

Meeting the cost of continuing care: public views and perceptions

A Joseph Rowntree Foundation Inquiry is currently considering options for financing continuing care for older people. A qualitative study among people of all ages, undertaken for the Inquiry by Rebecca Diba of Social and Community Planning Research, reveals how the public view the key issues involved. She found:

- f** There was widespread criticism of the current system of funding long-term care for older people. The means-testing of payment for residential care was the focus of particular complaint.
- f** The existence of a National Health Service, and the obligation to pay tax and national insurance, had led people to expect that care for older people would be free at the point of delivery. The state's failure to fulfil this expectation strongly influenced people's views about future funding.
- f** People believed that revenue from supposedly dedicated contributions such as National Insurance has not been used for its intended purpose. This undermined their faith in a state-led system for funding long-term care.
- f** Any new system of tax or social insurance for long-term care must meet some key standards to be acceptable. People wanted assurance that any revenue collected would be dedicated to a stated purpose, would be properly invested and would guarantee the provision of a specified level of care.
- f** People see a role for private insurance in the future. Some envisage that it may be the only option for the younger generation; others hope that it will work alongside state funding, with the state paying for a minimum level of care and private insurance being used to "top up" care to a higher standard.
- f** There was a view that the family should not be obliged to care for elderly relatives, and that those who are carers should be compensated for their time.

Introduction

As the number of people needing long-term care rises and the costs of providing care increase, the question of how the costs of continuing care will be met in the future becomes ever more pressing. In 1995 the Joseph Rowntree Foundation set up an Inquiry to investigate this issue. As part of their review, the Inquiry group required some understanding of the general public's attitudes towards the funding of long-term care of older people. The aim of this study was to explore public views about the current state funding system and to examine where responsibility for funding long-term care is felt to lie and how it should be paid for in the future.

At the time of the research, state funding of long-term care varied according to the circumstances of the individual and the type of care they required. State funding of care in nursing or residential homes was means-tested such that if a person's capital exceeded £8,000 they were no longer eligible for financial support from the state (in the 1995 autumn budget this was raised to £16,000). Domiciliary care services supplied by local authorities were also subject to a means test.

Study participants' current experience of, or involvement in, the long-term care of older people was very varied. At one end of the spectrum there were people, more often younger respondents, who had no personal experience of long-term care. At the other end of the spectrum, some of the older respondents needed care themselves and the subject was therefore very close to their hearts.

Although some respondents had no experience of long-term care, most had a degree of awareness of how it was currently paid for in the UK. Participants' thoughts on funding long-term care were heavily influenced by their attitudes towards the existing state system of care provision. Thus, their views on the funding debate tended to mirror what they saw as problematic within the current system.

Injustices of the state funding system

"They will take it all away from you, if you've been careful during your life, if you bought your house, if you've saved, if you've invested your money you go into a residential home and you pay...there are people I have known...who throughout their life have spent what they have earned, they've lived for the day...now why in effect should I subsidise them, when my husband and I both worked hard all our lives? We were both extremely careful and we both thought we were going to have a little to spare in our old age." (Rose, age 72)

The current system of funding the long-term care of older people was generally regarded as being unjust in certain key respects:

- People felt that they had been given a false promise by the state that long-term care for older people would be provided free at the point of delivery.
- The means-testing system for residential and nursing home care was felt to be unfair because it meant that thrifty individuals who had been careful and saved their money would have to pay towards their care, whilst the spendthrift would be eligible for state funding.
- The £8,000 threshold was thought to be far too low, particularly given that property as well as savings and investments were accounted for in the means test. The idea of being forced to sell their home to pay for care caused great distress amongst some people. This was partly because they had hoped to leave it to their children as their largest financial resource. For many it also represented an asset which they had worked hard to achieve.
- It was widely felt that nursing care for older patients should be provided free, within the services offered by the National Health Service. People were angry that such care was no longer free to all those who needed it.
- There was some objection to local authority charging for domiciliary care services.

Options for state funding

"It doesn't matter what you pay into, whether it's pensions, hospitals, road tax - it's all in the pot ... so whether you pay £20 extra a week to put your mother or granny into a home, it still goes in the pot." (Stewart, aged 49)

The public's opinions of the existing system helped to shape their views on where they felt responsibility for financing long-term care in nursing and residential homes lay. The overwhelming view was that people should see some return from money they had paid into the state through National Insurance and taxes.

However, although it was felt that the state should take a greater responsibility for funding long-term care, the public voiced concern about the ability of the state to fund care in the future. People believed that revenue from supposedly dedicated contributions, such as National Insurance, has not been used for its intended purpose, but put "into the pot" along with other government revenue. There was concern that revenue collected in the name of long-term care would follow the same path.

People also said that they would be reluctant to fund care if the injustices of the current system were not redressed. Thus, for people to be willingly pay more into the state, funding of long-term care would have to be seen to be fair and just. There were different views on how a just funding system could be established:

- Some people proposed a totally statutory system of long-term care.

“I think everybody’s entitled to a basic [level of] good quality care and ... You could fall on hard times, you can’t punish people and say you didn’t pay in so you get the basic care and you’ve got lots of money so you have good care.” (Joan, age 56)

- Others thought that the state should fund a basic level of care, leaving people with the choice of paying privately if they wanted a higher standard - a “top-up” option.

“There should be a baseline [that] everybody’s entitled to which is good...but when you get that level you’ve got a choice, then you can buy [a better standard of care], just like a hotel, you can get a basic hotel, you can get a five-star hotel.” (Mark, age 27)

- Some people took the view that individuals should make a contribution towards the ‘hotel’ costs in state-run homes by paying something towards the cost of accommodation, meals or domestic services. However, generally, there was strong objection to the proposal for residents in nursing and residential homes to pay the full hotel costs, whilst the state financed the care costs. People suspected that the hotel costs would amount to considerably more than the care costs and that they would be no better off than under the existing system.
- A further suggestion was to retain the current system of state funding in essence, but to increase the means-test limit to a more realistic level, allowing people to retain a significant portion of their capital.

In any event, taxpayers wanted assurance that their tax or social insurance would be dedicated to long-term care, that revenue collected would be put into a separate fund and invested and that a good standard of care would be guaranteed.

People recognised that the need for long-term care would increase in the future because of greater longevity within the population and the lack of adequate resources to pay for the care of an enlarging elderly population. Even if a state funding system conformed to the principles outlined above, some people would still doubt whether the state could meet the increased demand for long-term care. Whilst the proportion of the population needing long-term care was increasing, the proportion of taxpayers in the population was thought to be decreasing. Some people suggested, therefore, that the younger generation in particular might have to start planning private means of paying for long-term care, through private insurance for example.

Options for private funding of care

“Eventually we’ll probably be trained to think about paying for our old age...extra pension to pay for when you have to go into a home...I can certainly see...in the foreseeable future that younger people at a certain age bracket will be asked to consider it.” (Bob, age 66)

Some people were opposed to any form of private funding. Others could see a role for it in certain circumstances. Some suggested that savings and investments could be used to make a contribution towards the cost of their keep in a residential or nursing home or to pay for domiciliary care. Although the idea of using housing equity to pay for care initially provoked strong objections, on reflection circumstances were identified when people would be more willing to sell their home to finance long-term care:

- to pay for “top-up” care above basic state care
- to pay for sheltered accommodation

Likewise, people could see a role for private insurance in the future, either for the younger generation, in place of state funding, or as well as state funding to pay for “top-up” care.

Options for funding through the family

Under the existing system, unpaid carers, usually a person’s relative and often a female relative, provide the greatest proportion of care. There was considerable debate as to whether family members should be expected to care for their relatives. At one end of the scale, some people argued that relatives should care for their family “out of love” for them, or through a sense of duty or moral obligation.

At the other extreme, it was felt that people should not feel obliged to look after a relative if they did not have a good relationship with them. Moreover, it was also said that people may lose respect for their older relatives if traditional caring and supporting roles were reversed.

“A lot of people go back to living with [their] parents again. You ... leave [home] when you’re 18 to 20 or whatever...you’ve developed into a totally different person than when you were 18 and to try and live as a family again and look after them, you’re not going to get on ... you’re not being looked after, you’re not having your breakfast made by Mum, you’re making her breakfast.” (Richard, age 24)

People identified circumstances which would affect willingness to care for a relative, which included:

- the geographical distance between the carer and their relative
- the amount of space in the carer’s home
- the level of work commitments

- whether care can be shared with other relatives
- whether the carer has young children at home
- the health of the carer

An individual's willingness to care was said to depend on the type of care involved and the closeness of the relative who needed care. Moreover, it was also said that the views of the person needing care should be considered. It was felt that some individuals would not want to be looked after by their relatives, for fear either of losing their independence or of being a burden on their family.

There were mixed views on whether the family should be compensated for caring for relatives. Some people disputed the idea of compensation, and felt that people should care for relatives out of love or a sense of obligation. However, it was more often said that there should be a payment scheme for people caring for relatives. In some people's view, compensation should be available in all situations. Others felt that compensation should be awarded in certain circumstances. For example, if a person was forced to give up or cut back on their work, they should be reimbursed by the state for loss of earnings.

The suggestion that the family should pay for a relative's care was put to respondents, although it was not an issue that was mentioned spontaneously. People tended to think in terms of children whose parents needed care. It was thought that many people would not be able to afford to meet the costs of care and, having paid National Insurance and tax, people should be entitled to free care from the state. However, there were some people who felt that children should be expected at least to contribute towards the costs of their parents' care if they did not want to look after them.

About the study

The study evidence is derived from nine group discussions held with adult members of the general population, aged 18 or over, during October 1995. The groups were conducted in three locations, with three discussions in each area amongst different age groups (18-39, 40-59 and 60 years or over). Eighty-one people took part in the research and the sample was selected to ensure diversity in terms of housing tenure, employment activity, and social class.

The group discussions were tape recorded, transcribed verbatim and analysed using Framework, an analytic method for qualitative data.

Further information

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A full report, Meeting the costs of continuing care: Public views and perceptions, is published for the Joseph Rowntree Foundation by York Publishing Services (price £11.00).

Related Findings

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Social Care

78 Regulating residential care for elderly people (Jan 96)

80 The impact of charging policy on the lives of disabled people (Feb 96)

83 Towards a national system for continuing assessment in care homes (Mar 96)

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