

Consultation Response: voices of older people

The Care Act: consultation on draft regulations and guidance to implement the cap on care costs and policy proposals for a new appeals system for care and support

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1. Introduction

This report summarises the responses received from older people who took part in consultation events around the country between January and February 2015 to discuss the Government's proposals for a cap on an individual's costs for social care. Nine consultation events in total were held from different parts of the country. The local Age UKs that held them were: Age UK Coventry, Age UK Cheshire East, Age UK Herefordshire and Worcestershire, Age UK Lancashire, Age UK Norfolk, Age UK Shropshire, Telford and Wrekin, Age UK Sunderland, Age UK Redbridge and Age UK Rotherham.

A total of about 220 older people took part.

2. Overview

- Most older people who took part agreed that the idea of a care cap was a good one
- However, nearly all the participants felt the level of the cap was too high and therefore would not benefit them personally.
- All groups of older people who were consulted agreed that the eligibility criteria for care and support should be lowered
- The general view was that there was a lack of transparency in the proposals and that they should be simplified, particularly so as to reflect the needs of more vulnerable groups.
- Participants felt a great deal of work needed to be done on producing and delivering information and advice to support people to understand the changes and to access services.
- Serious concerns were voiced about the current state of social care: insufficient funding, the poor quality of services and the lack of focus in the system on prevention. There was disappointment that these issues were not addressed in the proposals.
- Considerable confusion and anxiety were expressed by participants in relation to the future and paying for care for them and/or their relatives. It is clear that many older people still don't know that they will have to pay for care at all, believing it to be free at the point of delivery, like the NHS. Many were shocked to learn this was not the case

The view was expressed by some that the Government had been less than fully up front about the proposals, leaving unchallenged the implication that they would protect people more than they actually will. The responses presented here provide important comments for the Government to consider whilst shaping the final proposals. They reflect repeated calls heard by Age UK during the nine events for the Government to acknowledge the insufficiency of care funding and the need for awareness campaigns so people know what the new care cap will deliver and what it will not.

3. Benefits of the proposals

A number of those who participated in the consultation events supported the cap on care costs in principle, agreeing that the general concept was positive.

People at Age UK Herefordshire and Worcestershire's event suggested that the proposals created more transparency in the system, encouraging people to think more about their care and therefore potentially improve their ability to plan. The fact that the cap would be a set amount and universal was seen as positive in light of this by participants at Age UK

Redbridge's event. People at Age UK Rotherham's consultation also felt that the proposed system would make residential care costs more transparent.

People at all consultation events also liked the fact that the change to capital limits would offer some more protection than is provided under the current system. Participants at Age UK Redbridge's event appreciated that this might deliver more peace of mind, while a group at Age UK Norfolk's consultation said they felt it gave a greater sense of financial security. It was also felt that it would ensure not everything they had worked for throughout their lives would be at risk; the desire to leave something for families after death was raised in regard to this.

A number of participants who took part in the consultations agreed the principle of the cap would be beneficial only if it were accompanied by changes to eligibility criteria so that the system provided more support to greater numbers. It was agreed within this that the current proposals meant some groups were likely to gain more from the changes than others, including people who need high levels of support, who many groups thought would be better off under the proposals. One group at Age UK Sunderland's event felt that the cap would help the very rich and the very poor but not those in the middle – the majority. People at Age UK Coventry's event discussed social justice in relation to this issue and one group thought the cap and wider changes to funding rules was a positive development, highlighting that £17,000 (the base capital limit) is a lot of money for many people. The higher threshold for savings was also liked by some. Other groups appreciated that the cap was an attempt to build a fairer system.

The fact that more people would need to go for assessments was also identified as a good opportunity to reach more people with information and advice at Age UK Herefordshire and Worcestershire's event, especially those who may not currently be engaged with the system. In a similar vein, participants at Age UK Shropshire, Telford and Wrekin's event welcomed the proposals for provoking more discussion on an important topic and for raising awareness of care costs.

In supporting the principle of enshrining a cap on care costs, people at Age UK Herefordshire and Worcestershire's event pointed out the flexibility of the cap, while participants at Age UK Norfolk's event stated that it could be lowered as the economy improves and that, on this basis, it is worth accepting at any level. This linked to a number of others' comments that the principle of the cap is a good one if it can work in practice and that it would probably need to be built upon to adapt to changing costs in the future. Some felt that, in this respect, it was good in theory.

There were some groups who participated in the consultation at Age UK Shropshire, Telford and Wrekin who felt there was nothing positive about the proposed changes, however. This was echoed by older people at Age UK Lancashire's event, who were perhaps generally on lower incomes, who identified very little they could see as an advantage to them personally. This meant that, even where it was acknowledged that the cap would benefit some people, overall, there was no group consensus in support of the proposals. Others felt it simply would not work.

4. Key issues raised

Level of the cap, daily living costs and top-up payments

Nearly all those who participated in the consultation events thought that setting the cap at £72,000 was too high. People particularly did not like the fact that the proposed cap is so

much higher than Dilnot's suggested lower limit of £35,000, which many thought seemed a reasonable amount, providing security which they believed the current proposals would not. People at Age UK Herefordshire and Worcestershire's event were sceptical as to why the Government had decided to make the cap so much higher. Generally the group felt that it seemed to be for political reasons. This was echoed at Age UK Norfolk's event, where one man said, "What seemed like a really good idea at the time (i.e. the Dilnot proposals) is now looking less good." Some people thought the cap was just 'good politics', when, in fact, not much is changing.

Many taking part in the consultation events thought the majority of people would not benefit from a cap at the level proposed and that it would make no difference to them personally. Others argued that some would actually be left worse off. Some participants agreed that the system would still be unfair, punishing people who had "done the right thing all of their lives", as a man at the Age UK Lancashire's event put it, such as saving and buying a house. One participant at Age UK Coventry's event said, "Everything I've worked for has gone down the drain", while another at Age UK Lancashire's event said, "It doesn't pay to save". At Age UK Redbridge's event everyone was hugely concerned about this and many felt they were still liable to lose almost everything. One man at Age UK Coventry's event said, "I should spend whatever money I've got while I'm well!"

Other people at Age UK Coventry's event said they thought that the proposals "are about punishing the majority of people for the sake of a few rich people." Some participants argued that the proposals will mean those who are less well-off will lose more proportionally than those who are wealthy who would receive greater protection, stating that the proposals provide "no answers for ordinary people". They feared that the proposals risked creating a two-tier system of 'haves' and 'have-nots'. People at Age UK Norfolk's event agreed saying it meant a net transferral of funding from poor to rich.

One group consulted at Age UK Shropshire, Telford and Wrekin's event were angry that the original cap announcement was misleading. They said it had seemed like once you paid £72,000 in total you got help, which they had subsequently learnt was not, in fact, the case. They wanted the Government to be upfront about what is involved in the proposals.

People at Age UK Shropshire, Telford and Wrekin's event also felt that the cap needs to be a lot simpler, arguing that it should not differentiate between care and living costs. Others thought that the Government should pay the commercial rate for care costs, ensuring parity between self-funders and council-funded individuals. People at Age UK Herefordshire and Worcestershire's event agreed, saying council rates should reflect the realities of the costs of care. They also discussed hotel costs in regard to this, with one group suggesting that it would be better for these to be adjusted by local authorities. They said they didn't think it was unreasonable to pay daily living costs but that these shouldn't be more than the State Pension.

The national limit for the cap was also discussed. People at Age UK Cheshire East's and Age UK Coventry's events thought that national levels for capital limits were unfair and said they would support localised or regionalised capital limits that better reflect house prices and wages in the area. Age UK Herefordshire and Worcestershire participants questioned what measure of inflation would be used to increase the level of the cap and whether their assets would grow faster than the cap level increases.

Complexity of the system and lack of clear information about the changes

People at all consultation events expressed their concern about the complexity of the system. Many people felt the proposals will further complicate a system that is already hard to navigate, whilst also feeling they weren't being given enough information about the changes. A man at the Age UK Rotherham event argued that the information provided is "far too complicated". This was echoed at Age UK Redbridge's event, where people said no one will be able to understand this system. Particular concern was expressed at Age UK Coventry's event about vulnerable groups and how they would cope with the "minefield of how to find care". Some participants argued that many people don't know what support is out there already and how to access it, and asked how they could be expected to understand these changes. Older people at Age UK Redbridge's event were particularly worried about people with dementia in this regard.

Due to the complexity of the system some people suggested that it would be those who know how to push and who have the right support who would get the assessment and therefore get the cap earlier. Participants at Age UK Herefordshire and Worcestershire's event said they felt there was a risk that vulnerable people would miss out or 'slip through the net'. They asked how support and advocacy would be available to help people know and access their rights. In relation to this, many people worried that the new system would still create disparity. One man at Age UK Cheshire East's event said, "My Mother paid her bills and taxes, then all her money drained away (paying for care), whilst she sat next to someone who hasn't had to spend a penny."

Overall, it was argued that the changes to the system should be made uniform and simplified. People agreed that information and advice provision must also be a priority.

Care funding and local authority resources

Funding for care services and financing the new system was a recurrent theme. People feared how the proposals would impact upon services that are already being stretched and cut and asked how the proposals would help people needing care now and in the near future who they felt were stranded.

When discussing changes participants would make to the proposals, older people at the Age UK Rotherham's consultation event questioned the amount of funding needed to get the system working. It was pointed out that since 2012 the local authority had already had to make substantial savings. One woman said the Government needs to think seriously about funding these changes, adding that "Older and disabled people are stuck already." Comments at Age UK Herefordshire and Worcestershire and Age UK Cheshire East echoed these concerns, with examples of how their local system was severely under-resourced, while people at Age UK Norfolk's event said, "Ultimately, there isn't enough money in the system to pay for care costs". It was said that Norfolk council personal care budget is severely overspent and that the proposals were working on the basis of costs which are already overstretched. Participants said that, as a result, they were now seeing many older people admitted to hospital and then being stranded there even when medically fit enough to come home, due to reductions in social care.

When discussing care funding more broadly, older people who participated in the Age UK Coventry consultation event said they believed money for care should come from the NHS, with additional add-ons being charged for. A similar approach was supported by one of the groups at the Age UK Cheshire East consultation. One group participating in the Age UK Shropshire, Telford and Wrekin event, meanwhile, said they would support higher taxation so that people are paying more towards their care while they're still working. Another said

they would like to see the Scottish system for over 65s replicated in England and Wales or for a specific NHS tax to be kept ring-fenced for health and social care to ensure a truly cradle to grave service. The introduction of stakeholder care plans, like stakeholder pension plans, with incentives to encourage people to pay into these such as tax breaks, were also suggested at Age UK Norfolk's event. Overall, people generally felt there needed to be much more transparency and honesty about paying for care and how it would be calculated.

During funding discussions, concerns were also raised about local authority resources to implement the proposals and the lack of details on how this would be done. One woman from Rotherham mentioned that there are already waits of three to four months for assessment in her area and suggested this would surely only get worse with more people needing to access the system. It was suggested that one year is too short a time period for local authorities to administer all the assessments needed for April 2016. Individuals at Age UK Herefordshire and Worcestershire's event questioned how the demand for financial reassessments could be predicted and how this would work with budget cuts at local levels. One participant at the Age UK Shropshire, Telford and Wrekin event asked, "If there isn't money to make the system work, then how can the cap be positive?"

Eligibility criteria and keeping people healthy at home

All groups of older people who were consulted agreed that the eligibility criteria for care and support should be lowered. Participants were concerned that the high-level criteria would mean people would reach crisis before being eligible for support. People argued that if the eligibility threshold was set lower then more people could potentially be kept healthier at home.

In relation to this, it was felt by a group at the Age UK Rotherham consultation that the proposals were at odds with the wellbeing principle in the Care Act. They thought the eligibility criteria should be set at the equivalent of moderate. Also referring to the Care Act's principle of wellbeing, one woman at the Age UK Norfolk event said, "You can't have wellbeing without the funding for it." A participant at Age UK Cheshire East's event suggested that this was another example of the Government focussing on residential care and that they should be more willing to fund home care. Age UK Sunderland consultation participants agreed, saying that the current system isn't preventative and means support only kicks in once someone reaches crisis point. At Age UK Herefordshire and Worcestershire's consultation event people asked, "What provisions are there to prevent people reaching crisis?"

Participants at the Age UK Norfolk event said that earlier intervention and earlier care when self-funding would mean a reduction in pressure on the NHS, saving money down the line. They felt changing the system is an opportunity to re-orientate services towards prioritising supporting people to stay at home, which they thought was often also what older people wanted. On this topic, Age UK Shropshire, Telford and Wrekin participants argued for better integrated services between health and social care to ensure support is provided to people with intermediate care needs in the community.

Age UK Lancashire event participants raised the issue of dignity in care. They said it was paramount to ensure people were always treated with dignity, which included valuing individual's needs and allowing for and supporting people's independence. Implementing a system for ensuring dignity, akin to that proposed by the National Pensioner's Convention, it was suggested.