is a health advice and information service available 24 hours a day and is managed by WAST. People living in Swansea, Neath Port Talbot, Bridgend and Carmarthenshire can access NHS Direct Wales via the 111 service, which not only provides health information, but also a signposting service that directs patients to the most appropriate part of the system.
24. DEWIS Cymru is a key information hub for carers looking for information or advice about their wellbeing. Funded initially by Welsh Government, the website is now funded and managed by Local Authorities across Wales so that information can be kept up to date and relevant. It acts as a signposting service for up to 6,000 local and national services across Wales.
25. Health Boards are using transitional funding and Integrated Care Fund to support local carers' centres to provide information and support, particularly for carers working in hospital settings (mental health and palliative care units). The Western Bay region (Local Authorities of Bridgend County Borough Council, Neath Port Talbot County Borough Council and the City & County of Swansea) has worked closely with Abertawe Bro Morgannwg UHB on a Hospital Outreach programme, which ensured that over 2,000 carers were in touch with designated Community Resource Teams and supported opportunities for collaborative working.
26. Health Boards are also supporting Local Authorities in the delivery of carers' information and awareness raising sessions. In the Western Bay region these were delivered at a number of Protected Time for Learning sessions for primary care staff. The region delivered awareness sessions for GP practice staff and provided training on methods of appropriate signposting to services, particularly in relation to 'on screen' messages. Practices across the region received regular information and newsletters. Transitional funding was key to making this happen.
27. Health Boards are also supporting specific projects and groups on a local level to increase awareness of the needs of carers and improve the quality of information and support services that are available to them. For example, in Bridgend, a Carers Forum and Bridgend Mental Health Carers Forum have been established that meet on a regular basis. Following the establishment of these groups, Bridgend County Borough Council, supported by Abertawe Bro Morgannwg UHB, held a carers visioning event in September 2017 for stakeholders to work on a shared vision for the future of carers services in Bridgend. Three follow-up consultation events to further shape the work are being planned/have been delivered and the Local Authority continues to work towards a position, supported by the Health Board, where it can recommission services for carers. Another example is the Young Carers Project in Swansea, supported by the Local Authority and Abertawe Bro Morgannwg UHB, which aims to achieve a better understanding of the needs of young carers across the region; and the Neath Port Talbot Carers' Service, which consults and engages with carers on a regular basis to identify needs and support service delivery.
28. In other areas Health Boards are implementing schemes that support GP practices to develop their awareness of the needs of carers. An example is Cwm Taf UHB's

accreditation scheme with Agored Cymru in GP practices. Agored Cymru is a QCF-awarding organisation that offers flexible courses for Welsh learners, including certificates in health and social care. Part of this work includes the provision and updating of a carers noticeboard for patients and recording which patients are also carers. Cwm Taf UHB have rolled out this scheme so that each GP surgery also has a 'Carers Champion' who acts as a point of contact for patients and/or staff to signpost to carers' services. Carers Champions receive relevant and timely information to disseminate through GP practices.

29. Hywel Dda UHB is a partner in the West Wales Regional Partnership Board and works closely with its three partner Local Authorities in the delivery of services to meet the needs of carers highlighted within their recently-published Population Needs Assessment. The West Wales Carers Development Group (WWCDG), which was initially established to drive forward the Carers Strategies (Wales) Measure 2010, is also represented on the RPB. The group has continued to evolve to provide a forum for collaborative and integrated partnership working.
30. However, the provision of information and advice is an overcrowded market with many duplicating and competing with other. Our members feel that carers need a single hub or contact that addresses all of their needs. This needs to range from advice on benefits and financial matters, accessing respite services, medical advice and advice on legal matters. Particularly for carers who find themselves having to care for someone living with dementia where there is no lasting power of attorney, there are often challenges in accessing the right support. From a health perspective, some carers say that they feel, in situations where the person they are caring for has either fallen or is experiencing poor health out of hours (OOH), that they have no choice but to call an ambulance because GP services, OOH services and district nurses have not been able to attend but advised them to call for an ambulance.

Whether local authorities and Local Health Boards have sufficient information on the number and needs of carers in their areas;

31. As mentioned at the beginning of our response, there are approximately 370,000 carers in Wales. It is acknowledged that this is the highest proportion of carers of all UK countries at around 12%.^x Of these, 103,594 people in Wales provide over 50 hours of unpaid care per week.^{xi} It is estimated that by 2037 there will be over half a million carers in Wales, a 40% rise on current levels. The fact that Wales has such a high proportion of carers, alongside an ageing population with co-morbidities, means that the provision of appropriate support and information services is considered a key priority for Local Authorities and Health Boards across Wales.
32. Local Authorities and Health Boards are working together to support local carers' centres. These centres work alongside Health Board Patient Advice and Liaison Service (PALS) and Patient Experience and Advice Service (PEAS) teams.
33. In the Hywel Dda UHB area, the Investors in Carers (IiC) scheme has been established as a collaborative project between health, social care and the third sector partners working in Ceredigion. Investors in Carers is a quality assurance scheme designed to raise

awareness of the needs of carers and encourage settings to provide information, advice and signpost carers for assistance to address areas of identified need. Although initially developed in Ceredigion, it has subsequently been rolled out across the Hywel Dda UHB area and is now co-ordinated through the Health Board. Originally developed for GP surgeries, the scheme has three levels: bronze, silver and gold according to the commitments to carers. The scheme acts as a tool for improving the lives of carers and providing a catalyst for change; helps to promote opportunities to support carers in ways which matter to them; provides a framework to foster and maintain engagement with carers and partner organisations; and provides a benchmark for continuous improvement.

34. To date, 92 settings across the Hywel Dda have achieved bronze level with an additional 48 working towards this. As of 31st March 2018, there were 7,339 Carers registered at their GP surgery and as a result of identifying the Carers nearly 800 people were referred by their surgeries for further information, advice and assistance during 2017/18. There has also been a significant adoption of the liC scheme across the Health Board's Mental Health teams, as liC is considered a supporting element of Hywel Dda UHB's Quality Assurance programme.
35. WAST uses a 'cleric' software system to capture information on non-emergency transport journeys where the carer will contact the service on behalf of the person they care for. In these situations, information will be kept about the carer and their needs i.e. whether they need to accompany the person they care for on a journey to hospital, their general health and wellbeing etc.

Other changes since the Act came into force which may impact on carers, for example changes to the services provided to people who are cared for;

36. Health Boards are continuing to work with Local Authority partners to improve recognition of carers and provide appropriate information and support. Cwm Taf UHB, for example, is working with Rhondda Cynon Taf Community Borough Council (RCT CBC) and Merthyr Tydfil Community Borough Council (MT CBC) to identify shared priorities and areas of key challenges.
37. Key areas of work have included the continued recruitment of and support to Carers Champions throughout health and social care and the third sector, ensuring Caring Awareness is embedded into various departments and organisations; the provision of Carer Aware training (including via e-learning platforms) to further expand the knowledge of both Carers Champions and staff throughout the Cwm Taf region; and the setting up of the Cwm Taf Partnership Group (CTPG) to oversee implementation of the Strategy. The CTPG reports directly to the SSWB Partnership Board. Looking ahead, the Health Board has set up a Project Group to implemented work of Cwm Taf UHB, RCT CBC and MT CBC.
38. Collaborative and integrated working between Local Authorities and Health Boards has improved since the passing of the SSWB Act 2014. In some cases, these improvements have taken the form of adaptations of existing models, while in other areas, new service models have been established to fully embed the integration agenda, such as the overarching service model for adult social care in Swansea. Other developments since the

passing of the Act include the development of an assessment tool to capture the ‘what matters’ conversation and the commencement of a review of commissioned carers’ services to establish best value and ensure services continue to be fit for purpose.

Broader Welsh Government policy on carers and how it should be developed;

39. Health Boards and NHS Trusts welcomed the announcement by the Minister for Children, Older People and Social Care in November 2017^{xii} that Welsh Government policy would target three national priorities to improve the lives of carers: supporting life outside caring; identifying and recognising carers; and providing information, advice and assistance. However, for carers to manage their own health needs more effectively, we need a more immediate and responsive health and social care system as a whole. This means that the system must support carers to stay healthy, maintaining their wellbeing and keeping them out of hospital. Health and social care workforce strategies aimed at carers must recognise that a strategy that supports the carers’ health and wellbeing is also a strategy that supports the health and wellbeing of the people they care for.
40. Our members are pleased that from April 2018 people in residential care are able to keep £40,000 of their savings and assets and that the Welsh Government has pledged to raise this figure to £50,000 by the 2021 Assembly election. Over 400 people benefitted from the first increase, with around 4,000 people in Wales currently paying the full cost of residential care. In England, those with assets and savings in excess of £23,250 must fund all of the social care they receive – only those with less than £14,250 are entitled to cost-free social care.
41. In terms of how Welsh Government policy for carers should be developed, our members would like to see carers be supported to take a more active role in the care that the person they care for receives, particularly in hospital settings. In the majority of cases, carers will form very close relationships with those they care for and understand how the person they care for is likely to react in particularly stressful and potentially challenging situations, such as an admission to hospital. It is also often the case that those who rely on the care that is provided for them tend to trust their carers deeply. In these situations, it is important that the carer is provided with an opportunity to share information potentially useful information with hospital staff that could improve the experience for the person admitted.
42. Against this background, John’s Campaign, which is actively supported by four NHS organisations across Wales, is a movement to support NHS staff to recognise the importance of working with carers as equal partners in the care and support of people living with dementia who are admitted to hospital. The campaign calls for a policy that means family carers would be allowed to visit their loved ones outside normal visiting hours according to their needs.
43. Our members also feel that to have a single grant for carers, rather than a number of individual grants, would be easier to administer and monitor, and would support more strategic commissioning of services. Finally, our members would encourage the Welsh Government to recognise the challenges that come with short-term funding

arrangements. Our members believe that a three or five-year arrangement would enable more effective planning and support the delivery of high quality services in future.

44. Finally, while we have highlighted in our submission where improvements can be made we must recognise the very difficult budgetary decisions that both the Welsh Government and Local Authorities have had to make due to austerity. The Wales Public Services 2025 report^{xiii} recently highlighted that between 2009-10 and 2016-17 Welsh Government resource spending, excluding depreciation, fell by 6% and Local Authority revenues fell by 7.5%, equivalent to £529 million. While there have been cuts to Local Authority budgets in Wales and difficult decisions have had to be made around services, the cuts to Local Authority in England have been more severe. Analysis by the Institute for Fiscal Studies^{xiv} shows that local government funding in Wales has been cut less than in England and there has been less of a sense of crisis in social care in Wales.

Conclusion

45. Across Wales, Health Boards are working collaboratively with Local Authorities to support the implementation and the vision within the SSWB Act 2014. While there is work to be done, the 2014 legislation has been effective in supporting the integrated working arrangements between Local Authorities and Local Health Boards and progress has been made possible as a result of multi-disciplinary working by NHS and Local Authority staff on the ground.
46. The Welsh NHS Confederation will continue to support our members to work with Local Authority partners to improve the lives and experiences of carers in Wales, and through the recently published *A Healthier Wales*, we have a real opportunity to provide seamless services for the people of Wales.

ⁱ Carers Wales, 2017. State of Caring.

ⁱⁱ Carers Wales, 2017. State of Caring.

ⁱⁱⁱ Welsh Government, 2018. A Healthier Wales: Our Plan for Health and Social Care.

^{iv} Carers Wales, September 2017. Track the Act: Briefing 2

<https://www.carersuk.org/files/section/5763/track-the-act-briefing-2-final-draft-year-1.pdf>

^v The Office for National Statistics, March 2012. 2011 Census: Key statistics for Wales, March 2011.

^{vi} The Welsh NHS Confederation Policy Forum, September 2018. The Key Priorities for Carers in Wales.

^{vii} Carers Wales, 2017. State of Caring.

^{viii} Carers Wales, 2017. State of Caring.

^{ix} Ipsos MORI, 2017. Experience of carers: What does GPPS data tell us?

<https://www.ipsos.com/sites/default/files/migrations/en-uk/files/Assets/Docs/Infographics/gpps-carers-infographic-2017.pdf>

^x Office for National Statistics, February 2013. 2011 Census analysis: Unpaid care in England and Wales, 2011 and comparison with 2001

<https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/healthcaresystem/articles/2011censusanalysisunpaidcareinenglandandwales2011andcomparisonwith2001/2013-02-15>

^{xi} Carers Wales, October 2017. Welsh Policy Forum – Policy Commission on Welsh Carers. Evidence submitted from Carers Wales’.

<https://www.carersuk.org/help-and-advice/practical-support/managing-someone-s-affairs/66-wales/news/5796-carers-wales-evidence-submission-welsh-policy-commission-policy-commission-on-welsh-carers>

^{xii} Welsh Government, November 2017. Written Statement: A Carer Friendly Wales

<https://gov.wales/about/cabinet/cabinetstatements/2017/carerfriendlywales/?lang=en>

^{xiii} Wales Public Services 2025, November 2017. Austerity and Local Government in Wales: an analysis of spending priorities, 2009-10 to 2016-17.

^{xiv} The Institute for Fiscal Studies, September 2016. Welsh budgetary trade-offs to 2019-20.