NURSING HOME CARE IN THE NEW MILLENNIUM - THE ROYAL COMMISSION ON LONG-TERM CARE*

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INTRODUCTION

There is a widespread feeling of outrage among elderly people and their relatives at the present system of funding long-term care. They believe that 50 years ago they had been promised care free at point of use 'from the cradle to the grave'. They have fulfilled their part of the contract by paying their taxes and believe that they have now been betrayed by the Government and society who are asking them to pay for long-term care, and even worse, to sell their homes in order to raise the money to so do. This sense of betrayal is partly the result of a misunderstanding of the differences between health care and social care. Health care has been largely free since the introduction of the National Health Service but social care is paid for, unless the person is unable to afford it. On the other hand, the sense of betrayal is justified by the fact that in the last two decades the boundary between health care and social care has changed, particularly with respect to long-term care of elderly people. Whereas long-term care used to be provided free of charge in hospitals, it is now largely provided in private nursing and residential homes at a charge to the residents (if they can afford it).

ROYAL COMMISSION

In 1998, the Government set up a Royal Commission to advise on a new way of funding long-term care. A Royal Commission is a totally independent body which reports to the Government, which in turn is free to accept or reject its report. The Royal Commission had 12 members and was chaired by Sir Stewart Sutherland, Principal of the University of Edinburgh. Its terms of reference were: to examine the short- and long-term options for a sustainable system of funding of long-term care for elderly people, both in their own homes and in other settings; and, within 12 months, to recommend how, and in what circumstances, the cost of such care should be apportioned between public funds and individuals, having regard to:

- the number of people likely to require various kinds of long-term care through the first half of the new century, and their likely income and capital over their lifetime;
- the expectations of elderly people for dignity and security in the way in which their long-term care needs are met, taking account of the need for this to be secured in the most cost-effective manner;
- the strengths and weaknesses of the current arrangements;
- fair and efficient ways for individuals to make any contribution required of them;
- constraints on public funds;
- earlier work done by various bodies on this issue.

In carrying out its remit, the Royal Commission should also have regard to:

- the deliberations of the Government's comprehensive spending review, including the review of pensions;
- the implications of their recommendations for younger people who by reason of illness or disability have long-term care needs.

The Commission's recommendations should be costed.

The Commission was asked to give an opportunity to all interests likely to be affected by its recommendations to give their views on issues within the terms of reference, and in particular to users and carers.

The Royal Commission consulted widely and received a very large volume of oral and written evidence from both individuals and organisations.

VALUES

The Royal Commission's first task was to establish the values against which it could consider long-term care for elderly people:

- older people are a *valuable* part of society and should be *valued as such*;
- old age will come to increasing numbers of the population and this should be seen as a natural part of life and not as a burden;
- to compartmentalise old age and describe old people as a problem is intolerable – morally and practically;
- old age represents an opportunity – for intellectual fulfilment and for the achievement of ambitions put on hold during working lives. Those who are involved in government, or who provide and develop products and services, should work to make available to old people the tools to enjoy education, leisure and their day-to-day lives;
- a more positive and inclusive climate should be created and nurtured, so ensuring the development of more opportunities which can be taken up by older people;
- the whole approach to long-term care should be to view the management of older peoples' needs as a set of positive actions over time which help people to lead the kind of fulfilling lives they want to lead – and to be able to continue to contribute to society in a positive way – both economically and intellectually – and not as the management of decline;
- the funding system for long-term care should provide the widest possible opportunity for older people to lead the lives they want, whether it be in their own homes or in other settings;
- in improving the recognition of the importance of old age, the funding system must also strengthen the links

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between generations and spread the financial responsibility.

THE DEMAND FOR LONG-TERM CARE

It is often stated that we are living on a 'demographic time bomb' and that there will be a huge expansion of the number of elderly people in the next few decades. In fact the evidence shows that that is not so. There has been a considerable increase in the number of old people, particularly those aged 85 and over, since 1930, and there will continue to be an increase over the next few decades. However, the biggest change has already taken place and the increase that is to come is manageable.

The demand for long-term care depends not just on the number of elderly people but on two other factors. The first is their state of health and, in particular, the presence of chronic illness and disability. There is very little evidence on this and projections for the future are speculative. Such evidence as there is suggests that elderly people are not only living longer but are also healthier than before. The second important factor is the availability of informal care, i.e. care which is given by relatives, most often spouses or children, and most often women. Many social changes are occurring which would seem to make it more difficult for informal care to be provided. These include more frequent breakdown of marriage, increased mobility in employment and many potential carers having full-time jobs. However, these changes have been occurring for the last few decades and there is no evidence that the availability of informal care is decreasing. Nevertheless, predicting future trends has to be speculative.

PAYING FOR LONG-TERM CARE

The Royal Commission found it very difficult to identify the present costs of long-term care. The funding comes from a wide variety of different sources, both statutory and private. The best estimate is £11.1 billion per year at 1995 prices. Of this, 64%, or £7.1 billion, is publicly funded and 36%, or £4 billion, privately funded, although the latter includes social security benefits which are paid to individuals who then use them to fund long-term care. The Department of Social Security does not keep records on how the benefits it funds are used and therefore there is no direct information on this. Projecting these costs forward over the next 50 years suggests that the cost would rise from £11.1 billion in 1995 to £45.3 billion in 2051. This would represent a change in the percentage of Gross Domestic Product (GDP) of 1.6% to 1.9%. This is a small rise and would not have disastrous financial consequences on the economy of the country.

However, 50 years is a long time to predict the future and there are considerable uncertainties with respect to the health of elderly people, the availability of informal care and the economy. What is clear from this 'funnel of doubt' is that it is possible to make projections with some degree of accuracy up to about 2010 but beyond that the uncertainties increase to such an extent that predictions are hazardous.

THE BACKDROP TO CARE DELIVERY

The Royal Commission set out some principles for the delivery of care:

1. there needs to be more effective joint working and a greater sharing of responsibility between health, social services and housing authorities;
2. there should be a greater emphasis on prevention, and on the promotion of health and independence;
3. there should be greater emphasis on rehabilitation;
4. there should be a more consistent framework for assessment and eligibility;
5. more opportunities should be available to enable people to stay at home;
6. more support should be offered to carers;
7. there should be more real choice offered;
8. services offered should be culturally sensitive;
9. there should be a greater emphasis on quality;
10. the system should be easier to access;
11. a new relationship of trust between clients, carers and services must be created.

COST OF CARE

The 'means test' is one of the features of the current system. Under this system those whose total assets, including the value of their house, is less than £10,000 pay nothing, those who have more than £16,000 capital pay the full cost, while those who have capital of between £10,000 and £16,000 pay a tariff of £1 per week for every £250 of assets. This means that the maximum tariff for those who have just under £16,000 capital would be £24 per week. If they have just over £16,000 capital they jump to full cost, which for a nursing home is £337 per week. There is a strong and justifiable sense of injustice about the means test. Clearly the means test can be altered in any of the three areas, the minimum, the tariff or the maximum. Altering the maximum has a small effect; for example, doubling it to £30,000 increases the number of people who benefit by only 4%.

The Royal Commission recommended that the value of the home should not be taken into consideration for the first three months of stay in nursing or residential care. This would allow the individual the chance to recover, or to change their mind and to return to their own home. This is particularly important for those who have been admitted as an emergency, or who have been transferred from hospital before full recuperation has occurred. The cost of this would be about £100 million at 1995 prices, rising to £500 million in 2051, and would have minimal effect on the percentage of either the GDP or the tax base which would be needed.

CARE

The Royal Commission considered that long-term care can be divided into three components:

1. personal care, which is the intimate care given to individuals who are unable to manage themselves because of chronic illness, disability or frailty;
2. living costs, e.g. food, clothing, heat, etc.;
3. accommodation costs.

The latter two are what everybody pays for themselves, wherever they live.

The Royal Commission provided a definition of personal care:

- personal toilet (washing, bathing, skin care, personal presentation and dressing and undressing);

- eating and drinking (as opposed to obtaining and preparing food and drink);
- managing urinary and bowel functions (including maintaining continence and managing incontinence);
- managing problems associated with immobility;
- management of prescribed treatment (e.g. administration and monitoring medication);
- behaviour management and ensuring personal safety (for example, for those with cognitive impairment – minimising stress and risk).

Personal care also includes the associated teaching, enabling, psychological support from a knowledgeable and skilled professional, and assistance with cognitive functions (e.g. reminding, for those with dementia) that are needed either to enable a person to do these things for himself/herself or to enable a relative to do them for him/her.

The Commission recommended that personal care should be provided free. In this way those who have chronic illnesses caused by conditions such as multi-infarct dementia and Alzheimer's Disease, and whose care is often provided in nursing homes, would be treated in the same way as those who had conditions such as heart disease or cancer who receive their care free in hospital. The total cost of providing personal care free would be £1.1 billion in 1995 prices, rising to £6.4 billion in 2051. This would result in an increase over 50 years of 0.1% in the percentage of the tax base or 0.2% of the GDP. The Commission believed that both of these are affordable.

Another financial recommendation of the Commission was that an additional package of services to the value of £200 million should be made available for older people with carers. The Commission was not specific as to how this money should be spent but they recommended that the needs of the elderly person should be paramount, and if they were assessed as requiring support, this should be given irrespective of whether a carer was available. The funds could be used for respite care if this was the desire of the older person and the carer. While the Royal Commission was preparing its report, the Government announced a new package of measures to support carers, and much of these would be subsumed in the recommendations.

FUNDING LONG-TERM CARE

The need for long-term care is a catastrophe, both personal and financial, and is unpredictable. About 20% of older people will require long-term care at some stage. It is a risk that should be shared by the community as a whole. Thus, some type of 'insurance' should be used to cover long-term care. There are a variety of ways in which this could be done. Voluntary private insurance could be used. However, many people would not insure themselves and the state might have to cover them. Long-term care insurance is available at present but has not been taken up to any great extent, either in the United Kingdom or in the United States. It is not popular with the insurance industry who find the risks difficult to calculate and to cover.

Compulsory private insurance would be an alternative. Once again there would be those who could not afford it and the state would have to cover them. The third alternative which was favoured by the Royal Commission is collective state provision. This could be national insurance, but in this case the contributions would only come from employed people. The Royal Commission favoured using the tax system. This has a number of advantages. It applies to everybody's income, including pensioners, it is progressive in that those who have higher incomes pay more, and it is flexible, so that if needs change, for example drug treatments which reduce the need for long-term care becoming available, then the funds can be shifted. The Royal Commission did not favour pre-funding or hypothecation.

NATIONAL CARE COMMISSION

Because of the uncertainties of the future, and because there are great variations in both the standards of long-term care and the ways of paying for it across the country, the Royal Commission recommended the establishment of a National Care Commission. It would have a number of functions, including monitoring the trends in the numbers of elderly people and the health of and support for elderly people. It would represent the consumer and perhaps set up helplines similar to NHS Direct. It would set national benchmarks for assessment methods and for eligibility, encourage better services and set quality standards. The Royal Commission felt that a national body to set national standards was needed but that each of the four countries would probably have a local body to implement these standards.

RECOMMENDATIONS

The Royal Commission made 24 recommendations which, as well as those already mentioned, covered the need for more research into the future needs of elderly people, on trends in health expectancy and on the benefits of rehabilitation and prevention. Other recommendations covered details on financial support, and the applications of the recommendations to younger disabled people.

CONCLUSION

The recommendations of the Royal Commission provide a new way of giving dignity, fairness and security to older people and their families. The Commission has finished its work, and it is now the responsibility of the Government to respond.

REFERENCES

Detailed references can be found in the Royal Commission's report *With Respect to Old Age* and in the three volumes of research which supported the Commission's work:

With respect to old age. A report by the Royal Commission on long-term care. The Stationery Office: 1999.

With respect to old age: long-term care – rights and responsibilities. The context of long-term care policy. A report by the Royal Commission on long-term care. Research Volume 1. The Stationery Office: 1999.

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