



CARING CHOICES

Who will pay for long-term care?

The Future of Care Funding

TIME FOR A CHANGE

JANUARY 2008

Overview

Caring Choices, a coalition of 15 organisations from across the long-term care system, sought to gather the views of older people, carers and others with direct experience of the system on how care should best be funded in the future. It was born out of widespread and growing concern that the current long-term care funding system is not fit for purpose. Throughout 2007, it has engaged with more than 700 individuals at events across England and Scotland and through an interactive website. The initiative – and this final report in particular – provides insights into potential areas of consensus as well as some of the difficult choices and trade-offs that will need to be made in order to create a funding system that is fair, effective and sustainable.

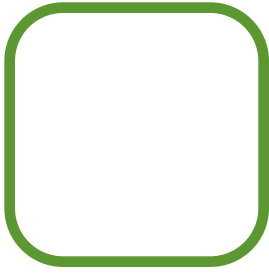
The findings reported below came from the discussions at the Caring Choices events and from a survey of those attending the events, web visitors and a number of partner organisation contacts.

Caring Choices found:

- **There was almost no support for the current funding system. Ninety per cent of participants at the events rejected the use of a means test to determine whether or not an individual receives any state-funded care. In other words, they supported a stronger 'universal' element, determined by care need rather than by people's income or wealth.**
- **The vast majority of Caring Choices participants wanted a simpler system, in which entitlements are clearer and people are able to plan ahead with greater understanding of what will be on offer.**
- **Almost all Caring Choices participants (99 per cent of those who completed the questionnaire) believed that more money needs to be spent on long-term care – regardless of what kind of funding system we have in place or where that money comes from.**
- **Just under three-quarters of all participants believed that the costs of long-term care should be shared between the government and the individual, although there was a range of views on how that could be organised and what the balance should be.**
- **Although Caring Choices participants demonstrated strong support for a system that gave a much clearer sense of entitlement to some level of state support, there were many calls for older people and their families to have control over the services they obtain with the help of this support.**
- **There were many calls for a wider range of care needs beyond those narrowly defined as 'personal care' (help with washing and dressing etc), such as shopping or help with gardening, to be better supported.**
- **There was a recurrent but unresolved debate about whether and to what extent existing general and non-means-tested disability benefits, such as Attendance**

Allowance, should be brought in to any reform of long-term care funding.

- **Most participants were in favour of the idea that the state should support schemes, such as equity release, that help to unlock private resources or encourage private contributions towards the cost of care. But there were mixed views on specific schemes and a clear sense that participants felt a variety of options should be encouraged rather than a single 'solution'.**
- **There was an overwhelming view, often strongly expressed, that the current levels of support, financial and otherwise, for unpaid carers is totally inadequate. Participants emphasised that this is an important issue, and that any settlement will fail if it neglects carers' needs.**



Introduction

The question of who should pay for the long-term care of older people has been the subject of debate among policy-makers and older people's organisations for more than 30 years. Various attempts have been made to create a fairer system and to ensure that the most vulnerable are given the support they need. At times major reforms have been contemplated, most notably through the setting up of a Royal Commission in 1999, which proposed a radical shift towards state funding – an idea that was rejected by the UK government, which was responsible for social care in England, although a version of it has been introduced in Scotland.

In the past few years, although this issue has not been at the top of the political agenda, there has been growing concern that the long-term care system is failing older people and their families. Despite local councils spending more money on services, the demands have been so great that it has become increasingly difficult to qualify for state-funded social care. As a result, more and more individuals and families have had to find and pay for their own care (Commission for Social Care Inspection 2006).

The extent of the problem was set out in two major independent reviews published in 2006: *Securing Good Care for Older People* by the King's Fund (King's Fund 2006) and *Paying for Long Term Care: Moving forward* by Joseph Rowntree Foundation (Joseph Rowntree Foundation 2006). These reports concluded that the current funding system was unsustainable, not least because spending would need to double in real terms over the next 20 years just to keep pace with the growing number of older people and the rising costs of care provision.

In order to ensure this issue was kept alive and that action was taken on the findings of these seminal reports, a coalition

of 15 organisations, led by the King's Fund, Joseph Rowntree Foundation, Help the Aged and Age Concern, set up the Caring Choices initiative. The aim was to raise awareness of future challenges, and to bring together those with most insight and understanding of the current system to generate and test ideas for the way ahead.

Throughout 2007, Caring Choices brought together more than 700 older people, carers, care providers and others involved in the long-term care system to discuss who should pay for long-term care, and how. This paper gives an overview of their discussions and explores the choices ahead in order to inform government thinking on how to reform a funding system that is regarded as unfair and ineffective.

Looking to the future, there are signs that the Caring Choices initiative – and the major reports before it – are having an impact on government thinking. In what could be one of the most important policy shifts in this area for a long time, the government has now accepted that the current system of funding needs reform. In its Pre-Budget Report and Comprehensive Spending Review, published in October 2007, the government committed to producing a Green Paper on options to replace the current system (HM Treasury 2007). Similar commitments have been made by the main opposition parties. And in December 2007, ministers signed a 'concordat' with local government, the sector's professional leadership, providers and the regulator pledging to create 'a high quality, personalised system which offers people the highest standards of professional expertise, care, dignity, maximum control and self determination' (Department of Health 2007).

There is now a real opportunity to create a fairer, more effective system that is built on a consensus and will provide a long-term solution to long-term care. To achieve that however, it is essential that debate on the topic continues and expands. This report makes a key contribution by bringing the voices of those involved in long-term care squarely into the debate. Only by listening to these voices will it be possible to design a new system that works and does what it says on the tin.

THE DEBATE: TESTING IDEAS FOR CHANGE

Caring Choices asked those involved in the long-term care system to tackle three big questions – about who should fund care; how individuals might best plan to pay for their share of care costs; and how best to support informal care (unpaid care by family and friends). It did this by bringing a range of individuals together at seven all-day events across England and Scotland and through discussion on a dedicated website – www.caringchoices.org.uk

Participants included older people, carers, service providers and commissioners, regulators and other statutory bodies, insurers and researchers. Most were drawn from members or contacts of the Caring Choices partner organisations: King's Fund, Joseph Rowntree Foundation, Help the Aged, Age Concern, Alzheimer's Society, Association of British Insurers, Association of Directors of Adult Social Services, Carers UK, Counsel and Care, English Community Care Association, IndependentAge, Local Government Association, NHS Confederation, Royal College of Nursing, Social Care Institute for Excellence, with support from Leeds Older People's Forum, Race Equality Foundation and Newcastle Elder Citizens Forum.

The events included presentations, small facilitated discussions, audience-wide discussions and an expert panel Q&A session. Sessions on the three big questions at the events concluded with electronic voting to try to capture the strength of feeling amongst all the delegates. Event participants and people visiting the website were also invited to complete a questionnaire covering the same subject area as the events but in more detail. These survey results are summarised on pp 30–35. It is important to note that these results cannot be considered as being representative of the population or even of all those involved in the long-term care system.

Six of the events were in England – Manchester, Birmingham, Bristol, Leeds, Taunton and London – and one in Edinburgh, Scotland. The Royal Commission of

1999 led to only modest changes to long-term care funding in most parts of the United Kingdom, although Scotland did introduce new entitlements that help to pay for 'personal' care (for example, washing and dressing) for all those assessed as requiring it. Therefore, the Scottish event had a slightly different format, to try to get a sense of how that reform was working in practice as well as how the system could be improved overall.

STARTING AT THE SAME PLACE

Event participants and web visitors were provided with background materials to try to ensure everyone had a clear understanding of the current system and also of the main findings of the King's Fund and Joseph Rowntree Foundation reviews.

Caring Choices materials explained that under the current system, long-term care is funded in a variety of ways depending in part on need but also on available funding in local authorities. There are broadly three types of care.

- **Informal – or unpaid – care**, where relatives or friends provide help with everyday tasks. Public funding pays for some respite care for carers, and an allowance is paid to full-time carers on low or no earnings. However, support varies from area to area.
- **Home – or domiciliary – care** is provided or, increasingly, commissioned by local authorities or directly by users themselves. Users may have to contribute towards the cost of this service depending on income and savings; the amount of funding available varies considerably from one local authority to another.
- **Care homes (nursing or residential homes)** vary in their funding arrangements. About 60 per cent of those in care homes are eligible for local authority assistance, but must contribute most of their pension and other income towards their fees. Those who have eligible assets of more than £21,500 (the capital limit

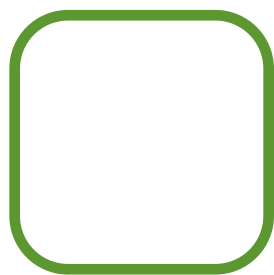
for 2007/8) normally get no local authority funding, although people in nursing homes have a flat rate payment (£101 per week for 2007/8) made by the NHS to contribute towards the nursing costs. Those who are assessed as having very high 'NHS continuing healthcare' needs have all their care home or long-stay hospital fees paid by the NHS, including accommodation costs.

Caring Choices also set out the main findings of the King's Fund and Joseph Rowntree reviews.

Securing Good Care for Older People – the King's Fund review led by Sir Derek Wanless – analysed trends for the next 20 years and considered how social care might be funded and how much it would cost. It concluded that both the structures and the funding levels of today's care system are deficient and will be unable to meet rising costs combined with rising demand in the years ahead. Having looked at various funding possibilities, it proposed a *partnership* model as the preferred option. This would provide the first two-thirds of people's care package free of charge, irrespective of their individual means. Individuals could then use their own money to pay for the remaining third where, for every pound they contributed, the state would match them, pound-for-pound. In this way means testing would effectively be removed from the social care system, although those on lower incomes who could not afford the top-up element themselves would be entitled to apply for a means-tested payment through the benefits system. The extra cost of this model would be between £1.7 billion and £4.2 billion extra per year, depending on whether some of the money presently spent on Attendance Allowance and Disability Living Allowance were redirected to help pay for a better care system. See *Securing Good Care for Older People: Taking a long-term view* (2006) at www.kingsfund.org.uk/publications

The *Joseph Rowntree Foundation's* programme on paying for long-term care brought together expertise in this area to identify three key deficiencies of the

existing care funding system: its inadequacy, unfairness and incoherence. It concluded that in the long term, a new system is needed that provides a much clearer set of entitlements, is seen to be fair and gives all older people greater security that they will not be faced with huge bills for long-term care. It also suggested a range of costed measures that could help the present system work better pending an overhaul, including support for products to help people release equity in their homes, a higher personal allowance for people being supported in care homes and higher capital thresholds for local authority support. See *Paying for Long-term Care: Moving forward* (2006) at www.jrf.org.uk



Five important areas of agreement

Throughout the Caring Choices initiative, most participants agreed that the present system is not working, that more money is needed and that there should be a clear entitlement to some level of state-supported care regardless of income or wealth. Just over three-quarters also agreed that individuals should make a contribution to the cost of their own care, rather than expecting the state to pay for everything. Finally, there was a resounding message that unpaid carers have been neglected, and that stronger support for them was needed.

The present system of funding long-term care is not fit for purpose

All types of participant – older people, carers, professionals – in the Caring Choices events said that they found the system irrational, confusing and unjust.

Some of this feeling comes from inconsistencies in the way that people become eligible for different services. The rules set at national level produce various anomalies, with people who have similar levels of disability receiving widely varying entitlements, ranging from fully funded care and accommodation for those who are assessed as meeting NHS continuing care criteria through to nothing for those with assets of more than £21,500 who do not meet the NHS criteria. There was also resentment of large differences in the way in which different local authorities manage long-term care, with significant variations in eligibility criteria and in the level of charges – the ‘postcode lottery’. However, many participants at Caring Choices events accepted the case for some local variability in a service led by local government.

The way that means-testing works within the current system was also seen to be unjust. Many participants expressed

outrage that people of modest means who have worked to build up savings or a pension can be impoverished by a prolonged period of disability or dementia. The fact that some people need to sell their home to pay for care home fees was widely resented. Frustration over means-testing is exacerbated by confusion over how it works, due to complexity in the rules and the interaction between the social care, health care and benefits systems.

‘ These people are not the private equity/hedge fund super rich whose presence in London is eagerly welcomed by politicians, but elderly people of very modest means. ’

Contributor to Caring Choices website

More money will be required to meet growing need

It is hard to calculate the total expenditure on social care as there are many sources of funding. But Department of Health figures for 2004/5, provided in *Securing Good Care for Older People*, puts the gross expenditure at around £8 billion.

Only five out of 728 people who completed the Caring Choices survey thought that future care needs could be met on existing levels of resources. The great majority believed that demographic change would necessitate more spending, whether public or private.

The evidence supports that view. Extra demand will come from a combination of the need to improve quality of care, its growing cost and the growing numbers of people who will require care in the future. Between 2002 and 2026, the projected growth in the population of older people, and a lengthening of the period of old age during which long-term care is required, is likely to increase the number of people requiring care by more than 50 per cent. Rising unit costs and limits to the supply of unpaid care will cause the total cost of care to double in real terms, even without significant improvements in quality.

Under the present funding system, a rising proportion of these increased care costs would have to be paid for privately.

Participants in the Caring Choices initiative nearly all believed that the state should continue to have a major role in helping people to afford this growing lifetime expense: only 4 per cent of respondents to the survey said that paying for care is mainly the responsibility of the individual and their family.

There should be a universal element of long-term care funding

The universal element of long-term care funding refers to an amount of care or payment that is provided to all with assessed care needs, without any form of means test.

In the past, research has suggested that most people believe that long-term care should be provided by the state, mainly free of charge at the point of delivery, like health care (Deeming and Keen 2003). In contrast, only a minority of Caring Choices participants said that personal care should be completely free. Yet there was a strong view among participants that there should be some entitlement to state funding to limit the cost for *all* individuals (regardless of income or assets) at point of use. This would reduce the risk of a large, unpredictable financial burden falling on those unlucky enough to require large amounts of long-term care.

Almost three-quarters of all Caring Choices participants said that the state should contribute to the cost of personal care for everyone, no matter how rich or poor. And at each of the Caring Choices events, when voting after a discussion, at least 90 per cent of the participants voted for a system in which everyone gets some contribution from the state.

There are many ways of providing a universal contribution towards the cost of care. At present, Attendance Allowance (or Disability Living Allowance) gives something to every older person with a certain level of disability. However, these payments are separate from the social care system and it is not clear how the money is used. Caring Choices debates suggested that the idea of a clearly specified entitlement to at least part of the cost of care is attractive, and may be one reason why 'free personal care', a form of which has been operating in Scotland since 2002, has had many supporters.

However, a policy like Scotland's that provides some care services without charging remains a long way from one that defines what individuals are entitled to. With local authorities continuing to set eligibility criteria that determine which care needs qualify for help, there are always likely to be differences in the amount of support individuals with similar levels of need actually receive. Participants at the Caring Choices event in Edinburgh complained that the 'postcode lottery' remains alive and well north of the border, in the form of variations in how serious a condition has to be to qualify for free care, as well as in the amount of care provided.

The knowledge that users of local authority personal care services living in their own homes will not be charged is nevertheless an important form of entitlement that has been welcomed in Scotland. Edinburgh event participants were broadly very positive. Yet it remains a 'soft' entitlement, different from systems in other countries where a given condition, assessed nationally, entitles someone to a stated level of care or cash equivalent regardless of where they live and of the unpaid support available. Many participants in Caring Choices called for as clear as possible a definition of what level of support people should expect for a given level of disability, although views were mixed about whether it would be worth giving up the local role in this matter entirely.

Funding of long-term care should be shared between the state and individuals

Only 20 per cent of all Caring Choices participants thought that personal care should be fully funded by the state. At the events, regardless of age and whether or not they were directly involved in caring, most people supported the idea of sharing the costs between the state and individuals or families. The proportions varied considerably around the country, with 29 per cent of people surveyed in Manchester but only 6 per cent in Taunton favouring free personal care; this variation may have reflected the way in which the debates unfolded, and the composition of the audience. Nonetheless, those favouring free care were in a minority on each occasion and amongst all groups.

Some participants made it clear that their acceptance of cost-sharing was a pragmatic response to the understanding that the government will not pay for everything. Some argued that this was a reasonable thing to ask of those who can afford it. Others based their argument on the extra sense of control and ownership for an individual who is helping to pay for a service that they use. Many nevertheless cautioned that those who cannot afford to contribute should remain protected.

‘It means you are buying a service and can act as a consumer rather than as a passive recipient of a state service.’

Caring Choices participant, Birmingham

‘Many older people would be happy to pay a contribution, so that they feel that they are not a burden.’

Caring Choices participant, Leeds

There was also, more specifically, support for a ‘co-payment’ principle in the funding of personal care, in preference to a system of free personal care. After hearing presentations that set out the findings of the King’s Fund and Joseph Rowntree Foundation studies and discussing the merits of co-payments, free personal care or mainly means-tested provision, participants in each of the six events in England were asked to vote for one of these three options. They voted for co-payments in preference to free care, by majorities of between just under two to one in Manchester to over four to one in Taunton. It was noticeable that co-payments enjoyed greatest support in Taunton, where the greatest number of participants were homeowners (over 90 per cent). This perhaps reflects the fact that people with assets are prepared to accept that they should pay something. It may also reflect concerns about the alternatives – free personal care would be funded through taxes and therefore would be something that they would have to pay into, but at the same time a means-tested system could lead to people with assets receiving nothing and therefore facing very high private care bills.

‘We all have a responsibility to contribute to the costs of our care.’

Care manager, Caring Choices website

This general support for co-payments was qualified in discussion by the importance attached to ensuring that extra help is given to people unable to afford the private contribution. This is consistent with the government’s desire to target some resources on the most needy while offering something to everyone (‘progressive universalism’).

It is important to note that participants did not feel that we have a fair form of cost-sharing at present. Even though about half of total care costs are paid by the state and half by users, this is an average and is not reflected in the amount each individual has to pay: some pay most or all of their care costs and others little or nothing.

It was also clear that participants do not recognise existing divisions of cost between an individual and the state as a form of co-payment. For example, Attendance Allowance may help to pay for some forms of care, but as its purpose is to cover the cost of disability more generally, it is not seen as a co-payment for long-term care. The means test itself is another invisible type of co-payment; those in care homes who qualify for local authority assistance contribute most of their pension and other income towards their fees with the local authority paying the remainder. Caring Choices participants indicated that for a co-payment system to have public acceptance, there must be clearer sharing of costs on a visibly fair basis.

Better support for unpaid carers is crucial

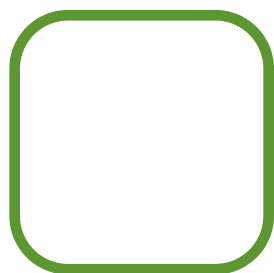
In recent years, debates about paying for care have been focused mainly on finding the resources to meet the considerable cost of professionally provided care packages and care home fees. The government and a number of analysts have acknowledged the important contribution made by unpaid carers, but have not focused on funding requirements in this area, perhaps because by its very nature ‘unpaid’ care

does not appear to be an issue about money. Yet there has been a growing realisation that carers do have needs, and that meeting them does have significant costs. At all the Caring Choices events, there were very strong calls for urgent change in relation to attitudes to and support for carers.

Participants saw this issue as both moral and pragmatic. Carers who are unsupported may face deterioration in their quality of life, their finances and even their health. There was also concern that the future supply of unpaid care, by far the greatest caring resource that we have, cannot be taken for granted. In fact, 43 per cent of all Caring Choices participants predicted that unpaid care would decline in the next 10 years, compared to 24 per cent who thought it would rise. This is even though nearly half thought that care provided in this way is generally better than paid-for services, compared to under a quarter who thought it is generally worse. To help to maintain the supply of the kind of care that people most want, it was therefore seen as crucial to provide better support for unpaid carers. The types of support that people wanted are discussed on pages 26–7.

‘We rely on carers, but we do not protect them from the desperate situations that you describe.’

Panellist, Leeds



Debates about the design of a new system

The above five points of emerging consensus from the Caring Choices initiative suggest a strong basis for designing a new system. However, the details of such a system will be much harder to determine. There are many trade-offs and tough decisions ahead, and many different perspectives on the best way to tackle them.

A Wanless-type system of co-payment (*see p 9*) was well received in general terms, but there was no particular attachment to that specific model

The idea of a public/private 'partnership' that shares the cost of providing an agreed 'benchmark' package of care commanded considerable support throughout these events. In the final event in London, politicians and others suggested that the partnership idea has a 'head of steam'. However, Caring Choices delegates did not generally comment on the exact form of co-payment advocated by Wanless (where the state meets two-thirds of a person's assessed needs and matches additional contributions by those who choose to make them). In general, delegates were interested in how much of any individual's package the state would cover, the types of services or financial support that would be included in such a package, and how eligibility would be determined, rather than in the precise detail of a co-payment formula.

There was a desire for a clear baseline entitlement, using nationally agreed eligibility criteria

As already discussed, most Caring Choices participants thought that everyone needing personal care should receive at least something from the state to help pay for it; it was trickier to agree what level that entitlement should be. For example,

views on what proportion should be paid for by the state and what by the individual varied widely. Among those who thought that individuals should get non-means-tested care packages, roughly equal numbers thought that 70 per cent, 80 per cent, 90 per cent and 100 per cent should be paid by the state.

Yet discussions suggested that such abstract figures did not mean very much to people. What they really wanted to know was what needs would be covered and what factors would determine eligibility. In particular, there was support for the idea that if people knew what would be used to define a baseline of financial provision by the state, they would be able to plan how to cover the rest, particularly if they could be assured that there was a limit to their own liability. Indeed, many welcomed the idea that individuals could make their own decisions over how much quality they buy, as long as they knew that there was a basic provision of adequate care.

As discussed elsewhere in this report, a definitive entitlement is an elusive concept unless we are willing to have a nationally assessed and nationally funded system, where eligibility depends only on a formula linking need to funding, rather than on local budgetary considerations and judgments. Even without a radical shift to such a system, the Caring Choices discussions suggest anything that improved certainties and consistencies is likely to be popular. Scotland has made an effort to give a sense of entitlement by defining (as 'personal care') a category of need that will be supported. In practice, however, this has worked imperfectly, and it may be helpful to impose national eligibility requirements on local authorities to reduce the local variability.

Arbitrary divisions between different kinds of care can be unhelpful, and the focus on 'personal care' can lead to neglect of other areas

Long-term care refers to care given to someone on a continuous basis due to a physical or mental condition. Some of this comes under *health care*, including *nursing care*. *Social care* helps people with everyday living, in ways other than through nursing care. This includes *personal care*: help for individuals to carry

out essential daily activities, involving physical contact (such as eating and washing), but arguably also including basic aspects of living such as cooking. Other forms of social care include: *domestic help*, such as with shopping and cleaning, which has been supported to varying degrees by local authorities; and *practical assistance* with a wider range of activities, including social activities and gardening.

Labels attached to different kinds of care by the system were felt by many participants to be artificial, drawing unnecessary distinctions between people who share a common need to be cared for but who each have their own individual combination of care requirements. For example, there is a very blurred boundary between social care (especially for very frail people or those with severe dementia) and nursing care. Many participants mentioned the difficulties in reconciling social care with health care systems, although there were no suggestions about how best this could be done.

‘There is no way of distinguishing between personal care and health care: this holy grail of the allegedly caring agencies merely demonstrates the futility of our current organisational divides.’

Contributor to Caring Choices website

In 1999, the Royal Commission on Long Term Care proposed that the best way of sharing the cost of social care between state and individual would be to make personal care free, but to require individuals who could afford it to pay other costs themselves, notably ‘hotel costs’ in care homes. This recommendation, and a form of its implementation in Scotland, has made the issue of ‘who should pay for *personal* care?’ central to debates ever since.

Caring Choices debates were also structured in a way that highlighted the issue of paying for personal care. Yet many participants suggested that the emphasis on personal care risked neglecting a wider set of care needs, including help with domestic tasks, social activities and practical forms of assistance. A recurring theme throughout the series was that these needs can be seen as equally important as personal care (certainly in the eyes of many older people and their carers),

and that we should not have to wait until someone needs help with basic personal functions before they are given support. This discussion was closely linked to that of eligibility restrictions imposed by cash-strapped councils: raising the threshold of support has meant that far less social/leisure-related and practical domestic help has been available.

In this context, Caring Choices saw some lively debates about the value of investment in 'prevention'. It was pointed out that it is hard, if not impossible, to prove a net cost saving from early intervention. For example, while preventing an older person from having a fall may avoid a severe deterioration for that person, it is extremely hard to predict who will have a fall, so such a gain could only be realised by helping a relatively large number of people, making the quantifiable 'return' on such investment small or non-existent. However, the prevailing feeling was that this should not be an argument against providing this type of help. In particular, many participants pointed to the positive contribution of these services to individuals' quality of life and well-being.

If the eligibility criteria are widened to include low-level (preventive) care, this has clear resource implications, requiring either more public money, a higher rate of individual co-payment, or less generous personal care packages. Caring Choices participants were not clear-cut about which of these options they favoured, but many argued that state help should not focus exclusively on meeting personal care needs.

‘I would like to challenge the assumption that personal care is more valuable than meeting other needs.’

Caring Choices participant, London

There was widespread support for offering people choice over the type of care they receive, but caution about requiring them to become informed consumers

The idea of choice was broadly welcomed in Caring Choices debates. Most participants agreed that users should be able to decide what kind of care is right for them, and offering direct

payments to allow them to buy the services they needed was a popular idea. However, some participants were concerned about the extent to which people requiring care would be able to shoulder the responsibility of choice. They believed that many older people would not want to have to shop around for the best provider, for example. But this caveat did not diminish the importance attached to giving users flexibility over the type of service that best meets their needs; this was seen to be particularly important for black and minority ethnic elders in particular, who may find that the range of services on offer are not those that they want. Some also argued that older people would like to be able to choose an 'extra bit of help' before they became very frail rather than extra assistance when they require personal care. In practice it is hard to build this kind of choice into a funding system, but as discussed in the previous section, the structure of entitlements (and decisions about trade-offs) could take these views into account. There was some discussion of and support for individual budgets which could provide real choice but with the option that responsibility for administering the process could be shared or even taken on by the local authority.

‘You need to advertise services through word of mouth and where BME elders go such as faith centres.’

Caring choices participant, Leeds

Disability benefits need to be considered as part of the equation, but there was no consensus on whether or how to restructure these entitlements

Many older people receive extra benefits intended to help cover some of the extra costs of having a disability (Disability Living Allowance for those aged under 65 and Attendance Allowance for those over 65). These payments cannot be left out of the care funding equation. One reason is that they represent a lot of public money – more than £3 billion in England is spent on Attendance Allowance alone (around half as much as is spent on social care for older people by councils). Second, it is difficult to have a debate about paying for care in the widest sense, including services that assist

people with a range of practical tasks that they are unable to perform themselves, without acknowledging the role of such benefits.

Debate about whether to merge or combine in some way funding for care and disability benefits caused deep controversy. This question was not the focus of Caring Choices, but when it arose, it provoked opposing perspectives. Some participants vigorously defended Attendance Allowance as a payment that works, giving maximum flexibility to individuals about how to meet their needs. Others felt it was too large an amount of money to be given out without greater accountability about how it was being spent. This is a tricky political issue, but a clear-cut decision is needed about whether to continue to run two parallel systems of funding. Even if the answer is 'yes', there is a case for being clearer about the purposes of Attendance Allowance and about how it relates to the resources made available more directly to fund care.

‘Don’t take away the Attendance Allowance and Disability Living Allowance national benefits entitlement. It is a life saver.’

Caring Choices participant, Taunton

‘Attendance Allowance is ripe for reform.’

Caring Choices participant, London

Most favoured state support for schemes to encourage and enable private contributions to care, but no one mechanism provides a ‘magic solution’

In most funding options, individuals are likely to pay some form of private contribution, and this raised the question of where a private contribution should come from. For a variety of reasons, mechanisms to help unlock private funding for care, notably long-term care insurance and equity release products, have not been widely taken up to date. Participants were asked whether it would be sensible for the government to offer financial support for such products.

Looking at each of the three specific options discussed at Caring Choices events, views were mixed.

(i) **Public support for private long-term care insurance products.** *Private products have not generally been offered on attractive terms, but this could change if a partnership with the state reduced the long-term risks for insurers, for example, by picking up the cost after the first few years for the longest-term claimants.* Just over half of people at the Caring Choices events thought that state backing for a private care insurance product might be appropriate. However, discussions revealed a large degree of mistrust in financial products of this kind and concerns about whether entitlements could be sufficiently tightly defined. Some also asked why the state should support a private scheme rather than just arranging 'social insurance' (a compulsory public scheme like that in Germany) directly.

(ii) **Public support for some form of equity release to contribute to care costs of people living in their own home.** *Possibilities suggested by the Joseph Rowntree Foundation include a publicly underwritten scheme with low interest rates along the lines of student loans, and an exemption from mean-testing under Pension Credit of up to £3,000 a year raised through equity release.* Just over half of participants liked the idea of some public support for equity release products used to pay for care. However, very few participants had experience of such products, and some had reservations about whether many people would be willing to enter into such arrangements. Here there was also a concern about the possible inequity of a system that offers extra support to those who own an asset but not to those who do not.

‘An extra £3,000 a year would go a very long way.’

Caring Choices participant, Leeds

‘If you’ve got a limited pot of government resources, do you want to steer money to homeowners?’

Caring choices participant, London

(iii) **A continuing care community** can offer the security of buying a property in a scheme providing lifetime care at a fixed cost, and public subsidy could help to make such a scheme more affordable to users. Participants reacted most favourably to this idea, liking the way that it spreads risk and therefore offers security and predictability that care needs will be properly met and at a pre-set price. They also welcomed the way that it addressed future housing and care needs simultaneously: one participant suggested a 'lifetime housing strategy' to enable people to live independently for as long as possible. Others voiced concerns about the effects of older people not living with people of other ages and cultures in the wider community. Government support to keep the entry price down was voted for by larger majorities than the other two private options, but again people raised questions about whether this would favour an already relatively privileged minority who could afford such products.

‘As a single person I didn’t want to be a burden on friends and neighbours as I got older so I moved to a housing with care scheme.’

Caring Choices participant, London

Overall, the discussion on supporting private options revealed:

- that most people had limited understanding of these options, indicating a need for a clearer presentation of what is, and could be, on offer;
- that making available a range of private choices felt more appropriate than supporting only a single mechanism, which would appeal only to certain users;
- that despite reservations about support for 'middle class options', most people accepted that there is a case for public subsidy to create stable and reliable mechanisms of this type, especially in the context of a care funding system that offers limited public support to the middle classes. At the last two events, in Taunton and London, participants were given the option of saying that scarce public resources should *not* be spent on such schemes, but only 16 per cent and 10 per cent respectively voted this way.

‘Whatever it is must be copper bottomed.’

Caring Choices participant, Bristol (supporting state guarantees for financial products)

Support for unpaid carers could take many forms, but a few key areas are particularly in need of improvement

There was a strong feeling that extra support for carers should be a priority, but this did not readily translate into a new set of proposals. Many participants emphasised that society needs to recognise and support carers in ways that are as much about our culture as about funding. There were a large number of suggestions about initiatives that could make a difference rather than a single main demand. Yet three areas in particular were mentioned repeatedly in Caring Choices as places where extra funding could make an important difference.

The most important of these was respite care services. Carers often feel they are left ‘high and dry’ by a lack of consistently available, high-quality services of this type. They emphasised the need for services whose availability is dictated by the needs of the carer and the older person, not by the convenience of the service. Many participants commented that supporting carers is not just about money but about local authorities’ attitudes and how well they listen to users’ and carers’ views.

‘I want money to pay someone I trust to look after my relative while I have a break.’

Caring Choices participant, Birmingham

Second, while unpaid carers are by definition not ‘in it for the money’, a more generous, widely available and less tightly means-tested carers’ allowance would make a big difference, many participants said. The present version was thought to be insulting in its level and inadequately promoted. Participants emphasised that caring can have huge financial implications,

whether by reducing employment income or creating extra spending needs, and a decent caring allowance would help some people in desperate straits. Most importantly, it would send a clear message that society valued the huge contribution that carers are making. It was also argued that this should extend to carers beyond pension age, presently not covered by the allowance, to recognise that pensioners who are carers are performing a valued task.

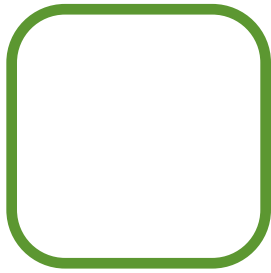
‘Carers feel anger about the poverty they are forced to endure because of their caring.’

Caring Choices participant, London

A third form of assistance, 24-hour help and advice in an emergency, was repeatedly mentioned as crucial. Here again, carers felt the need not to be left ‘high and dry’. This is a service that could make a big difference at relatively modest cost.

‘[Carers need] a menu of services that are available when you need them. Often these are not even brought together within the providers themselves.’

Caring Choices participant, Manchester



Conclusions

Caring Choices brought together older people, carers, service providers and others involved in the long-term care system to engage in an informed, intelligent debate about the best way of paying for care in the future. They responded by giving some clear pointers about the characteristics of a new funding system that are needed for it to work properly and to win wider public support.

Caring Choices participants wanted a system that is adequately funded to meet the care needs of the future, which will be greater than they are today. The majority wanted a contribution to at least some of the care costs of everyone who needs care, rather than the state concentrating its resources mainly on those who are worst off financially.

However, a crucial message was that most people accept that it is reasonable for users to make some contribution to the cost of care, preferably on a clear-cut co-payment formula, rather than rely only on the state. Within such a system, they want clarity and predictability about the support they could expect – ideally as a defined entitlement.

There were many calls for funding to help support people with lower levels of need – often described as preventive care – rather than just helping those who require substantial amounts of personal care. Crucially, many thought that these low-level services promoted quality of life and well-being. And participants indicated a desire for a system that allows them to choose what kind of care most meets their needs, and that promotes dignity and independence.

Finally, participants believe individuals want to feel supported, whether as recipients of care or as carers, rather than having to fight to get adequate services. They feel that the present system is particularly neglectful of the kinds of support needed by unpaid carers.

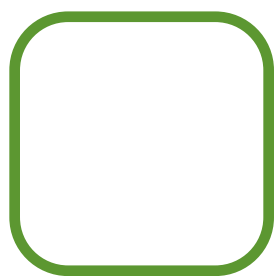
Meeting all these principles simultaneously will be far from straightforward: the discussions confirmed the judgement of care minister Ivan Lewis at the final event, that 'there are no easy answers'. Some of the potential details of reform do not yet command a consensus. The important thing in these cases will be to face up to some key trade-offs and to produce as clear as possible a system for the future, rather than a fudge between competing views. For example, what types of care are normally eligible for public support, and to what level? Should Attendance Allowance/Disability Living Allowance be brought into the care system, or should we retain parallel systems for care costs and wider costs of disability?

A crucial requirement in creating greater clarity will be to enable people to look ahead and plan for their possible care needs. At the final Caring Choices event, politicians agreed in principle on the importance of a cross-party consensus that will hold, just as for pensions. The public will want to see such agreement translated into real collaboration, and will be unforgiving if politicians revert to party positions.

Thus, while there are many ways to design a new funding system for long-term care, acceptance of a new settlement depends most of all on creating a fair and visible method of sharing the costs between state and individual, being clear-cut in what it promises and funding it adequately to meet these commitments. In short, tomorrow's older people will be willing to contribute to an equitable system for funding care, as long as it 'does what it says on the tin'.

‘People need a level playing field and a basis for rational decision at a time when they decide to save.’

Panellist, Taunton



Caring Choices questionnaire: summary of results

Who participated?

- 728 people in total filled in the survey
- 413 of these were participants at the six English Caring Choices events
- 273 were visitors to the Caring Choices website
- 42 were others approached to fill in the survey, mainly older people, including care home residents.

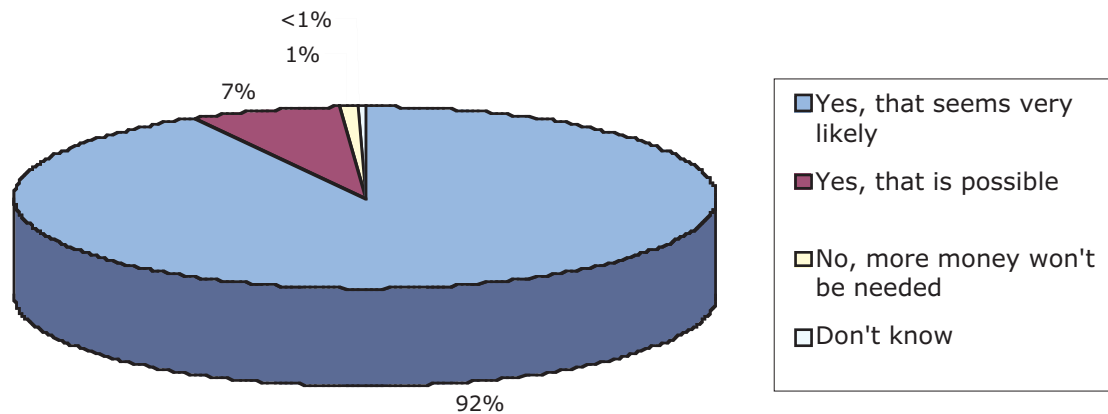
This was not a representative sample of the population, but brought together a wide range of people with an interest and involvement in care services. Thus, while the conclusions reported here should not be represented as public opinion, they give a useful picture of how different types of care funding might be received by those most closely involved in providing and receiving social care.

Of these 728 respondents:

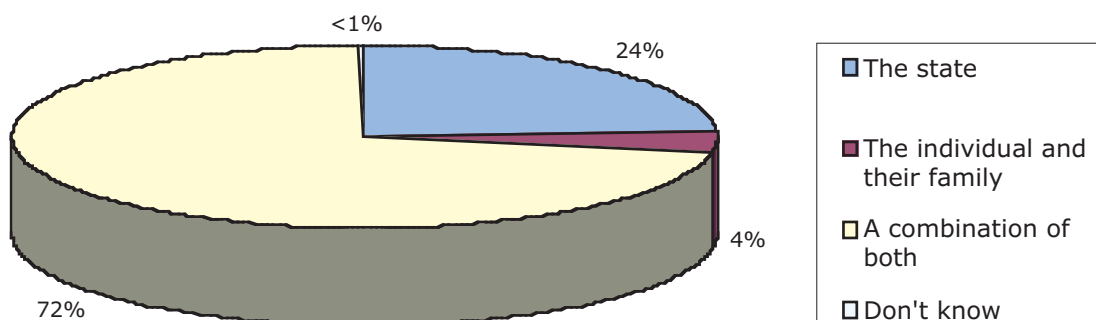
- 65 per cent were over 50, and 22 per cent were over 65
- 45 per cent were involved in providing unpaid care and 13 per cent were professional carers. Most of the rest were involved in commissioning, provision, regulation or research.
- 41 per cent had gross incomes below £20,000 a year
- 92 per cent of those who answered a question on ethnicity described themselves as white, about the same as in the population as a whole
- 69 per cent were women.

Some key results

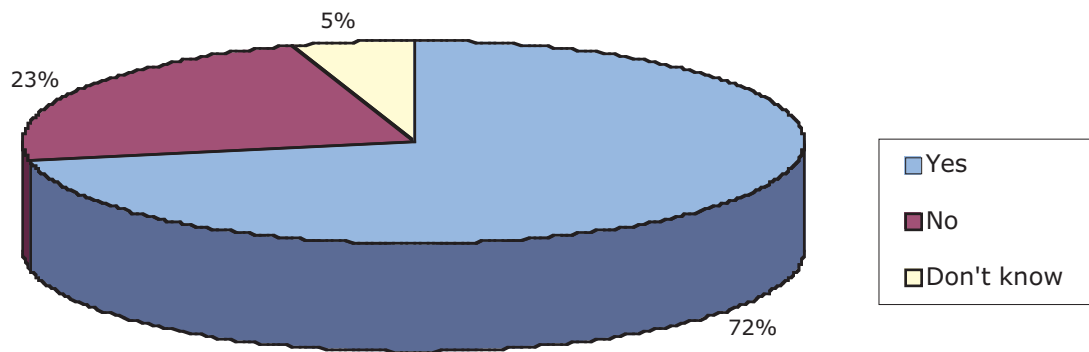
Do you agree that more money, whether public or private, will be needed to provide an acceptable level of care for older people in future?



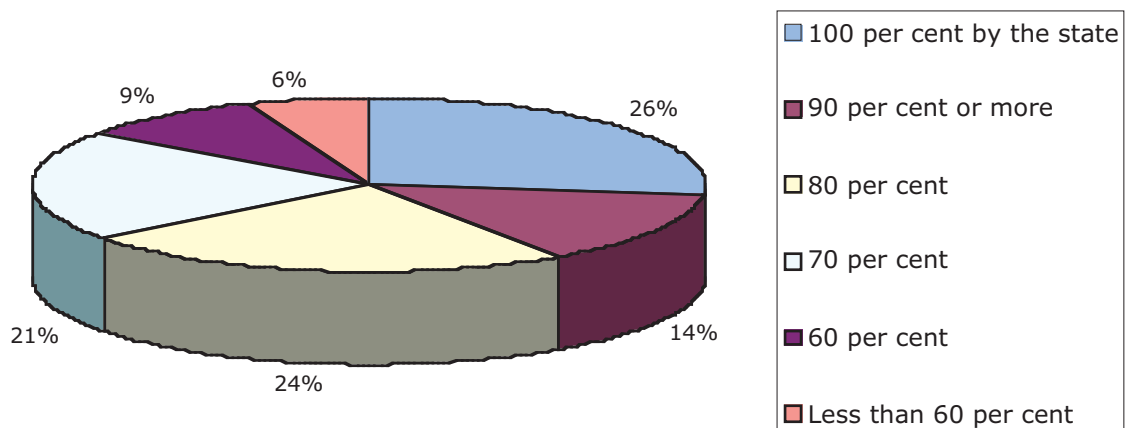
Do you think that providing care for an older person is mainly the financial responsibility of the state or the individual and their family?



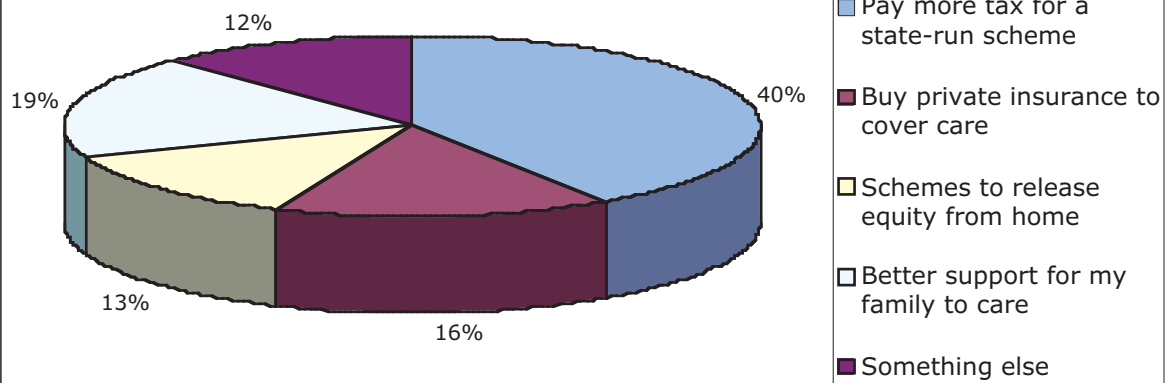
Should the state pay towards a package of personal care for every older person who needs it, regardless of how rich or poor they are?



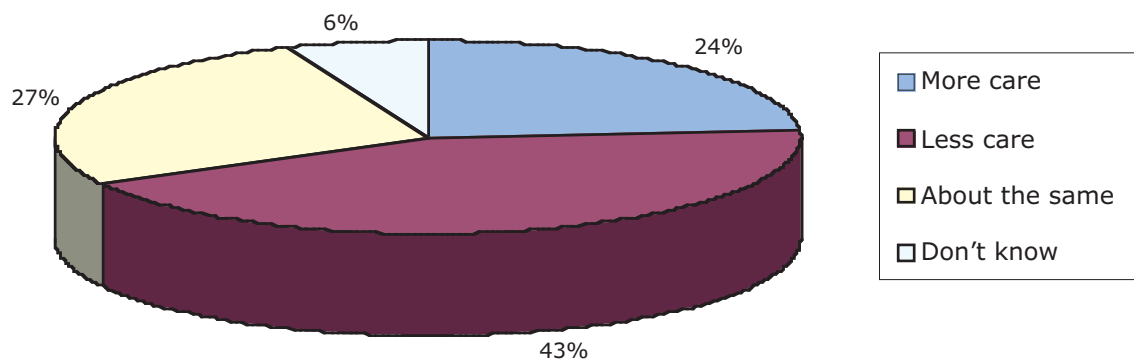
For those who said yes or don't know to the above question: What proportion of an individual's care package would you want funded by the state?



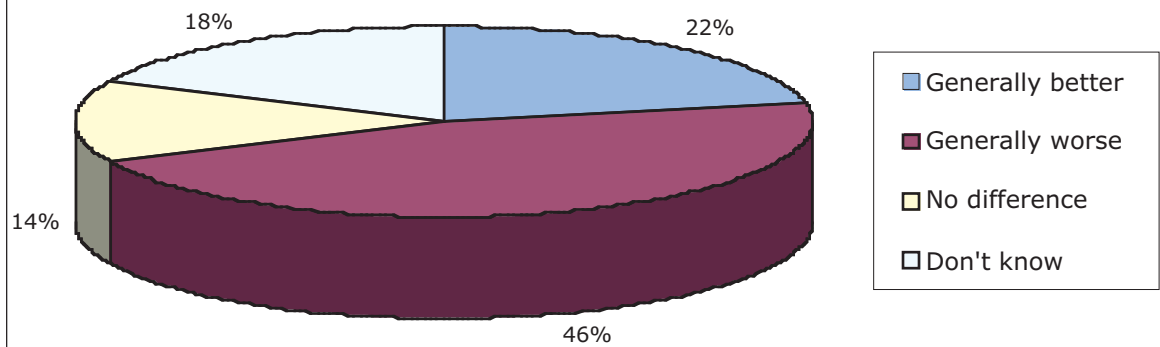
How would you prefer to provide for care you might need in older age?

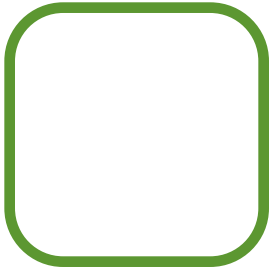


Do you think that in 10 years time families and friends will provide more or less care for older people?



How do you think that care which is paid for, compares with care provided by family or friends, for the person being cared for?





References

Commission for Social Care Inspection (2006). *The State of Social Care in England 2005–06*. London: CSCI. Available at: www.csci.org.uk/pdf/state_of_social_care_05-06_1.pdf (accessed on 6 December 2007).

Deeming C, Keen J (2003). 'A fair deal for care in older age? Public attitudes towards the funding of long-term care'. *Policy & Politics*, vol 31, no 4.

Department of Health (2007). *Putting People First: A shared vision and commitment to the transformation of adult social care*. London: Department of Health. Available at: www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationPolicyAndGuidance/DH_081118 (accessed on 2 January 2008).

HM Treasury (2007). *Meeting the Aspirations of the British People: 2007 Pre-budget report and comprehensive spending review*. Cm 7227. London: The Stationery Office. Available at: www.hm-treasury.gov.uk/media/7/4/pbr_csr07_completereport_1546.pdf (accessed on 6 December 2007).

Joseph Rowntree Foundation (2006). *Paying for Long Term Care: Moving forward*. York: Joseph Rowntree Foundation. Available at: www.jrf.org.uk/knowledge/findings/foundations/0186.asp (accessed on 6 December 2007).

Wanless D (2006). *Securing Good Care for Older People: Taking a long-term view*. London: King's Fund. Available at: www.kingsfund.org.uk/publications/kings_fund_publications/securing_good.html (accessed on 6 December 2007).



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CARING CHOICES

Who will pay for long-term care?



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This report aims to be an objective summary of the views expressed at the Caring Choices events and through the questionnaire and website. It does not claim to represent the views or policy positions of any of the individual partners.