



Consultation response

The future of social care in Wales

Plaid Cymru Care Commission

February 2019

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.

We welcome the opportunity to respond to the consultation on the future of social care in Wales.

Background

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

- 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.

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. 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.

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 older in our community. However, due to gaps in data, it is difficult to estimate the scale.

Theme 1: The value systems underlying social care

Age Cymru vision

Our vision for health and social care services in the future is one in which:

- older people living with health conditions and/or social support needs are able to take responsibility for self-care where possible, drawing on the advice and support of health and/or social care practitioners and harnessing the use of assistive devices where this is appropriate;
- health and social care services are seamless and free at the point of use;
- health and social care service frameworks offer choices for those with care and support needs;
- both residential and non-residential health and care services are of good quality;
- all users of regulated care services are within scope of the Human Rights Act.

Reducing and preventing need

As well as social care and funding reform, there is an urgent need to address factors which reduce older people's wellbeing and independence and fuel demand for services, eg, inadequate housing. The Welsh Government and local authorities must also be aware of, monitor and respond to the impact of changes in the environment where older people live upon the demand for social care. Such changes include closures of community facilities and cuts to public transport routes. All older people should be supported to make informed choices about maintaining and improving their health and independence. Opportunities for healthy living should be increased and barriers removed, particularly for disadvantaged older people. If we do nothing, the combination of unmitigated demand and historic general under-funding of social care risks creating a major crisis.

Person-centred services: Information, Advice and Assistance

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.

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. Without this funding, these services are not sustainable.

Theme 3: Role of the non-statutory sectors

Preventative services

Low-level preventative services can make an important contribution to older people's well-being. Such services, including befriending and advocacy, are often provided by the third sector. However, many third sector projects have a limited life span as a consequence of the way in which work is currently funded. It cannot be assumed that successful schemes will continue unless they have managed to achieve sustainability or they are successful with a grant application to a different funding provider. Services can thus appear or disappear, even when they have been successful and helped a large number of service users.

It is important that reablement has been included among the preventative services anticipated by the Social Services and Well-Being (Wales) Act. Reablement, a six week package to help people learn or re-learn skills necessary for daily living, should be offered on discharge from hospital where appropriate. Early intervention and a reablement approach to supporting older people can help to maintain their independence at home and delay the need for entry into residential care. Reablement also reduces pressure on health services by helping to prevent avoidable re-admissions.

Expansion of the range of preventative services is essential in light of demographic change. This will require a shift and increase in resources to provide the range of services that will be needed.

The Welsh Government, the 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. The Welsh Government should also ensure that public information is produced to encourage older people to pro-actively engage in self-care.

Theme 5: Staff recruitment, training and retention

Domiciliary care

Commissioning practices are fundamental to ensuring good quality social care is provided. Age Cymru was pleased to note that Welsh Government legislation now means that local authorities must ensure that they allocate sufficient time to provide the care and support required to meet individual need when scheduling home care visits. Commissioning needs to shift to an outcomes-based approach, reflecting the intention of the SSWA. 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.

The funding available in the public sector is not sufficient for sustainability of domiciliary care in the medium and longer term. Uncertainty around immigration and Brexit is a destabilising factor in an already fragile workforce.

Social care is a sector in which zero hours contracts and the minimum wage are widespread. Recruitment and retention of staff are difficult and undermine the ability to provide good quality care and continuity of care. This is especially problematic in light of the fact that a growing number of those receiving support are living with dementia.

We know that there is frustration at the lack of supervision of the work carried out by domiciliary care workers in particular. The lack of oversight, when coupled with the high workforce turnover, is viewed as a significant factor exacerbating threats to the human rights of older people.

Age Cymru is pleased that the Regulation and Inspection of Social Care (Wales) Act 2016 extends mandatory registration to domiciliary care workers in Wales who will need to be registered by 2020. This requirement will extend to care home staff from 2022. Individual registration of care workers can help to tackle the issue of standards and inappropriate behaviour, but it could also help to enhance to status of the role in the eyes of the public.

Night time domiciliary care

Age Cymru's Advice and Information team have become increasingly aware of a rise in the number of individuals stating they are unable to access night-time domiciliary care.

Responses to an FOI request showed that 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. Importantly, it was found that 4 local authorities provide no domiciliary care at night.

Local authorities must ensure that night time domiciliary care is available to those who need it.

Priority for any new social care model

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.

Care workers are highly skilled, but their skills are not recognised or valued. 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.

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.

Commissioning, funding, terms and conditions, professional recognition and career prospects must be improved to make the domiciliary carer role more attractive.

Theme 6: Effective working with health

Integration of health and social care services

It is widely recognised that a number of obstacles and challenges to providing quality person-centred care derive from the separation of the health and social care systems. The most obvious example is delayed transfers of care, where older people who are medically fit to be discharged remain in hospital because they lack the appropriate social care support that would allow them to return home. Alternatively some older people are inappropriately discharged without checks having place to ensure that they will be safe and cared for at home during their recovery.

Whilst funding is predominantly centred upon the health service, quality social care has an important role to play in preventing unnecessary admissions and ensuring that people are supported appropriately upon discharge from secondary care.

Integration between health and social care services is essential in order to provide holistic, flexible and integrated support. Welsh Government must ensure that barriers to integrated service provision, including cultural, organisational and financial barriers, are overcome, eg through services like Stay Well @home.

The 'Stay Well @home' Service in Rhondda Cynon Taf began in April 2017. The service consists of a multidisciplinary hospital based team of Social Workers, Occupational Therapists, Physiotherapists and Therapy Technicians located within Prince Charles and Royal Glamorgan Hospitals. The service operates 7 days a week between 8 am and 8 pm and is supported by a range of community based responses across health & social care provision. The service has been developed to: carry out initial assessments and organise or provide health, social care and third sector support so that people can have a safe and timely return home from hospital so that they don't have to stay in hospital; make sure that those patients who are admitted to hospital their situation will be assessed in detail before discharge with an expectation that some support will be needed.

The service has demonstrated: a reduction in the percentage of people admitted to a hospital bed from A&E; an increase in numbers of people admitted but earlier returns home; a reduction in the percentage of people admitted to a community hospital. In addition, both Prince Charles and Royal Glamorgan Hospitals have also experienced improvements in the level of escalation being experienced in recent months, reduced A&E breaches and significant reductions in the number of operations cancelled.

Prudent, preventative health and social care

Prudent preventative health care means that the approach of health and social care services must be to facilitate, encourage and support the adoption of better lifestyles and self care of those who might otherwise need additional care and support. This has implications for the training and education of care staff, and an expanded role for social prescribing.

For example, the Gwent Frailty Programme aims to simplify the processes so that agencies work together, deliver services to people in their homes, and work with them to preserve independence and dignity. The Programme aims to use the total resource envelope to provide for integrated service delivery which is multi professional and multi organisational and is based on a locality team approach. The Programme includes: prevention initiatives; crisis responses and reablement across the acute and primary / community sector, all of which need to align and work as part of the integrated approach that focuses on the individual. The person or carer can expect: one point of contact; one contact person with 24/7 availability and timely responses, and preservation of independence.

Commissioning

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. 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.

The third sector and public must be included in the development of local planning and commissioning strategies to improve appropriate preventative service provision across Wales. Where successful pilot programmes such as Stay well @ Home and the Gwent Frailty Project have been implemented, local authorities, Local Health Boards and NHS Trusts should ensure the good practice developed is identified and shared across Wales, as required by “A Healthier Wales”.

Regional Partnership Boards

“A Healthier Wales: our plan for health and social care”,¹ published in 2018, set out Welsh Government’s ambition to bring health and social care services together, so that they are designed and delivered around the needs and preferences of

¹ “A Healthier Wales: our plan for health and social care”, Welsh Government, 2018

individuals, and there is a seamless whole system approach to health and social care.

We broadly agree with this approach. However, we believe that successful integration of health and social care will depend to a large extent on the effectiveness with which Regional Partnership Boards make use of the Transformation Fund, among other levers, to address the issues within their areas and place local voluntary sector services on a sustainable footing.

We are very concerned about the effectiveness of RPBs' relationships with Third Sector partners in particular. We welcome the increases in the numbers of representatives of cared for people, carers and Third Sector organisations on Regional Partnership Boards. Age Alliance Wales and other Third Sector networks have expressed concerns about the transparency and accountability of RPBs and this is a barrier to wider engagement. AAW members also believe that the Third Sector does not currently have parity of esteem with other members, and that they are much less involved in decision making than many had originally envisaged.

We believe that Welsh Government should strongly encourage RPBs to build effective relationships with Third Sector partners. We welcome the WCVA's work to explore this issue.

We believe that health and social care organisations should deliver that ambition through:

- Pooled budgets to promote joint working;
- Better engagement of third sector, carers and people receiving care on Regional Partnership Boards, and
- Greater transparency and accountability in decision making by RPBs.

Theme 7: Future structure

In the light of the Holtham Report, the forthcoming Green Paper on paying for care, the National Assembly of Wales Finance Committee Inquiry into the cost of caring for an ageing population, and the extent of unmet need in Wales, Age Cymru has established a Task and Finish Group to develop a more detailed Age Cymru policy position on Paying for Care, including:

- what the charity believes would be a fair and sustainable mechanism for funding social care;
- the range and quality of social care services which should be provided for that funding;
- the action to be taken in the wider environment to promote health and social functioning, prevent dependency and minimise demand for social care services;

- people's responsibility to take care of their own and their families' health and social functioning, through better lifestyles and self-management, to maximise their years of independence.

The Task and Finish Group has met twice, and is aiming to make recommendations to the Age Cymru Board of Trustees early in 2019. We will share our conclusions with stakeholders in due course. In the meantime, our interim policy position is set out below.

Funding priorities resulting from any social care levy in Wales

We have three levels of priority, discussed separately below:

- priorities for personal care which should be delivered as a basic minimum in any service, however funded, but which are all too often missing;
- commitments and services funded by reprioritising existing allocations;
- priorities for additional funding for social care, however those funds may be raised.

We believe that the first two levels of priority should be addressed now; we also believe that, under any new "social care promise", people are entitled to expect the basic minima and existing commitments to be met and also to expect additional benefits in return for any new levy.

(i) Basic minimum of personal care

Dignity and respect

Nutrition and hydration

Good quality dementia care

(ii) Commitments and services funded from existing allocations

Assessment, eligibility and unmet need:

- (i) Everyone who is entitled to an assessment being able to have one rather than being screened out by inappropriate single point of access engagements.
- (ii) Assessments taking place in a timely fashion.
- (iii) Processes to be clear and transparent and avoid duplication and repetition.
- (iv) Referrals that flow from assessments taking place in a timely manner.
- (v) Authorities meeting their statutory obligations.

Integrated care:

- (i) Pooled budgets to promote joint working.
- (ii) Better engagement of third sector, carers and people receiving care on Regional Partnership Boards.
- (iii) Greater transparency and accountability in decision making by RPBs.

(iii) *Priorities for additional funding*

Considerably more support for carers

A paid, professional domiciliary care workforce

A right of appeal against decisions on eligibility.

Theme 8: Finances

Need for social care

The proportion of the population aged 65 and over in Wales has been growing at a faster rate than the proportion of the population aged between 18 and 64 and this is a trend that will continue in coming decades. The number of people aged 65 and over is projected to increase by 292,000 (44 per cent) between 2014 and 2039, whilst the number of people aged between 16 – 64 is projected to decrease by 5%. The need for social care increases with age, and the number of those aged 85 or over is growing at an even faster rate than those aged 65 plus.

In Wales, healthy life expectancies are increasing, but the number of years spent living with poor health is also increasing. 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 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.

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.

Demand for spending is projected to rise by just over 85 per cent by 2035, at 2016-17 prices, comprising a 20 per cent increase in spending per head and an increase in numbers requiring care of over 55 per cent. Even if the UK economy and the Welsh budget grows at 1 ½ per cent a year faster than care costs, spending a constant proportion of the budget on care will lead to a real increase in funding of only around 30 per cent for social care of the elderly by 2035. That would leave a gap between demand and available resources of over 50 per cent of current spending.²

² Paying for Social Care, *An independent report commissioned by the Welsh Government*, Professor Gerald Holtham, June 2018, p.2.

Funding

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 question of funding social care can be broken down into two parts: funding provided by government for statutory social care services; and the financial contribution that individuals are required to make for the social care they receive.

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.

Funding promise

There is an urgent need for a serious funding commitment to support the provision of social care for people who need care and support and to redress the negative impact of the current persistent and significant underfunding of funding for social care. The current model of funding for social care is inequitable, unsustainable and needs reform.

We recognise that a new social care levy is unlikely to raise sufficient funds to cover all care costs, and that there will continue to be a need for local authority and individual funding. Therefore, any social care promise should:

- Explain clearly to the public exactly how social care has been funded to date;
- Set out clearly and transparently how this will be different in future, including the whole basket of measures which will be necessary to fund social care in the future, including: any new levy; government and local authority funding; charges, top-up fees and co-payments; the nature and extent of any cross-subsidy involved;
- Set out clearly and transparently who is entitled to what levels of care, including: services free at the point of use; services for which there will be co-payments; services which must be paid for, and the role that means testing will play in access to different levels of service;
- Ensure that the governance regime is transparent and accountable, and thus enable public scrutiny of the new social care funding system and its outcomes.

Local authority funding

Direct payments can give people choice and control in how they achieve their identified objectives. The SSWA contains a commitment to expand and facilitate the use of direct payments. The take up of direct payment amongst older people has

been low due a range of factors, including a common assumption that they are not suitable for older people. Older people with care needs should have the same opportunity to choose to receive a direct payment and it is fundamental that direct payments are not refused, or fail to be offered, based upon assumptions made about an individual's age.

Individual funding

If charging individuals for care services is to exist it must be made as equitable as possible. Care services should have no interest in the ownership of property by people who need care.

We remain concerned about the unfair treatment of occupational pensions in determining a charge. While income from earnings is disregarded (rightly) for the purposes of determining a charge, occupational pension income is not. We believe this is fundamentally unfair on the basis that this income should be treated the same as employment earnings. To not do so is to treat retired people differently, and less advantageously, in comparison with people currently employed.

We are also concerned that there appears to be no means of financial assessment or monitoring of the cumulative impact of charges under the Social Services and well-Being (Wales) Act 2014, in the case that older people are signposted to a range of preventative services. There is a risk that people could experience financial hardship or be faced with charges that they are unable to afford as a consequence, especially as these charges currently appear to fall outside the maximum weekly charge that is applied to non-residential services. Older people would therefore be paying additional amounts of top of the maximum weekly charge.

The Welsh Government, the 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.

Eligibility

Older people who are not satisfied with the decision on their eligibility for services should have a right to appeal against that decision. Unlike the Care Act in England, the SSWA does not currently provide a right of appeal against decisions made by local authorities. The only mechanisms that are open to carers and those they care for to object to the outcome of eligibility decisions is to request a re-assessment, which requires submission of evidence that either a substantive need was overlooked or that circumstances have changed, or to make a formal complaint, weakening the overall intentions of the Act to move to greater co-production.

The Welsh Government should introduce a right to appeal decisions on eligibility, without having to resort to a formal complaint which is likely to focus on whether due process was followed rather than reviewing the outcome of the process.

Sub-group B: Carers

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 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.

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

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.

We believe that considerably greater support is needed for carers. Enabling more carers to stay in work may help to offset costs through greater productivity and reductions in state benefits. This should include training in better care techniques, like lifting, increased and more flexible respite opportunities to benefit the carer and person being cared for.

Carer's needs assessments and the support that flows should enable them to have a life of their own.

Welsh Government and local authorities should ensure that carers receive their full entitlements and remove the discrimination that stops them receiving Carer's Allowance once they reach state pension age.

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.

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 by. For adult children who have moved away, fuel or transport costs often increase significantly.

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.

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.

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.