

CARING CHOICES

Who will pay for long-term care?

REPORT Edinburgh 4 October 2007

Overview

In 1999, the majority report from the Royal Commission on long-term care recommended the introduction of free personal care for older people. The policy was rejected in England, but was implemented in Scotland in 2002. The fifth Caring Choices event was held in Edinburgh on 4 October 2007 to hear direct from older people, carers, providers, funders and commissioners of social care in Scotland about the impact of five years of free personal care.¹ Around 60 delegates attended, the majority being older people and carers.

There is widespread approval in Scotland of the policy shift, but the overwhelming message from participants in the Caring Choices event was that the change to the funding rules still leaves several problems and challenges to be addressed in the social care system.

- **An information deficit** Five years on, there remains considerable confusion among the public about what is on offer from the state and a lack of understanding of how free personal care operates. There are common misunderstandings about the meaning of 'free' that have been there since the policy inception. For instance, low-level personal care needs may not be eligible for free delivery, and the accommodation costs of care home places are not covered by the policy. Delegates said that a system that is not widely understood is difficult for users to navigate.
- **Local authority variations** Free personal care for older people is a national policy across Scotland and sounds straightforward, but obtaining social care is still a 'postcode lottery' because local authorities decide the eligibility criteria and determine the size of packages of care. Delegates complained that these very significant differences in implementation across local authorities add to the lack of understanding of the policy. 'Is free personal care a national policy, an entitlement - or isn't it?', asked one participant. Many delegates felt a need for the introduction of minimum standards or guarantees across Scotland.
- **Lack of choice** The rhetoric of choice is not translated into reality for many older people, including choice in relation to housing. In many parts of Scotland there are no care home places for older people who do want to move into residential care,

¹ Throughout this report the term 'free personal care' refers to the funding policy adopted in Scotland; in practice, not all personal care needs in Scotland are provided free of charge.

and a lack of accessible accommodation for those who want to remain in their own homes without being trapped there.

It was striking that many of the concerns voiced in Edinburgh echoed points that were raised during the Caring Choices events in England, demonstrating that people's main issues often go beyond the question of the funding model. Unfairness, lack of advice, and the need for advocacy cut across different funding systems.

The new funding system has been a popular policy change but, in practice, there is still a question of how services are being rationed, for instance, by waiting lists. Nevertheless, there was a consensus among participants that a policy of free personal care, currently accounting for around 1 per cent of the total Scottish Executive budget, is affordable in Scotland, although this may double over the longer term because of demographic trend. There was no specific discussion about how sustainability might be affected by the potential extra costs of removing some of the postcode lottery effects and/or improving quality.

Questions around three specific issues were raised with delegates in group discussions during the event.

- **Paying for care** Does an explicit entitlement to personal care help individuals to plan for the future; is it sustainable; and how should non-personal care costs be covered?
- **Informal care** How can providers of informal care best be encouraged and supported?
- **Local authority variations** Could new models help to improve the quality of services and lessen the financial burden for local authorities?

Equity of service provision, better information, value for money, sharing innovative developments, and higher service quality emerged as the main issues that now need to be addressed if the policy is to achieve its goal of independence and well-being for older people. These issues were strikingly similar to those raised at the Caring Choices events in England, demonstrating that people's main concerns often go beyond the question of the funding model. There are no easy solutions to the challenges, but it was agreed that putting the individual at the centre of the equation will be the key.

Free personal care in Scotland - a summary

The policy of free personal care for older people was introduced in Scotland in 2002, three years after the Royal Commission report on long-term care.

- In a residential or nursing care home, free personal care in Scotland means:

- a fixed £145 a week for the cost of personal care in the care home
 - £65 a week for nursing care (if in receipt of such care)
 - no resident now receives Attendance Allowance (currently paid at a high rate of £64.50 and a low rate of £43.15) or the care component of Disability Living Allowance (where the high and mid rates follow the Attendance Allowance rates). These benefits were previously paid to older people in care homes who were not in receipt of state funding towards fees
 - the 'hotel' costs of a care home place remain means-tested, and an older person with income and/or assets above the thresholds must fund these costs privately. The value of a home is usually included in the assets assessment unless the older person's spouse/partner remains living there.
- For an older person in receipt of support in their own home, free personal care in Scotland means:
 - there is no set maximum costs for the personal care element of a domiciliary support package
 - the older person can still receive Attendance Allowance or Disability Living Allowance (care component) if they are eligible on needs grounds
 - any nursing care is provided free by the NHS
 - the non-personal care elements of a support package (eg, help with domestic tasks) remain means-tested.

These rules mean that an older person in receipt of personal care at home may be significantly better off in Scotland than their counterpart in England. The comparison for a care home resident is less stark: a self-funding older person in a residential home in England can receive a maximum of £64.50 a week in Attendance Allowance compared with the £145 fixed personal care allowance in Scotland, a difference of around £80 a week. In England, one of the main complaints about the social care funding system concerns the necessity for some older people to sell their homes to fund care home fees. But for many people an extra £80 a week from the state might not remove the need to sell a home to meet the other means-tested 'hotel' fees.

Research for Joseph Rowntree Foundation by David Bell, Alison Bowes and Alison Dawson at the University of Stirling has assessed the impact of Scotland's free personal care policy. Key results of this work were presented to delegates at the Caring Choices event to aid the debate.

- Public expenditure on the policy has risen from £165 million in 2002/3 to £260 million in 2005/6, but still only accounts for around 1 per cent of the Scottish Executive's total budget.
- Free personal care continues to have wide public support.

- The total number of people in Scotland receiving free personal care has increased since 2002 by 18,700 to nearly 50,000. This is equivalent to 6 per cent of the population aged 65 and over. The increase cannot be explained by either rising numbers of older people or changing healthy life expectancy.
- The increase in the number of older people in care homes who receive the £145 free personal care payment, but who do not qualify for any means-tested support, is probably explained by the growing number of older people who have significant assets, especially housing.
- The increase in the provision of free personal care at home has been more dramatic. Between 2002 and 2005, the number of people receiving state-funded home care packages only increased from around 55,000 to 57,000. Within this, the number of people receiving free personal care at home rose from 26,000 to 41,000. This suggests the emergence of previously un-met need for personal care. The policy of reducing delayed discharge from hospital of older people has also increased the demands on local authorities for personal care services.
- As a result of the overall increased demands for free personal care, and the extra state cost to local authorities of paying for personal care under the present policy, there appears to have been a squeeze on the provision of state-funded non-personal care services (eg, domestic help).
- There is a big diversity across local authorities in the percentage of over 65s in receipt of free personal care at home, ranging from 2 per cent to 9 per cent.
- There are huge variations across local authorities in the reported weekly cost of free personal care at home. The most recent data show these varying between £35 and £233 per week – a factor of six. Accounting issues and local authority policies may explain some of this variation, but it is much greater than expected.
- The introduction of free personal care has not led to any reduction in the number of people providing unpaid care. These carers may, however, be carrying out different tasks, including compensating for the reduction in local-authority provision of non-personal care.
- The main areas for dispute since the introduction of free personal care have been the definition of personal care services (eg, whether food preparation is covered by the new policy) and the operation of waiting lists by local authorities as a means of controlling their budgets.

Paying for care

Does an explicit entitlement to personal care help individuals plan for the future; is it sustainable; and how should non-personal care costs be covered?

There remains considerable confusion and ignorance in Scotland about what free personal care actually offers an older person, said delegates. Some older people had been surprised to discover that not everything would be free, while others did not even realise they were eligible for free services. Further uncertainty is caused by the

big variation in what different local authorities provide. This makes it difficult to plan for the future. *'If you don't know what the policy is, it can't affect your behaviour,'* said one older person. Many delegates pointed to the difficulties in defining and understanding the difference between personal and non-personal care, and questioned why some important aspects of care were ignored by the policy. *'Companionship does not come under free personal care,'* said one person.

The confusion extends beyond social care to the various other funding streams that exist for older people, such as Attendance Allowance and Supporting People. *'What is Attendance Allowance for? People are not given enough information about how it can be used,'* said one delegate. *'My mum put it under her bed,'* admitted another. There was a strong consensus around the need for much better information about the various allowances available and their intended use.

Overall, it was agreed that the support system for older people needs to be clearer for society to understand, and only then will individuals be able to plan effectively for the future. Even the term 'free personal care' was described by one delegate as *'economical with the actuality'*, with suggestions that the name of the policy needed changing because so many aspects of an older person's care package are not actually free.

One key aspect of planning ahead is the question of where to live as one grows older. In future, it is expected that only those with very high care needs will live in care homes, leaving more people in the community requiring care in their own homes. It might also be assumed that the more generous provision of free personal care at home would be a reason for older people in Scotland to want to avoid a move into a care home. But the lack of real choice around housing options was a concern for many, with a shortage of appropriate accessible accommodation. *'Older people can't move to better housing options because they don't exist,'* said a delegate from the Highlands. *'Many older people are stuck in flats and don't get out. Most people want to stay at home so long as they have a network of friends and family, but many people are very lonely in their own homes,'* said another participant. Nor is a move into a care home always an option for those who do want it. *'There isn't adequate residential care. Many say that if there was well-run, good-quality residential care they would want to move, and the housing would be freed up for younger people.'* But some areas of Scotland don't have care homes.

Another delegate pointed out that around three-quarters of older people in Edinburgh are owner-occupiers and that more varied care options are also needed for those who want to continue to own their own home. *'We need to give people advice and information at an earlier stage so they move into a house/flat that will last for longer.'*

Loneliness and depression were raised as issues that the new policy has failed to address and where service 'modernisation' has often worsened the situation. *'The old meals service has been done away with, when a person one knew came in every day. Now it's a fridge, a week's supply of meals and a microwave. There is not the same human interaction.'*

Now that local authorities appear to be withdrawing from providing non-personal care, there were concerns that older people were being left to themselves to organise services. Older people are left in the dark about whether they are getting good value for money and some safety net is needed to protect vulnerable older people. *'Local authorities must regulate private suppliers so people aren't ripped off,'* said one delegate. The lack of information and support for an older person buying services was given as one reason for the low take-up of direct payments among older people in Scotland. It is important for service users to have a say in what they want to be provided – *'it is more efficient, adequate and democratic'* – but different older people need different levels of support, said participants. People should be given a say, offered choices, and then the local authorities should still have a role in arranging services for some people, while others who want to opt for direct payments need to know that private suppliers are regulated and overseen by the local authority.

There was broad agreement that the policy of free personal care is financially sustainable, even if the ageing society means that the costs are projected to rise to 2 per cent of the total Scottish Executive budget. Many felt that the older people's budget should be ring-fenced, or more clearly delineated as a resource for older people, and that people would accept paying higher taxes towards long-term care if the extra money would definitely be spent on older people.

Separately, there is also the question of the potential extra costs of addressing some of the shortcomings of the existing system, including reducing the postcode lottery, covering people with modest personal care needs, and widening the definition of 'personal care'. There was no specific discussion about how improving the system might impact on the long-term financial sustainability of the policy.

The question of sustainability is also bound up in the appropriate allocation of resources so that, for instance, if the delayed discharge policies reduce hospital costs and increase social care costs then there should be an appropriate shift of public resources. Some resources need to follow the discharged older person into the community.

Several participants voiced the opinion that more research and evidence would be useful on the pros and cons of integrating health and social care budgets in order to encourage the potential cost savings of a more holistic approach. However, the debate did not consider how greater pooling of budgets would work in practice, or

how it would be consistent with delegates' inclination towards greater ring-fencing of the budget for older people's social care.

Unpaid care

How can providers of unpaid care best be encouraged and supported?

There were calls for public funds to be spent more effectively and fairly, with complaints that older people did not receive the Carer's Allowance.

The information deficit was again seen as a major problem, with some unpaid carers in the audience unaware that free personal care is available for the older person living with them (they believed wrongly that it was only for dependent older people living alone). Information for carers should cover both services and benefits, and GPs have an important role in a successful information strategy for older people and their families/carers, said participants.

The provision of free personal care was welcomed by carers, with some offspring with caring responsibilities saying that they had previously felt uncomfortable when carrying out personal care tasks for a parent. However, there were important concerns about the quality, range and choice of services that are provided. Care assistants come at unsuitable times and are supposed to carry out an unrealistic workload within a short time. *'My mother's carer was allotted 30 minutes to get her out of bed, bathed, washed and fed,'* said one woman. Many older people have to contend with different care workers turning up on each visit so there is no possibility of building up a relationship. Often care workers lack the necessary skills and training. All this creates greater challenges for the unpaid carer to deal with.

Unpaid carers felt that the social care staff who carry out the assessments often do not understand what the older person and the carer really need. Unpaid carers are also increasingly themselves older people, and this needs to be taken into the equation. Assessments are too service-driven, rather than concentrating on the desired outcomes, said participants.

Carers wanted better access to training, for example, in how to lift and move an older person without injuring either party. For many people this is still not available, and even when training is on offer it is not possible for an unpaid carer to attend unless the local authority provides someone to take their place while they are away for training.

Finally, direct payments were raised as a way to improve the quality of services provided for the older person. There was again caution about the need for private agencies to be registered, but enthusiasm that the greater control would enable older people and their carers to specify the time and adequate provision of services. *'If you*

don't like it, you can change,' said one participant. Many liked the possibility of using a direct payment to purchase services from the voluntary sector.

One factor that was cited as possibly preventing the uptake of direct payments was concern among local authority staff about the possible impact on public sector jobs. This view was seen as strengthening the argument about the need for adequate advice, information and advocacy to support older people and carers in navigating all aspects of the system.

Local authority variations

Could new models of care help to improve the quality of services and lessen the financial burden for local authorities?

The big variation in care provision across different local authorities in Scotland was very unpopular among participants, and there was a belief among some delegates that some local authorities actually underspend on older people as a result of 'diverting' funds towards other services, such as children's care. The question was therefore posed as to whether there should be greater uniformity in eligibility criteria and common care standards across Scotland, with a clearer statement of entitlement for users. Should a degree of equity across Scotland be introduced for users under the policy of free personal care?

There was a suggestion from the panel that local authorities could be required to meet national minimum criteria for service provision, while also having enough local flexibility to protect local democracy and to encourage local experimentation and innovation. *'It is a good thing to have room for variation.'* It was also stressed that precise definitions for eligibility and entitlement were unrealistic, and could create incentives for local authorities to work around any definitions. A better approach is to work towards the desired *outcomes* for older people, such as the ability to live independently, and to ensure fair access across Scotland to services.

This raised questions about the need for a public debate on the balance between quality and quantity in service provision. Dignity for older people was still missing, and too little has been achieved so far on securing adequate standards for the quality of care, said participants.

Delegates discussed whether new models of care could make better use of health and social care resources. There were several positive reports of innovative thinking, for instance, one council had imaginatively adapted an existing rural day centre to offer a much wider range of community services, such as chiropody, thereby serving the local needs of older people and their carers more effectively. What remained a shortcoming, however, was the lack of sharing of such innovation and good practice across Scotland so that local authorities could benefit from each other's experiences.

However, it was pointed out that many earlier intentions regarding new approaches to care were not yet being adequately implemented, and that this needs to be addressed:

- the intended respite care for unpaid carers is often not offered
- quality improvements have not been achieved
- direct payments can increase the purchasing power for individuals, but the take-up rate remains very low among older people
- expectations are not being met in the provision of sheltered housing or other housing-with-care options
- carers are not sufficiently involved in assessments.

There was agreement that greater scope exists to utilise new housing and technology options within existing budgets. In particular, better outcomes can be achieved by combining low technology solutions together with human interaction, an approach that does not necessarily require a huge increase in resources.

One problem is that older people are often unaware of the care options that could be provided, and cannot therefore request them. Technology can help enhance the quality of care at home and reduce risk, as is proving the case in the West Lothian telecare project. The big challenge is the need to re-engineer the systems and staff around this type of new approach.

There is potential for more radical revisions to care models, including the role of communities in looking after older people and the scope for care villages that can provide varying levels of care for residents as they age. Social care departments particularly need to rethink the care of people with dementia, said some delegates, including their right to die at home. This illness particularly exposes the difficulties of drawing a line between health services and social care; if this divide can be broken down, then there could be more scope for some people in the latter stages of dementia to be cared for at home, backed up by respite care and specialist services.