

CARING CHOICES

Who will pay for long-term care?

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Overview

The question of how best to fund the care and support of older people is now back on the political agenda following the recent announcement by the government of a Green Paper identifying the key issues and options for reform of the current system in England. The sixth Caring Choices event, in Taunton, took place against this backdrop, with a sense of cautious optimism that it may be possible to influence the direction of future policy.

Such optimism was tempered, however, by concern that the level of public funding set in the Comprehensive Spending Review for the next three years was too low and will result in the further withdrawal of state support for low and medium care packages and in increased funding pressures when meeting high-level needs.

The event, on 23 October 2007, was attended by more than 60 people with experience of social care, including service users, carers, providers, funders and commissioners. Almost three-quarters of the participants were aged over 50, and 40 per cent were service users/older people or carers.

As at previous Caring Choices events, delegates said that more money, whether public or private, will be needed in future to provide an acceptable level of care for older people. Almost everyone wanted the current means-tested social care system replaced but there was an acceptance that the financial responsibility for providing such care lies jointly with the individual/family and the state. More than 80 per cent of participants said that they would prefer a change to a 'co-payment' funding system, where all dependent older people would receive some support towards their care costs regardless of their income/assets, while also making a private contribution that was affordable for them. There was less support than at previous Caring Choices events for a system where all personal care should be provided free.

In the context of the Green Paper, there were repeated calls for the political parties to reach a consensus about reform. One panel member said: *'We need an architecture for long-term care which is signed up to by all parties and the public and providers. People need a level playing field and a basis for rational decision at a time when they decide to save.'* Reform of the funding system, however, is no substitute for an increase in public spending on older people's care, said participants.

Participants debated three core questions:

- [Who should pay for personal care?](#)
- [How do we encourage people to contribute to care costs?](#)
- [How do we support the provision of informal care?](#)

There was agreement that reform must define 'basic needs' widely enough to preserve an individual's dignity. Older people must have choice, regardless of their level of income/wealth, and any system should also consider preventive services and non-personal care needs, rather than focusing only on personal care services. *'There is currently no incentive for government to invest in long-term savings, such as low-level interventions to deal with the high levels of depression among older people. We ignore these preventive approaches because they don't fit into our existing solutions,'* said one panel member.

Quality of care, and the link between quality and funding, needs to be recognised, said delegates. There were concerns that the current complicated and expensive regulatory system still does not stop the abuse of vulnerable older people.

Looking ahead, there is now a sense that the debate over the future of care and support for older people has reached a 'tipping point' for change, and that the Green Paper will need to address these demands. A period of public consultation is promised by the government, and the debate now needs to be taken into the community at large and across the political divide.

Who should pay for personal care?

As at other Caring Choices events, there was an overwhelming rejection of the current means-tested social care funding system but also an acceptance that providing care is a joint financial responsibility of the older person/family and the state. More than 80 per cent of participants said they would prefer a change to a 'co-payment' funding model where every older person, regardless of their income/wealth, has access to an appropriate package of personal care that is part-funded by the state and part-funded (if they can afford it) by the older person. In comparison, only one in seven delegates preferred a system of 'free personal care' in which the government would provide an appropriate package of free care services to all dependent older people. However, several participants rejected this option on the grounds that it was financially 'unrealistic'.

Co-payment was seen as 'fairer' than the current means-tested system, which cuts higher income/wealth individuals out of the state-funded social care system. *'Everyone pays [tax] into the Exchequer, so there needs to be a fairness about what you get out of it,'* said one participant. Equally, delegates said that co-payment would

depend on an acceptance by the public that personal financial contributions are necessary, mirroring the changes in attitudes regarding pensions where people now accept that a state pension is not sufficient and that private pension saving is also needed. Among the Taunton audience there was a general willingness to use some savings to pay for long-term care, but not to see *all* their assets eroded. However, at this event almost everyone was a homeowner, and two-thirds of people said the value of the home should not be taken into account when deciding whether someone should contribute to care home fees. At the same time, some participants called for an acceptance that not all older people will receive the same standard of care under co-payment, with greater choice inevitably still available for those who can afford to spend more.

It is in the detail of how a co-payment system would operate, however, where many questions remain. Under a co-payment system there is the question of how to determine the public:private split for the care costs. A majority felt that the state should cover 70 per cent or 80 per cent of the costs, but half of the participants also said that everyone who needs personal care should be means-tested to determine whether they should contribute towards their care.

Under co-payment it would have to be decided how widely to define 'care needs'. *'How do we define "basic needs", the needs for which co-payment will provide 70 per cent or 80 per cent? Are they linked to the need to preserve the individual's dignity?* queried one delegate. In particular, older people need to have funds to top up service provision according to their own priorities, and there was agreement that any system should consider preventive services and non-personal/domestic care.

It is assumed that a shift to a co-payment funding model would require the government to raise or divert more of its resources to fund older people's care. Delegates in Taunton were divided over how these extra public funds should be obtained, and many people felt that there would need to be various sources of additional funding. Among those broadly in favour of co-payment, the most popular options were to increase direct taxes and redirect disability-related benefits (which are not means-tested). Less approval was given to raising indirect taxes or redirecting NHS funds. However, there were also some heartfelt pleas against any potential reform of benefits. *'Don't take away the Attendance Allowance and Disability Living Allowance national benefits entitlement. It is a life saver,'* said one delegate. *'You always know it is there,'* agreed another. There were widespread calls for transparency, whatever the funding mechanism. *'The tax system is not transparent. People will want to see that if they pay a "social care tax" then it goes into a social care fund.'*

Some of the perceived shortcomings of the current funding system offer guidance to policy-makers as they assess the reform options for inclusion in the Green Paper.

- The current funding rules are too complex for an older person to be able to navigate a way through the system and obtain their 'fair share'. Older people and their carers find it difficult to 'get the right package of answers out of the complexity'.
- The complexity extends to the benefits system; older people are not claiming the benefits for which they are eligible, and which would provide more money to pay for care.
- However, there was also concern about abuses of the system, both in terms of benefits cheating by those at the bottom end of the income scale and hiding wealth to avoid paying charges by those with assets well above the means-testing threshold. Middle-income individuals felt they were getting the worst deal out of the system and that any new funding system should try to reduce this abuse.
- Clarity of charging is essential, both in terms of care homes offering a breakdown of their fees, and in terms of older people understanding the charges levied by local authorities for domiciliary care services. The lack of clarity about the complicated funding rules 'adds to a lack of quality and confusion about the choices that are available'.
- Regardless of income, it is important for older people to have choice.

Most of the discussion focused on the social care system, but funding for dependent older people comes from a variety of sources. Should it be rationalised into one 'pot', and, if so, who would manage it? One panel member said: *'If you have a National Health Service then it cannot be combined with means-tested social care or housing provision. So should you have these differences built into the system? No one dares raise that question politically because it would raise questions about NHS funding.'*

Less ambitiously, many delegates saw scope for financial efficiencies in the administration of the current systems. For example, a single financial assessment could operate across the different means-tested systems and services, and there could be a more 'joined up' approach by the health and social care services.

Above all, the need for long-term consistency and predictability was seen as crucial in the context of the current move towards reform of the care and support system. One panel member said: *'We need an architecture for long-term care which is signed up to by all parties and the public and providers.'* There was applause when he added: *'People need a level playing field and a basis for rational decision at a time when they decide to save.'*

How do we encourage people to contribute to care costs?

This Caring Choices event sought views about three types of schemes where government subsidies could potentially be provided to encourage people to contribute

privately to care costs: state backing for long-term care insurance products; a public equity release scheme for care funding, along the lines of student loans with a low interest rate; and public support for continuing care communities, where older people buy into a property-based scheme that will provide for any future care needs. The question was whether any of these options is worthy of public financial support and which, if any, should be prioritised for public funding.

For each of these options, participants were split almost equally over whether a subsidy would, or would not, represent an appropriate use of government money. When pressed about which single type of scheme should be considered most seriously for state support, the most popular was long-term care insurance, followed by continuing care communities and then (somewhat further down the ranking) equity release. One in six delegates, however, said that the government should not be spending money on supporting any of these approaches.

The perceived attraction of a state subsidy for long-term care insurance was in marked contrast with audience opinion at other Caring Choices events, where there has been little interest in insurance. This difference may indicate that the participants in Taunton were more familiar with using insurance products in other aspects of their lives. There were suggestions from delegates that this type of insurance could be combined with life insurance or pension schemes to make it simpler.

The relative popularity of the idea of using a government-backed long-term care insurance product contrasts with the reality that this part of the insurance industry barely exists any more because most providers have withdrawn from the market. Those delegates who were less enthusiastic about this option tended to be aware of some of the problems that had arisen with earlier products, such as providers deciding to change the terms of the policy. There were also concerns that, like flood insurance, some people would be unable to secure long-term care insurance cover if they were seen as too high-risk. The sceptics also voiced a general lack of public confidence in the insurance industry, particularly after the pensions crisis.

Equity release is a market that *does* currently exist, but this option was markedly less popular than the other schemes put forward for discussion. The main reservation was about value for money. Almost all participants at the Taunton event described themselves as homeowners, but only two people had personal experience of an equity release scheme (both said it had worked well, providing choice and flexibility). Downsizing into a smaller property is seen as a better option, although some homeowners with lower-value properties said that this would not be a meaningful solution for them. As with insurance, there was again a mistrust of the financial industry; problems with endowment mortgages were cited this time as undermining public confidence.

Retirement communities were popular during roundtable discussions, particularly if schemes are integrated into the wider (all age) community so that they do not become older people 'ghettos'. One older person explained: *'Society already marginalises older people and shuts them off from other sections of society.'* Many saw this type of community as offering a combination of independent living, an antidote to loneliness in old age, and a guarantee that future needs would be taken care of. *'You can live a normal life but you know you will get care and attention if you need it.'* The main reservation among participants was that there are currently relatively few affordable schemes of this type and that finding a place would be very difficult. The purely commercial 'retirement village' schemes were seen as very expensive. However, when asked a straight question about whether they would like to live in a retirement community, just over half the delegates said 'no'.

While no consensus emerged about a single best potential use of public funds in supporting such schemes, there was agreement on related issues.

- Overall, the differing preferences of delegates confirmed a common view that a range of schemes is needed to ensure that there is a suitable option for everyone. Thus the government would be wrong to focus on any one option.
- The three options put forward for discussion were seen as middle-class solutions for 'vulnerable' individuals who are not well-served by the current means-tested care system.
- Each scheme has some potential but there will always be a need for an underlying safety net for those not in a position to participate.
- It is very difficult for people to 'guess' or understand what level of provision they need to be making for long-term care, because of the difficulty in forecasting costs and also the uncertainty of forecasting need.
- Awareness of the need to plan ahead to contribute privately to care costs will be a gradual process and it is important that the options cover those who have not made enough provision.
- Reliable, *independent* advice about any such schemes would be essential so that an individual could make an informed choice about the most suitable way to fund the private costs of long-term care.
- The affordability of any pre-paid product, such as insurance, would depend for younger people on competing expenses such as paying off student loans and mortgages, and starting a pension.

If there was one main area of consensus it was in the need for the government to provide a stable environment when deciding whether to support such schemes so that individuals can make informed choices about providing for long-term care costs 20 or 30 years ahead. One panel member stressed: *'Don't change the rules arbitrarily in a way that makes it difficult for people to plan for the future.'*

How do we support the provision of informal care?

The one area of complete consensus at all the Caring Choices events so far has been exasperation at the woeful lack of support from the state for unpaid carers.

Participants from across the socio-economic and political spectrum repeatedly voice their irritation, anger and despair at the government's perceived lack of real commitment to meeting the needs of carers. *'A lot of carers feel they are shouting at a brick wall,'* said one delegate. Greater financial commitment is seen as crucial to providing adequate services, such as respite care, but the demand for greater support goes much deeper than just the question of additional money. Carers want much greater recognition by society of the physical, emotional and financial stresses of caring – and then they want the system actually to do something to alleviate these burdens, rather than just talking about them.

More than half of the participants at the Taunton roadshow are involved in providing unpaid care, either as a family member, friend or volunteer. As at other Caring Choices events, respite care, financial support, emergency help and basic information and advice all scored very high with the audience in terms of the improvements that would make the most difference to carers' lives. Clearer legal rights would also help, for example, on the entitlement to a carer assessment and for flexible working.

Participants pointed out that it is carers who bear the brunt of shortcomings and failures in the current system. Lack of basic care support can create 'a nightmare' for the carer, such as being let down by night services, or when there is no back-up available over public holidays. *'Carers are caring 24 hours a day, and support services need to be reliably available 24 hours a day.'*

There was agreement that the government underestimates the number of unpaid carers. *'Many people do not like to call themselves a carer – they might think of themselves as a family member – and therefore don't ask for or accept a carer's assessment.'* This calls for wider encouragement for these 'hidden carers' to have a carer's assessment. Equally, when a carer *is* assessed, it needs well-trained workers and commissioners to design an effective support package and to give the most appropriate advice.

Some participants had taken the government at its word regarding better carer support but were nevertheless disappointed. One woman had filled out the form to be put on the carers' register in the hope that this would produce some advice or help, but never heard anything more. *'It's so cynical,'* she said.

The imperative for adequate financial support for carers has been highlighted at all the Caring Choices events. The consensus is that there are enormous financial implications from being a carer and that a greater investment in benefits or

allowances is necessary to ensure carers remain financially independent and comfortable. The rate at which Carer's Allowance is paid is *'laughable – this works out at 5p an hour for the time that most carers put into caring'*, said one volunteer carer. And the fact that most people over pension age do not see the benefit of Carer's Allowance is deemed 'an insult'.

The lack of information and advice available for carers has come up at all Caring Choices discussions, and the majority of participants put this very high up their priority list. Knowing where and how to access support is a basic requirement, but information services vary greatly between local authorities. Each social services department ought to provide a database of the resources that are available, including information on voluntary organisations, suggested some delegates. *'Unless you know what you can ask for, you won't ask for it.'* Best practice shows that it can be done, but it usually is not. The existing systems are so complex to navigate that information and advice is crucial. Many participants felt that several other improvements would flow from this.

Respite care is another priority, but rarely available. *'Even if I paid for it there was nowhere for my dad to go'*. Carers particularly need a short break service and emergency respite in times of crisis. An entitlement to short breaks would be a good example of an effective preventive service, participants argued. *'The entitlements should be flexible, for example, people could accumulate them and save them up to be used when most needed or for a particular reason.'* It should also be possible to arrange respite care well in advance to allow carers to pre-book much-needed holidays.

One group of participants was particularly concerned about the difficulties faced by 'reluctant carers'. *'For a number of older people, the care is provided by someone who is not even a relative, often a neighbour. As the older person deteriorates, they step in and do more and more to help. The state relies upon this. But the carer is thinking, "how do I back out of this?" They are in an impossible position.'*

The audience was split when asked whether in 10 years' time families and friends will provide more or less care for older people, but there was agreement that a more cohesive society would be needed in order to 'encourage and enthuse' a new generation of willing carers. *'People need exposure to caring to realise that there is a return on providing care. We need to get the generations exposed to each other more.'*

Carers are articulate about their situation, but do not yet present a force that politicians have to recognise. One volunteer said: *'If only I could muster the pensioners outside County Hall ... But a lot of carers are totally isolated, lonely, and suffering from stress. There are probably more votes in tax cuts than in carers.'*