

CARING CHOICES

Who will pay for long-term care?

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Overview

Politicians from the three main parties say that cross-party consensus is achievable on reform of the social care funding system. Stephen O'Brien MP, Conservative Shadow Minister for Health, told delegates at the final Caring Choices event, in London: *'There is a large amount of political will at the moment to try and really solve this problem.'*

Ivan Lewis, the Labour Minister with responsibility for social care, said it was 'absolutely crucial' to achieve political consensus. He encouraged the Opposition parties to engage 'actively and positively' in the consultation events and the processes leading up to the recently announced Green Paper on reform of the funding system for adult care and support in England. One measure of the success of any reform would be that *'a very wide range of people feel the system is fair'*, he added.

Norman Lamb MP, Liberal Democrat Shadow Health Secretary, said consensus 'ought to be possible', and that for success any new system would need to be 'simple, easy to understand', seen to be fair, as well as empowering people to set their own priorities.

The three politicians were answering delegates' questions at the end of the seventh Caring Choices roadshow, on 14 November 2007. The event was attended by more than 60 people with experience of social care, including service users, carers, providers, funders and commissioners, and representatives of the organisations that make up the Caring Choices coalition. Half of the participants were aged over 50, and one-third were service users/older people or carers.

There was near unanimity among participants on the need for a 'radical rethink' in the forthcoming Green Paper on the funding arrangements for older people's social care. In line with the other Caring Choices events, there was support from around three-quarters of the delegates for a shift away from the means-tested current system to a 'co-payment' funding model, 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.

Ivan Lewis said it was important to be 'very open and honest with people' about the choices and trade-offs involved in reform. He added: *'There are no easy choices,*

there are no soft answers.' Among delegates it was felt that the wider public was currently both willing and able to engage in a robust debate about what a fair and sustainable settlement might look like. The degree of consensus that was achieved over pension reform, including acceptance of the joint responsibility between individuals and the state to provide for older age, is seen by many as a precedent for the debate that is required on reform of funding older people's social care.

Participants at the event addressed 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?](#)

Delegates indicated that the key foundations on which any new funding system should be built include clearer entitlements for individuals, less complexity, and the end to rules that heavily penalise those who have saved for old age. There should be greater acknowledgment that older people themselves contribute financially to society, through income tax on pensions, council tax, and by providing care for grandchildren and other relatives, as well as more generally supporting their local communities. Given such a role, older people deserve a fairer deal on paying for long-term care.

Who should pay for personal care?

The current social care funding system is widely perceived as 'unfair' and in need of change, and the Caring Choices debates have demonstrated an appetite for a public debate around possible alternatives. But the discussions have also illustrated that it will take some effort to reach a consensus on the way forward. In line with earlier events, around three-quarters of participants at the London roadshow 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, just over one in six 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. And one in ten preferred to retain the current funding model.

However, 'co-payment' is a concept that currently means different things to different people. Among those at the London event who supported the co-payment approach, there was no agreement on the appropriate actual split between public and private contributions, with opinion ranging from the state needing to fund less than 60 per cent of a care package to more than 90 per cent. There was also no agreement over whether or not means testing should still play some role in the care system regardless of whatever funding model was used – for example, to determine an

individual's private contribution to care costs – with just over half in favour of doing so. Similarly, half the audience thought that the value of a person's home should be taken into account when deciding whether or not they should contribute to care home fees, while 40 per cent of participants thought not.

Differing views about the treatment of assets are often indicative of conflicting opinions about inheritance, and this was the case at the London event. One participant said: *'I don't see why I should subsidise someone's inheritance.'* But others felt strongly that it is important that people are able to bequeath something to their children and should not see all their wealth eroded by being forced to fund a high level of care privately over a prolonged period of time.

While the details of a co-payment approach are clearly still up for debate, there is a consensus that the current social care funding system is not sustainable and that a co-payment approach appears to offer ways of dealing with some of the shortcomings of the current system. In particular, co-payment is perceived as 'fairer' because no one is completely excluded from public support due to their income/assets. *'Co-payment would provide some level of 'insurance' for those who choose to save/provide for their own old age,'* said one delegate. During the panel discussion, Norman Lamb MP said any new system should ensure *'people are encouraged to save for their old age and encouraged to spend to contribute to the cost of their care on a shared basis with the state.'*

It was felt that an explicit co-payment approach would also promote choice and control for users, while also encouraging greater transparency in charges. Under co-payment, more people will have a vested interest in the system and in raising quality. *'[The key question is] what will tip a co-payment system from feeling like a state-funded monopoly with little sense of choice, to feeling and acting like a private system where there is real choice, with a real market of providers and a sense of being in control?'*

As the government assesses options for reform, there were repeated calls from delegates for real clarity for all those involved. Individuals need to be clear about their entitlements under any new system, and local authorities need to know where the money will come from if central government makes promises regarding local government-provided services. This desire for clarity, plus a wish for less complexity than in the current system, raised concerns among some participants that a Wanless-style partnership version of co-payment could be *'equally confusing and unclear about entitlements and just as complex as the current system'*.

Part of the reform and consultation process must be to educate the wider population to have a better understanding about all the choices that face them about providing for later life. This covers both pensions (where the government has already instigated

reform) and the need for social care. *'We need to get the message across to people that they need to consider their future care costs, in the same way that pensions are advertised and explained.'* As with pensions, there is also a need for clear choices to be presented to the public so that a sensible and mature debate can be had on likely trade-offs.

As at earlier Caring Choices events, participants called for greater consistency across local authorities in terms of the level of care provided and of the charges for domiciliary care. A co-payment system with clear entitlements is seen by many participants as potentially providing a more standardised service, through benchmarks or minimum thresholds, although there would still be scope for some local variation. It would be necessary, for instance, to reflect the variation in local costs in any such system.

There was lively discussion of the role of disability-related benefits (Attendance Allowance and Disability Living Allowance) in the context of whether part of the benefits budget should be diverted to provide more public funds for social care. This suggestion prompted conflicting views from the audience. Some participants felt strongly that these benefits needed major reform as they were not being spent most effectively – the money was often simply added to the general household budget by poorer people, while some older people just saved the money. *'We are not using existing resources to best effect,'* said Ivan Lewis, the Minister, during the panel discussion. It was suggested by some participants that these benefits should operate more like Direct Payments, where the recipient may be expected to show that the payment has produced the desired outcomes. Others disagreed strongly, arguing that they provide true flexibility, choice and control for dependent older people. One area of agreement was that more evidence is needed about how disability-related benefits are actually spent, and their impact on recipients' lives. Personal control was supported strongly by Stephen O'Brien MP on the panel, who said most older people and their carers know what works best for them, and it is important to *'trust people'* to buy effectively what they need.

All three politicians recognised that an increasing number of homeowners feel it is unfair that under the current system the value of their homes could potentially disappear into care fees. But Ivan Lewis, the Minister, stressed that any system that is more generous on a universal basis will have to be paid for either by not spending money elsewhere, or by higher taxes. *'There are no easy choices, there are no soft answers,'* he said. The government's view is that a reformed funding system must be *'progressive', 'fair' and 'affordable',* he added.

Given the need to increase public spending on older people's care, some delegates suggested that funds could also be diverted *'carefully and transparently'* from the

NHS into personal care. Such a move could be part of a wider more 'joined-up' approach between health and social care.

How do we encourage people to contribute to care costs?

This Caring Choices event again sought views about three ways in which 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 option, there was majority approval that the use of public money would be appropriate. However, support was split fairly evenly between the three options when delegates were asked to prioritise just one scheme. Continuing care communities were marginally the most popular option, but one in ten delegates said none of the schemes should be given any public subsidy.

There was considerable scepticism about the viability of long-term care insurance, as several participants were aware that most providers have withdrawn from this market in recent years. Delegates also cited the public's lack of confidence in the financial sector, with reference to experiences with pensions and endowment mortgages. It was felt that government support or state guarantees would be necessary both to bolster public trust in an insurance approach and to make the premiums affordable. There was interest among some delegates in a US-style scheme where insurance companies would provide cover for the first, say, three years and the state would then step in and pick up the care costs. Any state-backed insurance option, however, raised the question for some participants of why the state should subsidise a private, profit-making insurance system in this way rather than opting for a social insurance model of social care funding as some other countries, such as Germany, have done. Some delegates suggested compulsory payment of an earnings-linked 'National Insurance care scheme', with the funds going into a ring-fenced care fund.

A government-backed equity release scheme was seen as a potentially attractive option in discussions, again because state backing was seen to increase public trust in any equity release product. It was notable that one in seven delegates had used an equity release scheme, a far higher proportion than at other Caring Choices events, a statistic perhaps linked to London property prices and/or the knowledge base of the audience. However, some participants were concerned about what the state would end up subsidising. *'Should the government support equity release for someone to go off on a cruise?'* In the case of a bone fide wish to fund care services through equity release, there was an awareness that the potential loss of means-tested benefits as a result of releasing capital or income from a property acts as a big disincentive for some homeowners, and that this problem needs to be addressed if the government

wants to promote equity release. Delegates who argued against state support for this option usually criticised it on the grounds that it would only benefit homeowners. *'If you've got a limited pot of government resources, do you want to steer money to homeowners?'*

Some participants were aware of the existing 'deferred payments' option that is already provided by local authorities, and which is in effect an interest-free equity release scheme for older people who move into a care home and do not want to sell their house. Relatively few people in practice actually secure a 'deferred payments' arrangement, and local authorities do not actively promote the scheme, presumably because it has 'negative financial implications' for budgets. Indeed the existing scheme might not be sustainable if it were more widely offered. It was suggested, however, that this might be the basis for a state-backed equity release approach. Alternatively, the government could underwrite a not-for-profit equity release product provided by the voluntary sector, other people said.

The discussions around the potential for care communities demonstrated considerable interest in this concept, and also revealed that several people were unaware of these schemes. This type of set-up, where residents are independent but receive increasing on-site support if they become less able, was seen as meeting the desire for something in between continuing to live in one's existing home and moving into a care home. The problem for older people is that private schemes of this type are often expensive, and that there is already a shortage of places in care communities, with long waiting lists. To develop schemes of this sort for middle-income people was seen as attractive, and something that the government should consider. It was also suggested that in urban settings, where suitable sites for retirement 'villages' may not be available, it might be possible instead to create a 'virtual' care community.

Overall, as at other Caring Choices events, it was seen as misguided to try to define a single government-backed scheme to promote private expenditure on care. The population needs a 'menu' of these options to suit different personal circumstances. And, regardless of government subsidies, consumers will require very clear advice and independent information about the complexities and risks of some of these financial products. Such products, whenever possible, also need to be made relevant to lower-income individuals, for example, perhaps with shared ownership options for those who want to buy into care communities.

How do we support the provision of informal care?

The difficulties faced by carers of working age, and the challenge of combining caring with a full-time job, were particularly highlighted at the London event, perhaps because the audience had a younger profile than at earlier Caring Choices roadshows. A number of specific issues emerged. First, the question of financial compensation,

both for those forced to give up their paid work because of the demands of caring, and also for people who combine the two roles. For the former, Carer's Allowance was seen as an inadequate replacement for a paid wage and the carer was also penalised because of the knock-on impact on a pension from having given up work. One participant spoke of the *'anger that carers feel about the poverty they are forced to endure because of their caring'*. For those who juggle to combine work and caring, there were complaints that their role was not recognised financially at all by the state. *'If you work full-time, and then you come home and do everything, providing night-time and weekend support, you do not receive any financial contribution.'* In both cases, money was seen as crucial because it enables the carer to buy in additional support to alleviate the physical and emotional pressures they live with. For example, many carers of working age no longer have any social life of their own, and would like to be able to afford to employ someone to watch over the older person so that they could occasionally go out at weekends or in the evening.

A related issue was the need for real flexibility at work for carers, although it was accepted that this would be more challenging within a small business than in a large company. It was generally felt wrong that a parent of a young child can be seen as more deserving of greater consideration when asking an employer for flexible working than someone looking after an older person. *'Looking after an older person is a thousand times more draining than looking after a child.'* One suggestion was that there could be a dedicated state fund to compensate smaller employers for the costs of providing flexibility for carers. An employee might then be eligible to work flexibly if, for instance, they could demonstrate that they provided care for an adult in receipt of disability-related benefits. On the panel, Norman Lamb MP said it is important to find ways to help carers, whenever possible, to stay in employment, in part because work provides a 'lifeline' of social contact.

Respite care, as at all other Caring Choices events, was top of the list of services that were cited as being of most need to carers. The respite service, however, has to meet the actual needs of the individuals concerned. *'Carers don't want to have to book three months ahead for a two-hour slot.'* One local authority delegate described a local Age Concern dementia day centre that could offer overnight care at fairly short notice – a service that had resulted from listening to what older people and their carers said they wanted. But this was an exception to the much-voiced view that respite care is either unavailable or inappropriate for the circumstances of the carer and the older person.

As at other events, the proposal of an emergency general support service that would be available 24 hours a day was very popular. *'There is an urgent need for emergency support, especially for people looking after older people with mental health problems,'* said one participant. This view chimed with suggestions at other events that a '999 helpline' service for carers should be set up. The gap in emergency

provision was noted by panel members. Stephen O'Brien MP, during the panel discussion said that it had been 'a real learning point' of the Caring Choices venture to demonstrate the importance that participants had put on the need for such a service.

The consistency of views across the Caring Choices events about the raw deal that carers currently receive has been striking. The lack of emotional support, an absence of high-quality information and the need for clear entitlements for carers has been raised each time. There appears to be a particular lack of understanding of the needs of black and minority ethnic carers and rural carers, for both of whom the risk of isolation can be especially high. Some delegates in London felt that GPs are increasingly crucial in facilitating support for carers, because the doctor's surgery can be the only point of contact for carers when there is no regular interaction with social services.

Some participants felt that the shortcomings of the social care system as a whole meant that many carers did not have a choice about providing care – 'and they should have that choice'. A fundamental principle for any new social care system or government policy for carers must be that unpaid carers and the people they care for should have a choice about the nature of their relationship. If the older person was better supported financially, then they would have a choice of who provided the care, especially personal care, it was suggested.

Delegates also stressed that the state could not rely on there being enough unpaid carers in the future. Half the delegates said that in 10 years' time families and friends will provide less care for older people. Families are changing, becoming smaller and more fragmented, and the previous reliance on middle-aged women to provide unpaid care is breaking down. In planning for the future, the social care system will have to adjust to these changes in society, and should not try 'to reinvent what has happened in the past'.

During the panel discussion, Ivan Lewis, the Minister, said the government's 'new deal' for carers, to be announced next year, would include practical measures to support carers. The work is looking at a number of issues including the 'impact on carers' of allowances, benefits and tax incentives, employment rights of carers, and the provision of respite care. He said that carers have repeatedly told him that they want a system that is 'on our side rather than a system we are constantly feeling we are battling with' and that they 'want a right to have a life of our own'. This echoes other previously expressed views that 'success' in social care should not be based on one's ability to 'battle the system' in order to obtain the resources and support needed to lead a full and active life in the United Kingdom.