

Consultation response
Impact of the Social Services and Wellbeing (Wales) Act
2014 in relation to carers
Welsh Assembly
August 2018

Introduction

1. Age Cymru is the leading charity working to improve the lives of all older people in Wales. We believe older people should be able to lead healthy and fulfilled lives, have adequate income, access to high quality services and the opportunity to shape their own future. We seek to provide a strong voice for all older people in Wales and to raise awareness of the issues of importance to them.
2. We welcome the opportunity to respond to the Health, Social Care and Sport Committee's consultation on the impact of the Social Services and Wellbeing (Wales) Act 2014 in relation to carers.

Background

3. In Wales, healthy life expectancies are increasing, but the number of years spent living with poor health is also increasing. Public Health Wales states¹ that men and women are likely to spend on average 17 and 20 years respectively living in poor health. Worryingly, differences in both life expectancy and healthy life expectancy between different areas in Wales are not reducing. In fact, men and women in the most deprived areas of Wales spend approximately 19 and 18 years less in good health respectively, and die on average 9 and 7 years earlier respectively, than those living in the least deprived areas.
4. The instance of diseases people in Wales are living with is changing. Although the number of disability adjusted life years (DALYs) due to cardiovascular disease has fallen by 42% over the last 26 years, there has been a rise of 25% in DALYs associated with neurological conditions including dementia. 45% of adults aged over 75 in Wales report having two or more long term illnesses.

¹ Public Health Wales Observatory (2018) Health and its determinants in Wales

5. In the UK 75% of 75 year olds have more than one long-term condition, rising to 82% of 85 year olds.
6. Many people in their sixties and seventies enjoy good health and do not need any additional support with daily living, but as we move into our ninth decade and beyond this becomes less common and more of us will need help. Increasing numbers of **those providing care** are themselves older people. The peak age for caring in the UK is estimated to be between 50 and 59 and the number of those aged 65 or over providing care is increasing more rapidly than the increase among the general population.
7. Good quality, properly funded support for carers **enables older people to live independently** for longer in their own homes and communities whilst enabling carers to receive respite and maintain their own health and independence as they age. Carers play a vital role in service provision that the health and social care systems are unable to cover. A small shortfall in the care provided by informal carers would have a large impact on formal care services.
8. Family and friends are increasingly being expected to provide care for their loved ones, but there are limits to what they can do. Changing family structures, greater geographical dispersal, demands of the workplace (likely to increase with rising State Pension age) and a reliance on older carers, often experiencing poor health themselves, all impact on the capacity of people to care for loved ones. There are likely to be many cases where families are providing significant levels of support but are simply unable to provide enough. Together with unmet need and a rapidly ageing population, this points towards families and communities reaching the limits of the care they are able to provide
9. For older people living with frailty or complex needs, their health and their quality of life is vulnerable to sudden change. A 'trigger event' such as the loss of a carer, can mean an older person experiences a rapid deterioration in their health and or a significant loss of their independence. This becomes all the more likely where carers are stretched to their limits.
10. Forecasts highlight the importance of ensuring that health and social care services adapt so that they can adequately respond to the needs of an increasing older population with complex care needs.² The rise in care needs contrasts with other trends that suggest that relying on families and other unpaid carers more than done so currently does not appear to be a sustainable solution. The supply

² A Kingston, *Forecasting the care needs of the older population in England over the next 20 years*, The Lancet, 30 August 2018

of unpaid care to older people by their adult children (in England) is unlikely to keep pace with demand, whereas care provision by spouses is growing and is projected to continue to increase in importance. Older spouse carers are increasingly likely to be living with disabilities themselves, resulting in mutual care relationships that are not yet well recognised by existing care policy and practices. Extending the retirement age of the UK population is likely to further reduce the informal and unpaid carer pool, who have traditionally provided for older family members, and so shift this responsibility to the state. These forces will unite to add further stress to social care budgets that help people to maintain independence within the community or fund long-term care needs.

11. It has been estimated that at least two-thirds of older carers already have long-term **health problems** or a disability themselves³. Carers often suffer from higher levels of arthritis, high blood pressure, long-term back problems or mobility problems, all of which can create difficulties in and be aggravated by the demands of caring. Caring can be exhausting as carers engage in a whole range of activities from boosting morale through to lifting the person being cared for. Large numbers of carers receive no training in how to lift safely. Paid care workers would carry out lifting only in tandem, due to health and safety concerns.
12. Physical exhaustion may be further compounded by a lack of sleep, due to the person cared for having trouble sleeping, getting up at night, or engaging in challenging behaviour, or to worry and anxiety. Caring can cause isolation from family, friends and colleagues, and can lead to carers feeling as though they have lost their identity. According to a survey carried out by Carers Wales, 87% of respondents felt more stressed as a result of their caring roles and 79% of respondents also reported feeling more anxious⁴. In a survey of older carers across the UK, more than 75% of carers aged between 60 and 69 reported that caring had had a negative impact upon their mental health⁵.
13. Reaching crisis point can result in short-term decisions being made that can place future **financial security** at risk, for example leaving a job or selling a house. The peak age for caring, 50-64, is often when workers are at their most skilled and experienced. In a Carers Wales survey, 51% of adult respondents (of all ages) had given up work to care and 18% had reduced their working hours. 23% of working carers were worried about their ability to remain in work. Older women are more likely to have given up work or reduced their hours as a result of

³ The Princess Royal Trust for Carers (2011): [Always on Call, Always Concerned](#)

⁴ Carers Wales (2015): [State of Caring 2015](#). NB, both of these figures have increased from the 2014 survey.

⁵ The Princess Royal Trust for Carers, 2011.

caring responsibilities. The situation is particularly acute for older women who are or were in receipt of a lower income.

14. A lack of flexible working arrangements is most commonly cited as the biggest barrier to carers remaining in **work**. Carers who do remain in work have to make compromises, for example using annual leave to provide care. Carers find it more difficult to pursue professional training and advancement. A lack of suitable and/or affordable care services also creates a barrier to remaining in work. Juggling multiple commitments can have implications for physical and mental health.
15. 36% of respondents to a survey of carers who had left work reported that they would no longer be able to **save for a pension** and 49% that they would be unable to save to meet their own future care needs⁶. Many carers rely on social security and state-funded care in later life. Once an individual claims their State Pension, they can no longer receive the full amount of Carer's Allowance, even though they continue to face the additional costs of providing care. This can create a sense of injustice. Many carers do not take up their entitlements, either because they are not aware that these are available to them, because of the complex application process, or because of knock-on implications for the finances of the person for whom they care.
16. A survey carried out by Carers Wales reported that 53% of respondents were struggling to **make ends meet**, with 36% of those respondents having cut back on essentials such as food and heating. Utility bills often become more expensive as heating and appliances may be used more often. 32% of respondents were using up their savings in order to get by⁷. For adult children who have moved away, fuel or transport costs often increase significantly.
17. Older people tell us that **what matters most** to them is a lot more tangible support for carers, especially for those caring for an older person with dementia, alongside a reliable service, committed staff with enough time, and some progress towards meeting unmet needs.

Assessments of needs

18. There is a disparity in the numbers of assessments carried out by local authorities, which appears to bear no relation to population, demography, health profile or disadvantage in communities.

⁶ Carers UK, September 2014

⁷ Carers Wales, 2016.

19. This may be because carers often **do not identify themselves as carers**, as they view care as a normal part of their relationship with the individual they are helping. This means they may lose out on the support that is available to them.
20. It may also be due to the nature of the **initial contact systems**. Although a single point of access to social services has been welcomed in some areas, it has been indicated to us that people contacting local authorities, by telephone or in person, are being referred to third sector agencies without appropriate consideration of their circumstances. We have been told that some local authorities allocate a fixed number of call-backs to residents at the beginning of each day, referring the unsuccessful callers to other agencies.
21. Older carers we have spoken to also raise concerns about: waiting times for assessments; being signposted inaccurately and referred inappropriately; difficulty in finding out what is available, and the use of jargon and duplication in the assessment process.
22. In April 2018 Age Cymru and Age Alliance Wales conducted a series of four focus group events with people aged 50 and over, in Wrexham, Bangor, Swansea and Newport, looking at issues including social care. We asked participants about their attempts to obtain the assistance of social services departments, from first point of contact onwards.
23. Many people gave positive feedback, finding access easy and contact centre and social services staff helpful and cooperative, and reporting very good outcomes, although staff were sometimes busy and under pressure. In one location, the social service department holds fortnightly surgeries in a local health centre. Users of this service told us that they found it very accessible, and the service was well liked. However, a sizable number of others at each of the four venues reported not receiving the same level of service.
24. Participants generally contacted their local authority by phone or in person at a single point of access. One older carer found information online beforehand, but felt that many others would not be able to access information online without help, and the person they cared for would not have been able to do so.
25. One individual found the telephone number online but received no response when calling, suggesting the information was out of date or the line not monitored. Another stated that advertised numbers were not accessible and messages did not result in returned calls.

26. A number of people with hearing loss told us their authority's telephone system lacked provision for their needs, despite the technology being readily available.
27. Some individuals told us that rather than approach social services directly, a third sector organisation's "gateway" scheme would contact the local authority on their behalf. However, one man told us that, when phoning on behalf of a friend who lacked confidence to make a call, it was very difficult to get the person dealing with the enquiry to accept he had been given permission to act on his friend's behalf, despite that person briefly speaking on the phone to confirm he had.
28. Others told us they found it complicated to obtain **specific help** and remained unsure about the department or individuals with whom they needed to speak.
29. One man's attempts to contact an older friend's named social worker on his behalf failed entirely. Staff were out of the office for extended periods, making them uncontactable (other than to leave messages – which in this man's experience were fruitless) or unavailable for meetings. One person, attempting to seek assistance with care for an older relative with dementia, said social services failed to signpost him to alternative sources of assistance, leaving him feeling "isolated". Another told us that a neighbour with glaucoma, who sought help around the home, waited over 12 months for an appointment, and that the meeting had been cancelled four times.
30. Others reported having to "chase for updates", having not received expected contact from social workers. One person was not informed their social worker had taken sick leave, and was not available, leaving them feeling "left out of the loop".
31. We also encountered a number of older people who would simply **avoid contacting social services**. One person felt they were making themselves a nuisance. She stated "Perhaps that's because I am older. I should not have felt that way, but I did". Another said it had been so difficult to obtain social services in the past that they would not attempt it in the future, stating "I can't face it". Another person simply stated: "Never contact Social Services. Trouble!"
32. The Social Services and Well-being (Wales) Act states that people are only **eligible for care and support** if their needs 'can and can only' be met by social services. We have heard from older carers that assessors have made unreasonable assumptions about their ability to cope without formal support.
33. We are also hearing through our helpline of people being told they cannot have an assessment prior to leaving hospital as a social worker is not available, but that they can put in support until an assessment takes place. In other cases,

people are being told that they are not eligible for support through social services as they are managing by buying support.

34. For example, Mrs G's husband was discharged from hospital with advanced dementia. No care assessment was carried out. Unable to cope without night time support, Mrs G arranged for a private care service to assist her husband for several nights per week, costing over £2000 a month. When Mr G was finally assessed, the care plan noted the need for night time care, but did not treat this as a responsibility of the local authority as it was judged that the family had managed to cover these requirements themselves. The expense of this privately arranged care meant that Mrs G tried to carry out as much of the care as she could manage herself, a situation she found very difficult.
35. Mrs G's lack of formal support and respite had a very negative impact on her health and well-being and she confessed to feeling lonely and desperate. Our concern, illustrated by this case, is that unreasonable assessments made by local authorities about the level of support needed, are pushing more and more individuals and carers to crisis point, ultimately costing the NHS more. The aim of the eligibility criteria is to increase access to and use of locally based preventative services, but we fear that it is actually being used as a means to deny much needed formal support.
36. Age Cymru made a Freedom of Information request to Local Authorities on 17 October 2017, as follows: How many adult* individuals in your authority have received assessments regarding needs for care and support since April 2016, when the Care and Support (Charging) (Wales) Regulations 2015 came into force? (*If possible those aged 65 years and older.); of those, how many resulting Care and Support Plans stipulated a need for night-time domiciliary care?; Of those individuals assessed as requiring night time domiciliary care, how many have received that night time care at a maximum weekly charge of £60 (or £70 per week as from 10 April 2017 following the implementation of The Care and Support (Choice of Accommodation, Charging and Financial Assessment) (Miscellaneous Amendments) (Wales) Regulations 2017?)
37. Only 8 of the 22 authorities were able to tell us how many people aged 65+ received night time domiciliary care during this period. From these responses, an average of just 1.92% assessments led to night time domiciliary care provision. Although there are no Welsh Government regulations or policies differentiating the entitlement to night time care from day time care entitlement, responses to our FOI requests indicated substantial differences in its provision from local authority to local authority.

38. At a focus group, an older man told us his daughter had had a serious road accident, and had to stay with him whilst she recovered. Despite his age and own physical limitations he received no assistance with her care until he demanded she be placed in respite care until social services could fully provide for her needs at home. It was only at this point that she underwent a care needs assessment, and he a carer assessment. This resulted in the provision of a wheelchair, among other things. Previously, he had to hire a chair at his own expense, as his daughter would otherwise have been unable to attend medical appointments.
39. Welsh Government must ensure that no assumptions are made that a person does not have needs to be met because a carer is available. The contribution that the carer is willing and able to make should be shown in the care plan, as should contingency plans if the carer is not able to continue to provide care. A carer should not feel under pressure to meet needs where they do not feel willing or able to do so.
40. A lack of **person-centred assessment** was not uncommon among focus group participants. One older carer of an older person said, that social services did not listen or respond to the concerns of the family of the person requiring care, or that person's carers. They believed that "more concern was given to benefits and who was going to pay for extra care". Whilst some were ultimately happy they believed it took staff too long to properly assess and respond to the situation.
41. Older carers' complex health and social care needs mean that the assessment process to determine the support needs of an older carer often needs to be multidisciplinary. For this to be effective, a number of institutional barriers need to be overcome, including some fairly fundamental issues such as data-sharing underpinned by ICT.
42. A small number of focus group participants had made a **complaint** about the responses they had received from social services, one through their local councillor. Several had not made a complaint, despite their dissatisfaction, because they did not feel it worthwhile, because the person cared for "did not want to make a fuss", or because "I thought they had enough on their plate".

Provision of support, including respite care

43. The Welsh Government's *Assessments and Social Services for Adults in Wales, 2015-16*⁸ showed that:

⁸ Assessments and social services for adults in Wales, 2015-16, available at <http://gov.wales/statistics-and-research/assessments-social-services-adults/?lang=en>

- a. the provision of adult community-based care services is falling year on year
 - b. the provision of home care is falling year on year
 - c. the provision of respite care is also falling.
44. Evidence suggests that provision is at the higher end of the spectrum for people with the most complex needs. Our sense is that people who would previously have received help are **no longer being supported**, and that this is increasing demands on informal carers.
45. We are worried that it is becoming increasingly unlikely that older people will benefit from the support of social services, and that the knock-on effect on carers is likely to increase.
46. From what we hear from the older people with whom we are in contact, from calls to our advice line, from our local partners and from colleagues in Age Alliance Wales, we believe that there is significant **unmet need** for support for carers in our community. However, due to gaps in data, it is difficult to estimate the scale.
47. We welcome the acknowledgement in “**A Healthier Wales**” of the key role that carers play. Carers want to feel like a partner in decision-making and receive an acknowledgement not just of the contribution that they make in providing care, but also their knowledge of the person for whom they care. Key parts of the document address delivering services in the community and tailoring preventative services, both of which are potentially helpful to carers. However, we await the evidence of how the policy is being implemented in practice.
48. We asked focus group participants about their experiences of obtaining social care after hospital discharge. Whilst many had not required it, those who had told us they had generally received very good care. We were told of people receiving help from contracted third sector agencies, positive support from reablement teams, timely adaptations being made to homes, and a range of other positive experiences.
49. There were a smaller number who had not had such positive experiences, however. We were told of people having to remain in hospital unnecessarily whilst awaiting the organisation of social care, and social workers having difficulty seeing patients in good time to make arrangements. One person told us of a relative with dementia who remained in hospital, unnecessarily, for six months, waiting for the local authority to find a suitable care home, before contracting Norovirus, which led to his death.

50. A health crisis for a carer can rapidly develop into a crisis for both the carer and the individual cared for. In order to prevent the need for a crisis intervention, for example a double hospital admission, contingency plans must be in place if the carer is unavailable to provide care.
51. We welcome the £1 million allocation to Local Health Boards to encourage carer awareness in GPs across Wales and for hospitals to improve support for carers on hospital discharge. Again, we await the evidence of the impact of the funding. We are concerned about the sustainability of the funding, and about how successful initiatives may be mainstreamed as normal practice within the NHS.
52. **Respite care**, especially the cost and quality, is a particularly significant issue. Older carers need to have more regular breaks as a number of them will tire more easily and/or suffer from their own health and mobility issues in comparison with younger carers. Dealing with challenging behaviour is particularly tiring and frustrating because of the need for constant vigilance.
53. Respite is viewed by many as an extremely valuable service, but there is a need for greater flexibility in the type of respite offered, to suit individual circumstances. Many carers are reluctant to use support or respite services as they do not trust the quality of the care provided. Worrying about care standards can lead to refusal of care to the detriment of the carer's own wellbeing.

Provision of information, advice and assistance

54. Some local authorities, responding to the definition of 'adults' in the Social Services and Well-being (Wales) Act 2014 are arranging generic 'all-adults' IAA services which are unable to meet the needs of older people and may amount to indirect discrimination under the Equality Act 2010. Older people need specialist **information** on, for example, retirement, changing or declining physical or mental health, sensory or cognitive impairment, bereavement, changes in housing or living arrangements and ageism. Many older people are unwilling or unable to use the Internet, or may not trust the accuracy and reliability of an Internet source. Many older people have trouble speaking and/or hearing on the telephone and this needs to be handled appropriately and respectfully.
55. One focus group participant said the information their authority provided on dementia services was out of date, whilst another person was given details of services which were no longer available. Many people stated they were aware of friends or relatives who had difficulty getting help from social services, or having to wait too long. One stated that when attempting to seek assistance "The

response wasn't good. [I was] asked for information I didn't have. Then [they] told me to sort it out myself".

56. Generic IAA services often refer older people to local older people's organisations, including Local Age Cymru Partners, who provide valuable services and expertise. However, many of these organisations have lost their service contracts, and do not receive any funding from the IAA service referring to them. Older people's organisations which receive referrals from contracted IAA services must be properly funded for the work they do.
57. The Social Services and Well-being (Wales) Act requires local authorities to consider whether an individual may need Independent Professional **Advocacy** (IPA) at every step of their journey through the social services system, including at their first point of contact. However, advocacy is often the last resort after other channels have already been tried.
58. Some older carers may struggle with complex formal processes, which they are expected to negotiate without any formal training or knowledge. An IPA has that training and knowledge. Carers may also find it difficult to disentangle their own concerns and interests from those of the person that they are seeking to represent, and may therefore need the support of an advocate to ensure that their own rights are upheld and that they are supported to challenge social services to obtain the right services.
59. Examples of issues dealt with by advocates in Wales include: arranging care and paying for care; dealing with finances or financial issues; neglect/ abuse/ scams/ financial abuse; change of accommodation; and dealing with utility companies⁹.
60. Staff working in IAA services therefore may need to refer some carers to an IPA service. Local authorities are required by the Part 2 Code of Practice (General Functions) to "ensure that staff within the service are suitably skilled to identify individuals who need an advocate, and that the service takes action to ensure those individuals are supported." We suspect that many carers are not receiving the advocacy support they need but it is difficult to quantify the scale of the problem in the absence of data.

⁹ Age Cymru (March 2011): *Advocacy Counts 3*: p20

Information collected by local authorities and Local Health Boards on carers and their needs

61. We welcome Social Care Wales and Data Cymru's work to develop a social care "one stop shop" data set. However, current data gathered about unpaid carers is weak and should be more comprehensive and accurate.
62. The English Longitudinal Survey on Ageing (ELSA), Healthy Ageing in Scotland (HAGIS), the Northern Ireland Cohort for the Longitudinal Study of Ageing (NICOLA) and The Irish Longitudinal Study on Ageing (TILDA), provide the data to estimate unmet need in the rest of the UK and in the Republic of Ireland. Wales is now the only UK nation without an equivalent data set on which to base our evidence.
63. Identification of carers is a key obstacle, both self-identification and identification by health and care professionals. Carers UK's "Missing Out" report noted that in Wales 55% of carers took more than a year to recognise their caring role, while 24% took more than five years to identify as a carer. This is particularly true in relation to older carers (aged 80 years old or above) looking after a spouse or partner, and carers of people with dementia, where there may be perceived to be an element of stigma and a wish to keep things private.
64. Carers Wales' "Track the Act" programme found that most Welsh Local Authorities do not capture any data on carers' needs assessments for carers of people under the age of 18. This may include the needs of grandparents caring for grandchildren, sometimes in addition to caring for their adult children and others.

Broader Welsh Government policy on carers

65. Task and time based **commissioning** makes it increasingly difficult for staff to delivery good quality support and preserve the health and independence of the carer being supported. Commissioning needs to shift to an outcomes-based approach, reflecting the intention of the Social Services and Well-being Act.
66. Commissioning practices, lack of sustainable funding and the price paid to **domiciliary care** and support service providers by the local authority can impact upon recruitment, retention and staff morale. Zero hours contracts and the minimum wage are widespread, undermining the ability to provide good quality support.

67. A high turnover within the workforce militates against continuity of support and exacerbates threats to older people's human rights, especially for carers of people living with dementia, as unfamiliar faces can lead to confusion, fear and more difficult behaviour.
68. Domiciliary care is fundamental to an older person living a more independent life and maintaining their dignity. The relationship between quality and dignity is critical – it is not just about what support is provided, but about the way in which it is provided. Commissioning, funding and terms and conditions must be improved to make the domiciliary carer role more attractive.
69. We are keen to see decisions about **paying for care and support** separated from decisions about getting it, in order to alleviate the stress the current decision making process causes older people and their families. Age Cymru's longstanding view is that a far more equitable system would be to ensure that care and support services should be provided free at the point of use in the same way as NHS services, instead of the cost simply falling on those people unfortunate enough to develop care needs, including their needs for support as carers.
70. The maximum weekly charge for non-residential care in Wales represented a clear step forward in seeking to make services affordable and eliminating inconsistency in charging levels and practices. We are supportive of the aims of the intermediate care fund, however, we are not necessarily seeing our local partners being able to access the fund in the same way that health and local authorities are to develop the innovative services that were intended.
71. It is important that older people have access to good quality **housing** that meets their needs and minimises their need for formal or informal care. Older people generally wish to remain in their own homes.¹⁰ It is vital that they have access to services that help them to adapt and improve their homes to help them to live independently for as long as possible.
72. Further investment is also needed in specialist housing, for example co-housing, Intentional Communities, home sharing models, retirement villages, park homes and intergenerational living,^{11,12} as it reduces demand on informal carers as well as on residential care homes and hospitals, and benefits both the carer and the

¹⁰ Welsh Government (2012) Consultation document. The Strategy for Older People in Wales. Number: WG16742. 25 October 2012.

¹¹ Welsh Government (2017) Our Housing AGEnda: meeting the aspirations of older people in Wales. A report by the Expert Group on Housing an Ageing Population in Wales. January 2017.

¹² Age Cymru (2016) EnvisAGE Towards an age friendly Wales. Article by C. Boswell and J. Beauchamp: Housing options for older people in Wales.

cared-for person. The presence of a warden is a key factor in reducing demand on the health services. Retirement housing should be built within age friendly communities, to ensure residents can access local services and facilities that support independence and wellbeing.

73. Carers should be able to build up adequate retirement **income**. State pension changes aimed at ensuring that carers who have missed National Insurance Contributions are able to obtain a full state pension should apply to people who reached state pension age before 2010. The UK Government should simplify the application process for Carer's Allowance and ensure that working for 16 hours a week on the National Living Wage never exceeds the eligibility threshold for Carer's Allowance. The benefits system should be reformed to ensure all carers have adequate incomes. This should include financial support for older carers who often receive no financial recognition of their role.