



Consultation Response

The Cost of Caring for an Ageing Population

Finance Committee

January 2018

Introduction

Age Cymru is the leading national charity working to improve the lives of all older people in Wales. We believe that 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.

We welcome the opportunity to respond to the Finance Committee's Inquiry into the Cost of Caring for an Ageing Population.

We would like to make the following comments in relation to the terms of reference cited for the Inquiry:

To examine patterns in demand for social care services for those of pension age and the related costs of delivery of residential and non-residential care, taking account of the role of informal carers who provide unpaid services to those requiring care;

1. By 2019, the population of Wales aged 65-84 years is expected to rise by 27% and the population aged 85+ years, by 127%¹.
2. In Wales, healthy life expectancies are increasing, but the number of years spent living with poor health is also increasing². Public Health Wales states 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

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

² Public Health Wales Observatory (2018) Health and its determinants in 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 areas³.

3. 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.
4. Wales Public Services 2025 states that local authority spending on social care for older people is not keeping up with population growth. It estimates that spending may need a 2.5% year-on-year increase until 2021 to return to the per head spend in 2009 - 10⁴. Although spending on local authority adult social care since 2009 has remained static in Wales, the growing number of older people means that spending per older person has actually fallen by over 12%.⁵
5. The statistics cited above indicate that demand for residential and non residential care will undoubtedly increase. Social care has historically suffered as a consequence of under-funding and this situation has been further aggravated in recent years as a result of widespread reductions in public sector budgets. The continued provision of good quality social care is unsustainable without a significant investment of funding to address the issue of persistent under-investment.
6. Although it is clear that caring for Wales' ageing population will require significant investment, the cost of not caring could be much higher. A failure to invest in services that keep people safe and healthier for longer will undoubtedly increase pressure on emergencies services, already struggling to cope with demand. (More than 82,500 people went to A&E in the month of November 2017, an increase of just over 2,660 compared to November 2016⁶).
7. In order to maintain the cost of caring at a manageable level, the Welsh Government must ensure that older people in every part of Wales can access effective hospital discharge programmes, support for carers and locally managed preventative services that are agile and responsive to need.

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⁴ Wales Public Services 25 (2017) A delicate balance? Health and Social Care Funding in Wales.

⁵ Wales Public Services 25 (2017) A delicate balance? Health and Social Care Funding in Wales.

⁶ NHS Confed (2017) Available @ <http://www.nhsconfed.org/news/2017/12/numbers-of-people-attending-accident-and-emergency-in-wales-are-up>

8. Informal carers

The increase in the number of years people spend in poor health will inevitably place additional pressures on unpaid carers. According to recent figures there are more than 370 000 carers⁷ living in Wales, representing 12.1% of the Welsh population. It is estimated that unpaid carers save the economy £8.1 billion a year⁸.

9. Too often in these financially difficult times, carers are increasingly relied upon to fill gaps in provision. As eligibility criteria has tightened year on year, fewer and fewer people are eligible for state-provided social care. Sadly, many carers and those they care for do not receive help until they are at crisis point. By this stage, not only are the health – physical and mental – and the financial future of the carer deeply compromised, but the required intervention is significantly more costly and intensive than preventive measures implemented at an earlier point. Carers play a vital role, both economically and socially. The health and social care systems simply could not cope without them. Reliance on carers is not a sustainable basis for meeting growing demand. Without adequate support for carers, pressures on the NHS and the social care system can only continue to grow.
10. Age Cymru believes that the Welsh Government must make greater provision for older carers across Wales in order to ensure they achieve an acceptable quality of life, in terms of mental and physical health and wellbeing, and opportunities for social and financial inclusion.

To examine the financial pressures on the social care system, such as increases in wages, automatic pension enrolment and staff recruitment and retention difficulties, including the related financial impacts arising from the UK leaving the European Union

11. Commissioning practices are fundamental to ensuring good quality social care is provided. One area in which difficulties have been evident in recent years has been with the practice of task and time based commissioning.
12. Commissioning needs to shift to an outcomes-based approach, reflecting the intention of the Social Services and Well-being Act. Purchasing care in units of time, or simply according to cost, makes it increasingly difficult for staff to delivery good quality care and preserve the dignity of the person being supported.

⁷ Carers Trust (2018) Wales Available @ <https://carers.org/country/carers-trust-wales-cymru>

⁸ Carers Trust (2018) Wales Available @ <https://carers.org/country/carers-trust-wales-cymru>

13. The price paid to the service provider by the local authority also has implications for the terms and conditions of those employed in the sector, and can impact upon recruitment, retention and staff morale. Social care is a sector in which zero hours contracts and the minimum wage are widespread. As a consequence, recruitment and retention of staff are both difficult, undermining the ability to provide good quality care. There are also implications for the ability to provide continuity of care. This is especially problematic in light of the fact that a growing number of those receiving support are living with dementia. Providing appropriate care to people with dementia requires continuity in terms of the staff providing care, as unfamiliar faces can lead to confusion, fear and even an exacerbation of difficult behaviour.
14. It is clear that the commissioning process needs to be led by people who have knowledge about, and experience of, the personal care services that they are commissioning. Without appropriate knowledge, there is a continued risk that the level and type of service commissioned are unsuitable to provide the necessary support to those on whose behalf they are being commissioned.
15. Domiciliary care services face a number of challenges if they are to provide a high quality service to the vulnerable older people of Wales. The care they provide is not 'basic', which suggests low-level, but rather 'fundamental' – essential 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. We have high expectations of our domiciliary care workers, which are not reflected in the way in which the role is viewed in broader terms. It is a difficult job yet society does not always appear to value the contribution these essential workers make in providing care for the vulnerable.
16. Conducting difficult work for low pay creates problems in recruitment and retention. Indeed, it is a testament to the dedication of many domiciliary care workers that they continue to do their job. Low pay, in combination with the perceived low social status of the role, is off-putting for many. This problem will only exacerbate the difficulty of delivering quality care as demand grows.
17. A high turnover within the work force is viewed as a significant factor exacerbating threats to the human rights of older people. Many of the issues that make it difficult to recruit domiciliary care workers also make it difficult to retain domiciliary care workers, especially when the difficulty of the role is not adequately compensated in comparison with jobs in other sectors that appear to be easier and which receive equal or higher levels of pay.
18. A core element of both recruiting and retaining domiciliary care workers is to

improve the terms and conditions relating to the role, to make the job both more attractive and also more competitive with the terms and conditions offered in other sectors to which staff could be lost, for example retail.

19. However, it is not clear that terms and conditions can be improved sufficiently to make the role more attractive to people without tackling the difficulties relating to commissioning processes and sustainable funding that must underpin improvement in those terms and conditions and provide sufficient rewards and incentives for undertaking a challenging role.

To consider the financial impact of current Welsh Government policies - including recent social services legislation and reforms to social care funding - on local authorities, care providers and service users; (section from Crisis in Care.)

20. Paying for care

Regulations derived from the Social Services and Well-being Act aim to introduce a single framework for both residential and non-residential care with regard to financial assessment and charging. However, there is a fundamental debate over the basic fairness of charging people for the care and support they have been assessed as needing. Age Cymru's longstanding view is that a far more equitable system would be to ensure that care services are provided free at the point of use in the same way as NHS services. This would ensure that care is available to everyone at their time of need and spread the cost of care services across the population, instead of the cost simply falling on those people unfortunate to develop care needs.

21. Currently in Wales there is a maximum weekly charge for non-residential care, which increased from £60 to £70 per week in April 2017. This policy represented a clear step forward in seeking to make non-residential care services affordable and eliminating large amounts of regional inconsistency in charging levels and practices. Paying for residential care in later life is a cause of concern for many older people wishing to pass on a financial legacy to the next generation. Consequently, Age Cymru recognises that the proposed increase to the capital limit will be welcomed by many. Although the local government financial settlement provided £4.5m to fund the commitment of increasing the capital limit used by local authorities that charge for residential care, our key concern is to ensure that the social care system is funded to meet the needs of our ageing population.

22. Eligibility criteria

Age Cymru has concerns about how the eligibility criteria contained within the Social Services and Well-being Act is being implemented by local authorities. The new criteria states that people are only eligible for care and support if their needs 'can and can only' be met by social services. However we have

heard from older people who feel that the assessors have made unreasonable assumptions about their ability to cope without formal support.

23. For example, Mrs G's husband was discharged from hospital with advanced dementia but 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. The bill for this support was over £2000 a month. When Mr G was finally assessed, the care plan did note 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 responsibility as she could manage, a situation she found very difficult. (See appendix 1 for case study).
24. 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.
- 25. Residential care 'top up' charges**

People entering residential care should have choice over their accommodation. In reality, choice is often limited, particularly in rural areas. Older people can be placed in a situation where there are no places available within a close proximity of where they or their family members live at a rate that their local authority is willing to pay. This can result in people being faced with little actual choice, and having to arrange third-party top-up payments in order to stay living locally or moving to an unfamiliar location that may be far away from friends and family.
26. Although the Social Services and Well-being Act's Code of Practice⁹ requires authorities to assess an individual's and their relatives' ability to pay prior to placing a person in a home requiring third party payments, it is nevertheless found that relatives can be issued with unexpected bills. Age Cymru has been informed that even relatives in receipt of welfare benefits have been asked to contribute to their relative's care costs. It appears that in some cases, local authorities are failing to explain the requirement for relatives to pay top ups

⁹ Social Services and Well-being (Wales) Act 2014: Part 4 and 5 Code of Practice (Charging and Financial Assessment), Welsh Government (version 2 – April 2017)

and are simply passing the additional payment requirements to relatives without their prior agreement or knowledge. (See appendix 2).

To consider future social care needs and related costs, including the projected increase in the proportion of the population of Wales of pension age;

and

To assess the fiscal levers available to the Welsh Government to reform the arrangements for funding social care. This will include the consideration of alternative models, including international examples, for the funding of social care to ensure a good quality, fair and sustainable service in a time of increasing demands on the health and social care systems;

27. The Institute of Welsh Affairs has predicted that the number of people aged 65 and over receiving residential care services would increase by 82% between 2015 and 2035, and the numbers receiving community based services by 67%. However the Welsh Government's *Assessments and Social Services for Adults in Wales, 2015-16* shows that;

- the provision of adult community-based care services is falling year on year
- the provision of home care is falling year on year and
- the provision of respite care is also falling.

28. Age UK has drafted these principles for reform which Age Cymru supports:

- A guarantee of sufficient quality and quantity of care for low income older people
- New financial products to meet the remaining costs of care for middle to high income older people, such as private insurance
- Payments to support the additional costs of disability continue to be available on a non means-tested basis as a national, legal entitlement
- Adequate funding for advice, assessment and support to arrange services
- An end to age discrimination in the provision of care and support
- A system which supports rather than penalises families and carers
- Alignment with the NHS and other local government services such as housing support
- A flexible system which gives users control and permits different types of care services, such as advocacy, to develop.

29. Reform cannot be achieved without a large investment of new money.

If we merely maintain the current funding level, the projected rise in older people living with complex needs means that we will cause misery and danger for hundreds of thousands of frail older people.

30. The Health Foundation found that adult social care funding in Wales as a whole (i.e. younger adults as well as older) would need to rise by 4% each year to a near doubling by 2030 and pushing spending up to £2.3 billion. Wales Public Services 2025, also found that local authority spending per older person has declined over the last seven years by around 13% and that £134 million a year more would be needed by 2020-21 to get back to 2009-10 per-capita levels¹⁰.

To consider the findings and conclusions of the Parliamentary Review

31. Age Cymru welcomed the Parliamentary Review of Health and Social Care and its finding that too much care is reactive. Although we have stated earlier in this response that local authorities seem to be struggling to implement the Social Services and Well-being Act, adherence to the legislation which promotes preventative services should prevent families and individuals from reaching crisis point and save money in the long term.
32. We therefore support the Review's recommendation that '*care should be organised around the individual and their family as close to home as possible, be preventative with easy access and of high quality.....delivering what users and the wider public say really matters to them.*'
33. We also fully support the vision of a '*one seamless system for all.*' In our response to the Parliamentary Review, Age Cymru recommended that this could be achieved by the following steps;
 - Regional partnership boards must identify areas where pooled budgets and joint commissioning can be effective by increasing the focus on the provision of person-centred care.
 - The Welsh Government, local authorities and other funders must work together and with third sector organisations, to ensure that the preventative services they provide are maintained on a sustainable footing.
 - Where successful pilot programmes have been implemented, local authorities, local health boards and NHS Trusts should ensure the good practice developed is identified and shared across Wales.

¹⁰ Wales Public Services 2015 (2017) A delicate balance? Health and social care spending in Wales.

- Local authorities and local health boards should develop effective mechanisms for the sharing of information and data.
- Older people need to be at the centre of all decisions and developments that impact upon their health and well-being including the social care that they receive.

Appendix 1

Case study regarding eligibility criteria

Mr G is in his 80s, has dementia, severe mobility difficulties and is heavily reliant upon his wife for personal care throughout the day and night. When Mr G was discharged following a lengthy period in hospital, Mrs G (also in her 80s) was told her husband would require two night time carers, as well as daytime care provision.

Although Mr G was assigned a social worker for a short period after discharge, a care needs assessment was not carried out for over 8 months. The couple were not provided with the resulting care plan for over 6 months and although the local authority claimed a financial assessment had been carried out, it was never located.

Unable to cope without night time support, Mrs G arranged for a private care service to assist her husband for several nights per week. The bill for this support was over £2000 a month. When Mr G was finally assessed, the care plan did note 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 responsibility as she could manage, a situation she found very difficult. Despite this, the authority did not assess her needs as a carer until Age Cymru's intervention, whereupon social services arranged and paid for night time care provision for two nights per week as a means to allow Mrs G to rest. This took place over a year after her husband's original discharge from hospital.

Appendix 2

Case study regarding top up fees for residential care

Over the last few years Trish's mother, who is living with dementia, became increasingly confused and was often found wondering the streets of Cardiff, sometimes without a coat. As her condition worsened, it became clear that she could no longer cope with living on her own.

Trish contacted Cardiff Social Services and explained that her Mum's case was now an emergency and that she needed to be placed in a home that would offer some form of safety and security. A temporary place was found for her at a care home, albeit at the opposite side of the City.

Trish's Mum was then assessed by Cardiff Social Services and found to be in need of stimulating activities because of her levels of intelligence, as well access to her own shower and toilet due to previous surgical procedures.

Three care homes in Cardiff were found to be suitable but Cardiff Social Services stated that Trish would need to agree to pay a top up fee of £550 a week before her mum could move in. Trish's financial situation means that she has no way of meeting such a 'top-up fee. Instead the local authority suggested a number of care homes that did not match the assessed needs of her mother.

Trish's mother was forced to spend 10 weeks in a care home that did not meet her specific needs. Her communication skills deteriorated and she lost the means to undertake simple tasks such as using a door handle.

Finally, after a raft of letter writing and a series of frantic telephone calls, the local authority agreed to pay the top-up-fee for Trish's mother which allowed her to move into a home that can deal with the complex needs of advanced dementia. As a result, Trish's mum is now physically active, communicative and content.