

The Costs of Caring for People with Dementia and Related Cognitive Impairments

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National Council On Ageing and Older People

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As Chairperson of the National Council on Ageing and Older People, I am very pleased to present this study on the economic, social and personal costs of caring for people with dementia.

The National Council on Ageing and Older People has undertaken a programme of research into dementia in Ireland. Following a request from the then Minister for Health to consider ways in which services for people with dementia and their carers might be improved, *An Action Plan for Dementia* was published in 1999. *An Action Plan for Dementia* provided a framework for the provision and planning of services for people with dementia in Ireland.

The Costs of Caring for People with Dementia and Related Cognitive Impairments is a complementary report to the *Action Plan* but with a more quantitative focus. The role of carers is one that is often taken for granted and is seen by many as a free resource. Dr O'Shea explores what caring for a person with dementia entails in terms of the carers time, finances and stress. Evaluating the cost of caring for a person with dementia is the main focus of this study.

As the report notes, it is wrong to assume that caring for a person with dementia also imposes a net burden. The Council pays tribute to all carers of older people and is aware that caring often confers a benefit on carers in terms of feelings of fulfilment and satisfaction. However, when the demands of caring for a dependent person exceeds the resources a carer has to give, this can be to the detriment of the person caring and the person being cared for.

The importance of *The Costs of Caring for People with Dementia and Related Cognitive Impairments* is in emphasising that the role of carers can no longer be taken for granted. With the prevalence of dementia increasing, supports need to be in place for carers. These supports should take the form of information, respite, financial aid and professional medical advice. A significant finding of this study is that a high proportion of carers are older people themselves and many are women. This reflects the way women have been assigned the role of carer in their homes, which has traditionally been viewed outside the economic sphere.

Additionally, the report points to a number of possible solutions from extension of the social economy to the setting up of a Care Management system in Ireland.

On behalf of the Council, I would like to thank the author, Dr Eamon O'Shea for his dedication, commitment and hard work in preparing this important study. Thanks

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Dr Michael Loftus

Chairperson, National Council on Ageing and Older People
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Council Recommendations

The National Council on Ageing and Older People

COMMENTS AND RECOMMENDATIONS

Introduction

1. This report follows the recent publication by the National Council on Ageing and Older People of *An Action Plan for Dementia* (1999). That report was requested by the then Minister for Health to consider ways in which services for people with dementia and their carers might be improved. The report also complements a recent unpublished Council study on quality and effectiveness of long-term care provision for older people in Ireland. *An Action Plan for Dementia* aims to serve as a model of best practice for the provision and planning of services to meet the individual needs of people with dementia and their carers. The report takes as its guiding principle the recognition of the individuality of the person with dementia and her or his individual needs. The objective of the Council's programme of research in the area of dementia is the creation of a person-centred, positive and holistic approach to the development of dementia services in Ireland. This report takes a quantitative approach focusing on the cost of providing care for people with dementia. The report adopts a broad service philosophy that home care is generally preferable to residential care and that care services should be person-centred. The Council endorses and advocates such a philosophy in caring for older people. This is also in keeping with principles set out in *Shaping a Healthier Future* (Department of Health, 1994) and in particular the target set therein that 90 per cent of people over 75 should reside in their own homes in the community.

Objectives of the Study

2. The main objective of this study is to estimate the cost of community care for people with dementia and related cognitive impairments taking account of all categories of resources that entails. A second objective is to provide an overall estimate of the economic cost of dementia in Ireland across all forms of provision including family care, community care, primary care, acute care, psychiatric care and residential care. This incorporates a discussion of the policy implications arising from the analysis of these costs.

Parameters of the Study

3. The report sought to identify the prevalence of dementia in Ireland and estimate

the projected number of persons who will suffer from dementia in the future. Identifying the population of service users is an important component of planning for services. Some European level data was available to show that there are just over 31,000 people, 18,000 females and 13,000 males, with dementia in Ireland presently. However data was not available to allow for a comparison of prevalence rates of dementia in Ireland over time. In projecting prevalence estimates, the report notes that dementia is more common in older age groups. More people are now living to an age where dementia usually arises. More cases are also now being detected earlier. Thus the report estimates that the number of people with dementia will increase by 5,000 between 2001 and 2011. An accelerated increase will occur thereafter in line with the ageing of the population.

The report also sought to identify where people with dementia were resident and cited estimates that just over 22,000 people with dementia reside in the community, just over 7,000 in long-stay care and just over 500 in psychiatric hospitals with an unknown number of people with dementia occupying acute medical beds.

In general, however, the data available on the prevalence of dementia in Ireland was limited and did not allow for comparisons over time. Later in the report the issue of under-reporting of dementia as a cause of death is also raised. ***The Council recommends that the collection of data on dementia be developed and improved so that service planning for people with dementia can be undertaken on a sound basis.***

4. The report notes that services for people with dementia in Ireland are currently underdeveloped and fragmented. Ruddle *et al.* (1997) also found that access for dementia sufferers and their carers to necessary domiciliary care, day care, respite and day hospital services is limited and variable. ***The main implication of this is that the responsibility for caring falls mainly on families, while people with dementia only come into contact with services in the event of a crisis. The Council believes that this situation is unacceptable both for people with dementia and for their carers.***

While the report notes that the lack of provision made available to family carers is evidence that the attitude of policymakers is to regard them as a free resource, it argues that care provided by families requires resources and therefore is costly. The Council welcomes the inclusion of all the resources families invest in caring in the approach taken by the author. The report describes how some of these are easily measured, such as expenditure on

capital items, medicines and services. Others are more difficult to estimate, such as time, labour or leisure foregone, and the way caring has been shown to affect the health of carers or the quality of carers' relationships with families or friends. The Council is pleased that the report manages to enumerate and make visible these costs, which so often remain hidden. Building on this analysis the report then estimates the overall economic and social cost of dementia in Ireland and discusses the major policy implications arising from the findings.

5. In summary, the report sets out to estimate the cost of care for each person with dementia residing in the community, on the basis of the resources families invest in caring and the cost of the health and medical services they use. On the basis of the population of persons with dementia, the total cost of providing care for people with dementia across all forms of provision is then calculated. The policy implications of these findings are discussed.

Data and Methodology

6. The study generated data from a range of sources in order to arrive at the overall economic and social cost of dementia. A survey of carers generated information on the nature and cost of care provided in the community and the level of service utilisation by people with dementia and their carers. This is described as a 'bottom-up' approach to identifying the cost of caring for people with dementia. Two methods of identifying carers were used to satisfy the requirement of representativeness. A random group of carers were identified through a 'sift' of the population to identify anyone providing care to a person who experiences symptoms of dementia on a regular or occasional basis. The 'sift' involved including a one-page questionnaire in the ESRI's monthly EU Consumer Survey which is administered to a random sample of the population over a six month period. The 'sift' questionnaire asked firstly if the respondent cared for an older person either within the household or outside the household. If they answered yes, they were asked further questions on the main symptoms affecting the older person under their care to identify if the person cared for exhibited symptoms of dementia. A total of 80 carers were interviewed for the survey as a result of this process. A second group of carers in contact with two support groups, The Alzheimer Society of Ireland and the Western Alzheimer Foundation, were also surveyed. A total of 98 carers were surveyed from this source. A final number of 178 carers participated in the survey for this report.

7. This is complemented by a comprehensive 'top-down' approach estimating the cost of caring for people with dementia across all forms of provision, including

family care, community care, primary care, acute care, psychiatric care and residential care to establish the distribution of the overall burden of dementia. The range of sources from which the costs for each form of provision were derived are described.

8. These findings present a comprehensive picture of the resource implications of caring for people with dementia across the range of provision. ***In the Council's opinion the methods used in this study are valuable in terms of making visible the complete range of resources families invest in caring for people with dementia, detailing the full extent of the resource implications of dementia in Ireland and identifying how the burden is distributed.*** The issues raised for public policy and service provision are discussed.

Dependency, Carer Characteristics and Care Provision

9. Drawing on the survey data, the nature of dependency among people with dementia being cared for in the community is described using the validated Crichton Royal Behavioural Rating Scale. Of the two groups, the people being cared for by those on the Alzheimer list had a higher level of dependency than those being cared for by the group identified through the randomly generated 'sift' of the population. When asked to make a judgement on the functional abilities of the people being cared for across five basic activities, the results show that most people in both groups were very dependent. Carers have to provide high levels of support for people with dementia in relation to basic activities of daily life including personal care, administration of their affairs, housekeeping, meals preparation, laundry and shopping.
10. The findings show that a typical carer of a person with Alzheimer's in Ireland is female, married, aged between 40 and 54, engaged in home duties and related to the person being cared for. However, a significant number of carers are themselves old. ***The Council agrees with the views expressed in the report that older carers should be recognised as having special needs and as being in particular need of support.*** Meanwhile, the report anticipates that the availability of people to provide care is likely to change from 2010, when the proportion of people over 70 will begin to increase significantly, women's labour force participation increases and the opportunity costs of engaging in home care will increase in line with market opportunities. ***In light of this projection, the Council recommends that State provision of community care for people with dementia be developed sufficiently so as to be able to cope with such an eventuality.***

11. The report looked at the sources and levels of income of carers surveyed. A low number of carers receive their main source of income from wages, salaries and profits – under 30 per cent of the Alzheimer list group and 36 per cent of the 'sift' group. The report finds a low take-up of the Carer's Allowance and relates this to the restrictive nature of this payment. Meanwhile over two thirds of the households in both surveys experience difficulty making ends meet. ***The Council is most concerned that people in our community who are providing such valuable care for vulnerable older citizens in attending to their needs and who assist in achieving the target of retaining ninety per cent of older people at home in the community, should experience financial hardship. The report refers to the Review of the Carers' Allowance which recommended that a new dependency-related continual care payment be introduced for all carers. In line with this the Council recommends that a non-means-tested Constant Care Attendance Allowance should be paid to people caring full-time for dependent older relatives. This would acknowledge the resources, effort and opportunity costs involved in providing full-time care for older people at home, similar to the Domiciliary Care Allowance.***
12. In keeping with the findings of Ruddle *et al.* (1997) this study also found that only a small proportion of people receive home-based services. In general, those surveyed through the Alzheimer list had a higher level of service use, reflecting the higher level of dependency of the people being cared for by this group. The most commonly used services are the home care attendant (by 27 per cent of the Alzheimer list and four per cent of the 'sift' list) and home help services (by 25 per cent of the Alzheimer list and 17 per cent of the 'sift' list). However levels of use for both are still low. Private personal assistants are engaged by one fifth of households on the Alzheimer list at an average cost to the household of £111 per week. Five per cent of respondents from the 'sift' survey engaged a private personal assistant.
13. Public Health Nurses attend the homes of almost three quarters of the Alzheimer list respondents and 62 per cent of the 'sift' list respondents. GPs visit 65 per cent of the 'sift' list respondents and 50 per cent of the Alzheimer list respondents. Use of other health-related services is low, chiropody being the only service used to any significant degree, ranging between 17 and 27 per cent for the two groups. The report notes the absence of a variety of community care provisions and that the Public Health Nurse remains the bulwark in meeting the needs of vulnerable older people.

14. Day care services are used by almost half of respondents from the Alzheimer list but only 12 per cent of the 'sift' list. The report relates this to the fact that the Alzheimer Society of Ireland is the main provider of dedicated day care services for people with dementia. ***In this regard the Council reiterates the recommendation from An Action Plan for Dementia (1999) for more consistent and longer-term funding arrangements between the health boards and the voluntary groups providing services to people with dementia.***
15. Day hospitals are used by very small proportions of those surveyed, ranging from one to three per cent of respondents in the two groups. Those who had used an overnight hospital stay for medical care ranged from 31 to 26 percent for both groups. Respite care in a hospital or nursing home had been availed of by half of the Alzheimer list respondents but by only 16 per cent of those from the 'sift' list.
16. When asked about health and social care requirements, respondents from both groups wanted more respite care. This is in keeping with findings from other studies undertaken by the Council and others (Blackwell *et al.* 1992; Ruddle and O'Connor, 1993). *An Action Plan for Dementia (1999)* includes a recommendation for the expansion of respite services to provide relief for carers and ensure their long-term ability to care for the person with dementia.
17. Continuing demand was expressed for those services already availed of by respondents – the Public Health Nurse, Home Helps, home care attendants and chiropody as well as additional day care places. ***The Council reiterates its call for legislation governing the provision of essential services to older people as stated in its recommendations relating to the findings of The Years Ahead Report: A Review of the Implementation of its Recommendations (Ruddle et al. 1998). The Council wishes to see the following services designated as core services underpinned by legislation and appropriate statutory funding: the Home Help Service, Meals-On-Wheels, Day Care, Respite Care, both inside and outside the home, Paramedical Services and Sheltered Housing.*** Such provisions would address the basic needs expressed by carers for people with dementia.
18. Compared with the findings of low utilisation of health and medical services, family care provision was found to be high. Overall mean daily provision of care was six hours for those on the 'sift' list rising to almost 12 hours for those on the Alzheimer list. The constant nature of care involved in caring for a person

with dementia is reflected by the finding that around 20 hours a day was spent on surveillance by both groups. This compared with the optimal time spent caring reported by respondents, which ranged from six hours daily for respondents from the 'sift' list to eight hours daily for respondents from the Alzheimer list. That the time demanded of family carers is so much greater than the optimal time carers would choose reflects the low level of support provided by the State and raises concerns regarding the welfare of carers and people with dementia. As described in the report, it would be wrong to assume that providing care for a dependent person at home always imposes a net burden on carers. This may only be the case after the provision of care exceeds the optimal amount a carer can give, which may vary from person to person. Until this point, caring often confers a net benefit on carers in terms of feelings of fulfilment and satisfaction and financial reward. The report notes that optimality depends on the level of support that carers receive from the State, both financially and through service provision. The Council believes that the fulfilment of the above recommendations in the form of payment of an allowance to carers and the improvement of the provision of core community care services would improve the conditions of caring for older people with dementia in the community. This would ensure health and social gain both for the person with dementia and for their carer by ensuring that carers are only required to provide care to their optimal level.

Cost of Care in the Community

19. As noted above, this study set out to look at the cost of caring for people with dementia in the community having regard to all of the resources this entails. The cost of these resources is often not market-based and is therefore difficult to value. If family members give up market work to look after a relative, a ready-made evaluation of opportunity cost exists in terms of the wage foregone. However, such market valuations do not exist for the lost leisure time of carers or the psychological strain which results from caring for a person with dementia. The Caregiver Strain Index and the General Health Questionnaire, both validated instruments, were administered to carers as part of the survey to measure levels of strain and stress. In general, the findings demonstrate that caring for people with dementia places a heavy strain on carers who display a worrying level of psychological distress. The Council agrees with the argument put forward in the report that while these costs cannot be given a monetary value they are real costs for the carers.

20. Three ways of measuring the cost of family care are used in the study – what carers themselves feel they should be paid, an opportunity cost approach and a replacement cost approach. The upper limit carers estimate for their own time is £150 per week, translating to between £2 and £4 per hour. The opportunity cost approach bases its valuation on opportunities foregone in order to engage in caring. The opportunity cost of paid work is considered here on the basis of the financial implications for those carers who report having stopped work, reduced their hours of work, took early retirement or temporary leave or been denied career advancement as a consequence of caring. The mean weekly loss of income is £156 for those from the Alzheimer list and £92 per week for those from the 'sift' list or an average of between £39 and £99 per week across all carers. When other opportunities foregone, including leisure time, unpaid work and voluntary activity are included, this increases to between £130 for the Alzheimer list and £72 per week for the 'shift' list. Finally, a weekly replacement cost valuation was estimated to reflect what the State or Health Board would have to pay if family care were absent. On the basis of a Home Help hourly rate of £3 per hour, this amounted to between £134 for the 'sift' group and £244 for the Alzheimer group. On the basis of the National Average Hourly Earnings for Women, the replacement value rose to between £269 and £487 respectively for the two groups.
21. As discussed above, utilisation of community care services by people with dementia and their carers is low, reflecting low levels of provision. Based on the reported levels of utilisation, a weekly *per capita* cost is estimated for overall community care use by people with dementia. Costs are estimated for the main elements of care used which are: Home Help, Home Care Attendant, Private Personal Assistant, Private Nurse, GP, Public Health Nurse, Chiroprapist, Day Care and Respite Care. The weekly per capita cost of community-based services comes to £69 per week for the Alzheimer group list and £32 per week for the 'sift' group. A weekly per capita estimate is also calculated for therapeutic aids, house adaptations and drug costs and totalled £14 for the Alzheimer list group and £6.60 for the 'sift' group.
22. Additional weekly costs incurred by carers arising as a direct consequence of caring were identified as heating, transport, own personal care, own health care, training and other. These were calculated to be over £21 for the Alzheimer list group and over £9 for the 'sift' list group. The report notes that, when taken in conjunction with the finding that a significant proportion of carers experience financial strain, these amounts are significant.

23. The total cost of community care for people with dementia is calculated on two bases for the two groups. This total amount includes the cost of family care, community care services, therapeutic aids, house adaptations, main drugs and additional carer costs. The costs are on a *per capita* weekly basis. An opportunity cost valuation for respondents from the Alzheimer list, who were found to have higher levels of dependency, is £234, while for those from the 'sift' list the opportunity cost is £120. On the basis of replacement cost valuation, the overall cost of community care for respondents on the Alzheimer list is £591, while for those on the 'sift' list it is £317.

The Overall Social and Economic Cost of Dementia in Ireland

24. The overall economic burden of dementia on Irish society is calculated in the study by combining the cost of community care for people with dementia, calculated on the basis of survey generated data conducted with two groups of carers, with all other economic resources associated with coping with dementia. The resources associated with dementia, including those used to prevent, diagnose, treat and generally cope with the disease covered in this analysis, are: mortality and life years, in-patient acute care, in-patient psychiatric care, family care, primary and community care and residential long-stay care.

25. With regard to mortality and life-years lost, the data show that deaths from dementia account for 0.73 per cent of all life years lost across all diseases. Female life years lost amount to 1,299 years while male life years lost amount to 727 years, reflecting the fact that female deaths are higher than male deaths in all age categories over 65 and that female life expectancy is longer.

26. In acute hospitals, the total annual cost of caring for patients with dementia was estimated at over £5 million. This was calculated on the basis of average length of stay for patients with dementia in acute hospitals using 1996 figures and combining unit cost data based on average case mix (minus mental disorders) using HIPE data. It is considered that this is an under-estimate of the cost of caring for people with dementia in acute settings because, as will be discussed below, the HIPE data collection system misses additional dementia-related bed days.

27. For psychiatric care, the average weekly costs per in-patient bed were estimated at just over £650 per week based on published data from the Department of Health for 1995, uprated to 1998 prices. Total annual cost is obtained by multiplying average cost by length of stay by discharges, and the total annual cost was estimated at just under £14 million.

28. An opportunity cost valuation of family care as described above was considered the most appropriate calculation to use as it is a measure of what carers sacrifice in order to care. This valuation is calculated at £130 per week, which is the equivalent of a total cost for family care of £154 million annually for the total population of people with dementia.
29. The data on primary and community care is based on service use data gathered from the survey as discussed earlier. As stated here, rates of use of the Public Health Nurse and GP are highest while utilisation of other services is low which, it is argued, reflects provision rather than demand. The overall cost of care in the community, including respite care and some private provision is £16 million pounds annually.
30. The annual cost of dementia in residential care is estimated across five residential types: health board geriatric homes, health board welfare homes, health board district hospitals, private nursing homes and voluntary homes. The majority of people with dementia who need residential care are located in private nursing homes and this is where the highest costs are recorded. Direct public funding of residential care for people with dementia accounts for £21 million, or just 25 per cent of the costs of residential care. The report notes the expectation that there is also public subvention of private provision though there is no way of estimating the extent of that in relation to residents with dementia. The total cost of all residential care for people with dementia is estimated at £82 million.
31. The total baseline cost estimate for dementia in Ireland is £328 million per annum. Working on an estimate of 30,000 people with dementia in Ireland, the total cost of care spread across people affected with the disease is £9,000 per person per year. The report notes that this estimate comes at the lower range of published estimates in the international literature. Some sensitivity analyses of these costs were conducted. These show that valuing carer time on the basis of a replacement cost valuation of the hourly home help rate or on the basis of the national average industrial wage for women would greatly increase the cost for family care and thus the total cost.
32. Family care accounts for 57 per cent of the overall cost of care rising to 64 per cent if family care is valued on the basis of home help replacement cost. By contrast, the inadequate provision of community care is evident by the fact that only 6 per cent of the cost of dementia is attributable to community care services. The Council notes that these are striking figures and illustrate the

extent to which families carry a disproportionate burden of care in relation to dementia.

33. Meanwhile both the baseline and sensitised estimates produced by the report reflect actual not optimal levels of provision. There is widespread agreement that the current level of service provision in Ireland for dementia sufferers and their carers is wholly inadequate. *An Action Plan for Dementia* (1999) calls for a cash injection of £46 million over three years to begin to bring service provision to an adequate level. ***The National Council on Ageing and Older People looks forward to seeing progress on the implementation of An Action Plan for Dementia (1999).***
34. Finally, the author raises some issues regarding the limitations of the data. Assigning a replacement cost valuation for family carer time on either the hourly home help rate or the average industrial wage for women would have raised the cost of family care. In the case of the latter it would have tripled the valuation. The in-patient acute care costs are also considered to be an underestimate as they do not take account of the marginal costs in terms of additional service use and length of stay related to dementia among older patients admitted to hospital for other reasons. The prevalence of dementia and other cognitive impairments among older people admitted to hospital is estimated at 20 per cent and the study estimates that 18 per cent of all bed days are additional dementia-related days. If both of these higher estimates are used the overall cost of dementia increases from £328 million to £453 million.

This raises the need for a study on the impact of dementia on acute care costs in the form of additional dementia-related days in hospital. This is not reflected in HIPE data because only specific illness is recorded. However, dementia and other forms of cognitive impairment are common in older people admitted to the general hospital for other reasons. The difficulty lies in estimating the additional costs, in terms of service use and length of stay, associated with dementia in this group. A major element of the additional cost of care is associated with patients awaiting transfer to more appropriate forms of care. The difficulty is that we do not have data on the extent to which dementia increases the waiting time for patients awaiting transfer.

Developing the Social Economy

35. The author of this report proposes the development of the social economy as a means of improving the level of service provision necessary to meet the needs of people with dementia in relation to home care services, community nursing

services, respite facilities and day care services. This is proposed as the solution to a situation where there is a demand for services that is not met either by the labour market, or the State, who cannot or will not intervene with the result that community, voluntary or co-operative forms of organisation are required to meet these needs. Provision from this sector is proposed in the report on the assumption that the likelihood of this investment coming from conventional public sources is low given constraints on public expenditure linked to our commitment to Economic and Monetary Union within the EU.

36. ***The Council takes the view that the study shows that the needs of people with dementia are a pressing priority. An Action Plan for Dementia (1999) makes recommendations as to how these needs can be met and refers to the role of both the State and the social economy. While the role of the social economy is recognised and recommended for development, the role of the State as a provider of services is still emphasised:***

We recommend a renewed emphasis on meeting existing policy objectives for people with dementia and their carers, through legislatively based support for the equitable provision of community care services.

We recommend that the voluntary sector should be more formally involved in both the formulation and implementation of policy with respect to people with dementia and their carers.

We recommend the development of the social economy and the nurturing of social entrepreneurship at a local level as a means of meeting the needs of people with dementia and their carers in a flexible and innovative way.

In the short-term we recommend that additional resources for dementia care should be allocated to health and social care budgets; in the long-term we recommend further exploration of moving to a social insurance system for the funding of long-term care.

(An Action Plan for Dementia, 1999)

37. These recommendations recognise the potential of the social economy but reiterate the onus on the State to commit resources to the care of people with dementia. While the role of the voluntary, non-profit and co-operative sectors in providing for older people with dementia is valued and endorsed by the

Council, there is a need to be cautious in relation to the potential of this sector in the context of current economic prosperity. Moreover, voluntary organisations are currently experiencing difficulties recruiting volunteers. While this model of provision appeals to the benefits of caring there is a need to be aware of the current difficulties in the voluntary sector.

38. The commitment in the National Development Plan to the promotion of a social economy scheme as one of its package of social inclusion measures should be taken into account in considering this proposal.

Care Management for People with Dementia and Related Cognitive Impairments

39. This study and other Council reports have revealed the paucity of community care provision. The report suggests the introduction of care management as a tool to develop an adequately resourced, needs-led approach to community care focusing on assessment, enhanced individual choice and the support of carers. The basic philosophy of care management is to facilitate more flexible and individualised packages of care for vulnerable older people living at home in the community. Care managers must extend and expand client utilisation of services, develop the capacity of existing services to respond to client need, nurture and encourage new forms of provision and promote service efficiency and effectiveness (Moxley, 1989). The core tasks of a case manager are case finding and screening, assessment, care planning, implementing and monitoring the care plan (Challis, 1994). If properly implemented, care management schemes can lead to improved morale and reduction in care needs for older people, improvements in the well-being of carers compared with non-recipients of the service and a greatly improved chance of people remaining in their own homes without a significant increase in costs (Challis, 1993).
40. Care management is particularly important for those on the margin between community care and continuing care in hospital or a long-stay institution. The key issue with respect to care management is to identify the categories of older people who are likely to benefit most from care management. If it is assumed that marginal costs are lower for community care at low levels of severity while residential care is cheaper for more advanced dementia, people with intermediate levels of dependency are the most relevant group from a policy perspective. Care management can increase the ability of care in the community to deal with cases of greater severity of illness.
41. The Council believes that the aim of future services for people with dementia should not be to reduce the resources given to their care but to improve the

quality of care by improving resource allocation and accountability so as to result in health and social gain for them and for their carers. Care management is a strategy through which this can be achieved. The primary role of care management must be to improve the quality of life of people living at home in the community as opposed to focusing on cost effectiveness. Any introduction of care management in Ireland must be accompanied by sufficient resources to enable it to function effectively. These include dedicated resources and staffing at the level of community care areas complemented with increased provision in community care services. **To this end the Council believes there is an urgent need to establish pilot projects in care management and to measure and evaluate their effectiveness as advocated in *An Action Plan for Dementia (1999)*.**



Executive Summary

Executive Summary

Introduction

Dementia poses particular challenges from both the clinical and policy perspectives because of the heterogeneous nature of the condition, its multiple causes, the debilitating nature of the disease and the absence of a cure. Dementia is also a costly condition, drawing on a variety of public and private resources, and there is increasing pressure to define the cost components with a view to improving resource allocation and accountability in this area in the long-term. While services for people with dementia in Ireland are currently underdeveloped and fragmented, costs remain significant, particularly for family carers, who provide the bulk of the care. That the burden of care for dementia falls mainly on families is not all that surprising given the limited access of people with dementia and their carers to home care services, day care services, day hospital services and respite care. Unfortunately, the allocation of resources to meeting the needs of people with dementia and their carers has not matched the rhetoric of support found in various policy documents and statements on the importance of such services. The recent *Action Plan for Dementia* (O'Shea and O'Reilly, 1999) was an attempt to provide a renewed framework for the provision and planning of services for people with dementia in Ireland. This report should be seen in the same light, though with a more quantitative focus.

The Dementia Population

Changes in the age structure of the Irish population will mean a rise in the number of people with dementia. In line with the ageing of the population, the major increase in the number of people with dementia is likely to occur after the year 2011, with the numbers increasing only by 5,000 between 2001 and 2011, but accelerating thereafter, particularly in the period 2021 to 2026. Traditionally, it is families who have borne most of the burden of care for dependent older relatives and this, despite warnings to the contrary, is likely to continue, albeit imperfectly, into the future. Family care is usually provided free of charge, but this does not mean that it is free, since carers make many sacrifices in order to care. Establishing the nature of these sacrifices and how they should be valued is an important part of this study. The impact of caring on the health and psychological well-being of carers is also documented in this study.

Community care costs for people with dementia are also enumerated, quantified and valued in the report. In addition, an effort is made to estimate the gap between the services currently delivered to people with dementia and their need for services as identified by carers. The analysis of existing community care provision is augmented by a comprehensive 'top down' burden of illness study which estimates the overall cost of dementia in society. Costs are estimated for all forms of provision including residential care, psychiatric care, acute care, primary care, community care and family care. The economic burden of a disease on society is essentially the value of all resources used to prevent, diagnose, treat and generally cope with the disease. The value of the analysis is that it provides important baseline data on resource allocation and places the spotlight on current resource use, highlighting where, and on whom, the burden of dementia currently falls.

The Overall Framework

The burden of illness estimate provides an important overall framework for the subsequent discussion of policy issues. In that discussion the main focus is on ways to grow and develop community care services for people with dementia. The two main ways of achieving growth and development in community care services may be through the enhancement of the social economy and the development of care management structures. While the state will continue to provide the bulk of provision and financing in the area of dementia, new initiatives to support local, non-statutory providers of services can yield significant benefits for people with dementia. Similarly, new care management care structures can ensure that the right services get delivered to the people who need them most at the most appropriate time.

There is a high degree of sensitivity and stigma associated with dementia in Ireland making it difficult to identify potential carers for the study. When this is combined with diagnostic uncertainty with respect to the illness itself, the identification problem becomes even more acute. To help overcome this problem we have selected carer participants for the survey from two different sources. The first group consists of a non-randomised selection of carers of people known to have Alzheimer's disease or dementia. The second group consists of carers drawn randomly from the general population through a sift process, on the basis that they are likely to be caring for people with dementia and related cognitive impairments. The additional community and family caring costs associated with dementia are analysed in the two groups. Costs are estimated using both opportunity cost and replacement cost methodologies. An opportunity cost approach allows one to focus on both formal and informal resource use. This, in turn, facilitates a comprehensive approach to costing care: one that includes current and capital elements, private and public aspects, and tangible and non-tangible items.

Carers are mainly women, married, aged between 40 and 54, and engaged in home duties. A small but significant number of carers are older people themselves. The overall mean daily provision of care for carers looking after people known with certainty to have Alzheimer's disease is just under 12 hours, which is in keeping with the results from other surveys on care provision for people with dementia. The mean daily hours of care provided by carers looking after people with dementia and related cognitive impairments from the randomly generated survey is six hours per day, or approximately 40 hours per week. Many carers refer to the constant nature of care, with very high figures recorded for surveillance and supervision of the person with dementia. While people are committed to the care of dependent kin, their preference is for more freely chosen levels of care provision. Given the choice, carers would prefer to be caring less than at present. For the carers of people known to have Alzheimer's disease, the optimal caring day is eight hours, equal to what most people consider a normal working day, or just under 70 per cent of what they are being asked to do at present.

The data on formal care provision in this study confirm the paucity of community care provision for vulnerable older people living in the community. Services are largely confined to the core areas of general practitioner and public health nurse provision, with lower provision in the areas of respite care, home help, home care attendant and chiropody. Day care services are more prevalent in the group of known dementia sufferers than in the general cognitive impairment group. Some services, such as social workers, community-based physiotherapy, meals-on-wheels and sitting services, are not provided at all. The study also asked carers to state their preferences for additional services for both the person under their care and themselves. Although the response to this question was poor, suggesting that carers have low expectations with respect to community-based support services, additional respite care was the service most frequently requested by carers. Carers were much more forthcoming about wanting payment for caring with most people expressing a desire for some form of payment, with the majority satisfied with a payment of between £50 and £150 per week.

The overall cost of community care for people in the group known to have Alzheimer's disease is £234 per week, while the cost of care for people in the group with dementia and related cognitive impairments is £120 per week. While these estimates should be seen as preliminary in nature given the difficulties with the data, differences between the two groups are consistent across all items of resource use. The main element in the overall cost of community care is family care provision. The above estimates of community care costs are based on an opportunity cost valuation of family care provision. Replacement cost valuation

yields higher community care cost estimates, rising to £591 per week for people known to have Alzheimer's disease, when the replacement valuation is based on the hourly average industrial earnings of women.

The results of the burden of illness study confirm the central role of the carer in the management of people with dementia. Family care accounts for 57 per cent of the overall burden of care measured on an opportunity cost basis. That proportion rises to 64 per cent if family care is valued on the basis of home help replacement cost. The contribution of family members to the caring process is a consistent finding in the literature where such costs have been measured. The major contribution of family care is in sharp contrast to the relatively low provision of community care for people with dementia. Only six per cent of the overall cost of dementia in society is attributable to community care services. Just under one third of the total costs of dementia are attributable to residential care.

Caring for highly dependent people can be a source of major strain and psychological distress for carers. These are real costs even if they cannot be valued in monetary terms. The results of the community survey show very high levels of strain among carers, particularly for those caring for people known to have Alzheimer's disease. Over half the carers of people known to have Alzheimer's disease find caring completely overwhelming. Almost all of the carers in this group report upset because of changes in the person under their care. More than three quarters of these carers also report emotional adjustment due to caring, while the same proportion report upset due to the behaviour of the person under their care. Even more worrying, almost three quarters of carers of people known to have Alzheimer's disease score above the cut-off point in the General Health Questionnaire. These findings indicate high levels of psychological distress among carers, which requires an appropriate policy response. An expansion of respite care services would be an important practical step in reducing the stress levels of carers. Carers also need training in coping with the difficulties of looking after people with dementia. Where these training programmes are in place they have been shown to be a cost-effective way of relieving stress and reducing the psychological morbidity of carers, leading to delay in the placement of the person with dementia in an institution.

There is a significant gap between the needs of dependent older people living at home and existing levels of community care provision. Bridging this gap will be the major policy challenge in the years to come. While the state will continue to be the most important provider and funder of services for people with dementia in the future, new forms of service delivery and financing will also be important. The social

economy can be an important source of locally-based innovation in community care provision. For that reason, there is a need to explore ways of developing entrepreneurial supply-side responses to the problem of social need outside of conventional public sources.

The social economy, if properly regulated, contains the potential to address some of the social care problems facing dependent elderly people and their carers. Currently, social care production is, by and large, controlled by the state, and administered through the health boards. This control exerts a powerful conservatism on the organisation of social care and serves to dampen any sustained attempts at innovation and development by local and community groups. If progress is to be made in meeting social needs at a local level, the control which has been established by the state in the area of community care provision must be diluted. Partnership between the health board and local social economy-type providers should be developed and nurtured through new administrative and regulatory structures. Greater flexibility and choice in service delivery can be achieved through the careful integration of local economy production into mainstream community care provision for people with dementia.

34 An effective system of care for people with dementia and their carers must also be able to deliver appropriate care at the right time to people most in need of that care. Care management is the most effective mechanism for developing and co-ordinating existing fragmented systems of community care for people with dementia. Care management can also lead to the development of new services. For these reasons experimentation with care management structures should begin immediately in both an urban and a rural area. Care management should be targeted on people with dementia living at home but on the margins of residential care. Caseloads should be small so that sufficient time and resources can be allocated to each case. The care manager should have control of budgets, which would allow them to purchase existing services and encourage the development of new services. Control over resources is an important factor in enabling care managers to respond more effectively to the varied individual needs of older people.

The stated objective of public policy with respect to the long-term care of older, dependent people is to allow people to live in their own homes for as long as is possible and practicable. In recent years there has been a reduction in the number of public long-stay beds, but there has not been a compensating increase in the level of resources for community care. This trend has created enormous pressures on people with dementia and their families, as well as stretching existing community care services to breaking point. These difficulties have been well

documented in this report. Dealing with the problems identified in the report requires the following policy responses: significant investment in community care services for people with dementia; an expansion of respite care services, training and other supports for the carers of people with dementia; statutory support for the development of the social economy in locally-based services for people with dementia and their carers; and experimentation with care management structures for people with dementia and their carers.



1

Chapter 1

Introduction

Chapter 1

Introduction

1.1 Opening Remarks

Dementia refers to a group of diseases characterised by a gradual and irreversible impairment of the intellect, memory, and personality, without any alteration of conscious level. Dementia can result in a previously able-bodied and independent person becoming completely dependent. Alzheimer's disease is the most prevalent dementing disease, accounting for more than half of all cases of dementia. Dementia poses particular challenges from both a clinical and policy perspective because of the heterogeneous nature of the condition, its multiple causes, the debilitating nature of the disease and the absence of a cure. For these reasons, people with the disease may sometimes fall between the cracks of the health care system, between purely medical provision and purely psychiatric provision. People with dementia may also be discriminated against because of a lack of awareness and training amongst service providers and ignorance about the disease amongst the general public.

Dementia is a costly condition, drawing on a variety of public and private resources, and there is increasing pressure to define the cost components with a view to improving resource allocation and accountability in this area in the long-term. Recent developments in drug therapy offer new opportunities for people with dementia and will increase the pressure for earlier and wider diagnosis of the disease, leading to increased costs in the future (Rogers, Friedhoff, *et al.* 1996). Currently, services for people with dementia in Ireland are underdeveloped and fragmented. Access for people with dementia and their carers to home care services, day care services, day hospital services, and respite care is both limited and variable across the country (Ruddle *et al.* 1997). Unfortunately, the allocation of resources to meeting the needs of people with dementia and their carers has not matched the rhetoric of support found in various policy documents and statements on the importance of such services (Report of the Working Party on Services for the Elderly, 1988). The Government is, however, coming under increasing pressure to develop comprehensive community care services for people with dementia in all parts of the country. The recent report *An Action Plan for Dementia* (O'Shea and O'Reilly, 1999) was an attempt to provide a framework for the provision and planning of services for people with dementia in Ireland. The current report should be seen in the same light, albeit with a more quantitative focus.

Planning for dementia is critical if services are to be put in place now to deal with current and future demands for services. The rise in the number of people with dementia is likely to place increasing demands on health and welfare services as well as on families. Traditionally, it is families who have borne most of the burden of care for dependent older relatives. Family care is usually provided free of charge, but this does not mean that it is free, since carers make many sacrifices in order to care. Establishing what these sacrifices are and how they should be valued will be an important part of this study. Family care costs are estimated using both an opportunity cost approach and a replacement cost approach to the valuation of care provision. The impact of caring on the health of carers is also documented in this study. The study also provides estimates of the distribution of the burden of dementia across all forms of provision in this country, including residential and acute care facilities. In addition, there is some policy discussion on ways to grow and develop community care services through the enhancement of the social economy. New ways of organising the delivery of services for people with dementia are also discussed within the framework of care management structures.

1.2 Prevalence of Dementia in Ireland

There has been a huge advance in our knowledge of the epidemiology of dementia in recent decades. Studies on the prevalence of dementia, which seek to estimate the number of people with dementia at a given point in time, show a sharp rise in the prevalence of dementia with age (Jorm *et al.* 1987). A meta-analysis of the results from a number of European prevalence studies done for EURODEM (Hoffman *et al.* 1991) shows the highest rates in the oldest age categories, up to 95 years of age (Table 1.1). Although dementia can occur at any age, cases below the age of 60 years are far less common than in older age categories. When the disease does occur in younger age categories it poses different types of challenges for family carers and the health services. While changes in the prevalence of the disease across age categories tend to be consistent across European countries, country-specific prevalence studies tend to show different overall results depending on the methodology used to calculate rates, ranging between 4.3 per cent and 8.3 per cent of the population aged 65 and over (Kay and Bergmann, 1980). Prevalence depends on how we define and measure dementia (Jorm *et al.* 1987).

Table 1.1: EURODEM Prevalence Rates for Dementia.

Age Group	Males %	Females %	All Persons %
30-59	0.2	0.1	0.1
60-64	1.6	0.5	1.0
65-69	2.2	1.1	1.4
70-74	4.6	3.9	4.1
75-79	5.0	6.7	5.7
80-84	12.1	13.5	13.0
85-89	18.5	22.8	21.6
90-94	32.1	32.2	32.2
95-99	31.6	36.0	34.7

Source: Hoffman et al., 1991

Table 1.2: The Number of People with Dementia in Ireland 1996: Based on an Application of EURODEM Prevalence Rates to Population.

Age group	Males	Females	All Persons
30-59	1321	663	1984
60-64	1099	346	1445
65-69	1326	732	2058
70-74	2306	2434	4740
75-79	1761	3274	5035
80-84	2550	4684	7234
85-89	1492	3873	5365
90-94	669	1852	2521
95-99	134	487	621
Total	12,658	18,345	31,003

Source: Census of Population, 1996 by EURODEM prevalence rates.

The application of EURODEM prevalence rates to the most recent census of population data for Ireland (Central Statistics Office, 1997) suggests that there are just over 31,000 people with dementia in the country, made up of 18,000 females and 13,000 males (Table 1. 2).

Estimates by Lawlor *et al.* (1994) suggest that there are just over 22,000 people with dementia living in the community in Ireland. Estimates of the number of people with dementia in long-stay care in Ireland vary between 3,755 and 7,380, with the latter figure likely to be the more accurate indicator of prevalence in long-stay institutions. The number of people with dementia in psychiatric hospitals is estimated at just over 560 people (Moran and Walsh, 1992). Estimates of the number of people with dementia in acute care hospitals are not available for Ireland, although estimates from one health board suggest that 18 per cent of acute medical beds are occupied by people with significant cognitive impairment (Clinch and Hickey, 1992). The number of people with dementia estimated from the aggregation of prevalence data from Irish sources corresponds closely to the numbers generated by the application of EURODEM prevalence rates to Irish population data. We can say with some certainty, therefore, that there are just over 30,000 people with dementia living in Ireland.

We do not know if the number of people with dementia is on the increase in Ireland. The reason for this is because we do not have the data to allow us to compare rates over time. What is happening is that more cases are now being detected at earlier stages. This is due, in part, to improvements in primary and community care diagnostic and assessment services linked to increased public awareness about the disease. Incidence rates are also rising because more and more people are living to the age when dementia usually strikes. An extrapolation of the international incidence rates to the elderly population in Ireland suggests that approximately 4,000 new cases arise in the general community population every year (Keogh and Roche, 1996). The projected growth in the number of people with dementia is shown in Table 1.3. In line with the ageing of the population, the major increase in the number of people with dementia is likely to occur after the year 2011, with the numbers increasing only by 5,000 between 2001 and 2011, but accelerating thereafter, particularly in the period 2021 to 2026.

Table 1.3: The Projected Growth in the Number of People with Dementia in Ireland, 1996-2026: Population Projections by EURODEM Prevalence Rates.

Age Group	1996	2001	2006	2011	2016	2021	2026
30-59	1984	2067	2269	2447	2566	2602	2612
60-64	1445	1513	1792	2139	2252	2357	2319
65-69	2058	2010	2169	2587	3111	3296	3473
70-74	4740	4465	4532	4923	5929	7186	7688
75-79	5035	5354	5131	5263	5784	7060	8662
80-84	7234	7637	8165	8021	8415	9441	11,777
85-89	5365	6308	6916	7604	7672	8255	9492
90-94	2521	2874	3452	3928	4411	4578	5063
95+	621	562	690	839	985	1115	1179
TOTAL	31,003	32,790	35,116	37,751	41,125	45,890	52,265

Source: Central Statistics Office (1995) projections by EURODEM Prevalence Rates

1.3 Objective of the Report

The main objective of the report is to estimate the costs of community care for people with dementia and related cognitive impairments in this country and to discuss the public policy issues arising from the analysis of these costs. All major categories of resource use are included in the analysis, including health board provision and family care provision, in an effort to identify the distribution and burden of costs across all forms of care. The current study will extend and develop the information base on the implications of dementia and related cognitive impairments for health and social care services in this country. The study throws new light on service utilisation using a 'bottom up' approach to generating data on family and community care provision. The value added is the detailed exploration of the costs of care falling on families and on the State.

This community care analysis is complemented by a comprehensive 'top down' burden of illness study which estimates the overall cost of dementia in society. Thus, the second objective of the study is to provide an overall estimate of the

economic burden of dementia in this country. Costs are estimated for all forms of provision including residential care, psychiatric care, acute care, primary care, community care and family care. The economic burden of a disease on society is essentially the value of all resources used to prevent, diagnose, treat and generally cope with the disease. The value of the analysis is that it provides important baseline data on resource allocation and places the spotlight on current resource use, highlighting where, and on whom, the burden of dementia currently falls.

Public policy for people with dementia and their carers will also be examined in this study, particularly the important issue of the development of additional services through the enhancement of the social economy. The gap between existing community care provision and the needs of people with dementia has been well documented in other studies (O'Shea and O'Reilly, 1999; Ruddle *et al.* 1997). While the State will continue to provide the bulk of provision and financing in the area of dementia, new initiatives to support local providers of services can yield significant benefits for people with dementia. The role of public policy in the support of social economy-based initiatives will be considered in this report. New forms of organisation for community care will also be considered, particularly in the area of care management. Care management is concerned with getting the right services to the people who need them most at the most appropriate time. The development of care management structures has been identified as a key element in the recent *An Action Plan for Dementia* (O'Shea and O'Reilly, 1999).

1.4 Outline of the Report

The report begins with a discussion in Chapter 2 of the literature on carer burden, including the issue of the valuation of family care. Both of these issues are important in the context of the estimation of family care costs to be undertaken later on in the report. The motivations of carers are also addressed in this chapter. Chapter 3 discusses the role of economic evaluation in dementia care. We examine the nature of costs and benefits in dementia care as a backdrop to the subsequent analysis of resource use later on in the report. Though the analysis in this study is concentrated on the estimation of costs, some discussion of benefits is necessary if only to remind ourselves of the importance of outcomes in this area, even if they are difficult to measure. Some readers may find the discussion in this chapter overly technical in places, particularly the discussion on outcomes. Readers who are interested only in costs and the analysis of costs can ignore this section.

Methodological and data issues are discussed in Chapter 4. We include in this chapter some new estimates of carer populations in Ireland. These estimates are derived from repeated 'sifts' of the population undertaken by the ESRI. The

problems with the data, or more particularly the difficulties of generating sufficient carer respondents, are discussed at some length in this chapter. The data on service usage is considered in Chapter 5. The main findings in this area are the major role played by women in the caring process and the relatively low level of community care provision for people with dementia and related cognitive impairments living at home. Carers make many sacrifices in order to care, thereby confirming the importance of an opportunity cost approach to costing family care.

Costs are considered explicitly in Chapter 6 where we attempt to link resource use data with unit costs to give overall estimates of the cost of family care and community care for people with dementia and related cognitive impairments. Dementia is an unrelenting burden that can lead to carers becoming demoralised and psychologically distressed. Carer distress is measured in this chapter using the Caregiver Strain Index and the General Health Questionnaire. Chapter 7 develops the analysis of financial costs by providing a 'top down' estimation of the overall burden of dementia in this country. The cost of illness study incorporates all of the main elements of care, building on the family and community data prepared in Chapter 6, but also providing aggregate estimates of all types of in-patient and residential care for people with dementia.

Chapter 8 deals with the critical issue of expanding community care services for people with dementia and their carers. Repeated calls for additional resources from public sources have, so far, failed to yield dividends in terms of increased funding from the Exchequer. The private sector has not shown any willingness to become involved in either social care provision or financing. The need to explore innovative ways of increasing both supply and demand in social care services, through investment in the social economy, is now critical, given the constraints on public provision and the absence of private alternatives. Chapter 9 looks at the potential of care management as a way of resolving the mismatch between need and resources for people with dementia living at home. The recent *An Action Plan for Dementia* (O'Shea and O'Reilly, 1999) clearly signaled the importance of care management in planning for dementia and this theme is further elaborated upon in this chapter. Chapter 10 brings together the main threads of the report.

2

Chapter 2

Caring, Carers & Costs in the Community

Chapter 2

Caring, Carers and Costs in the Community Eamon O'Shea and Jennifer Stewart

2.1 Introduction

Carers are an important input into the care of people with dementia and, from a societal viewpoint, they are not a free resource. The time involved in caring for a person with dementia means that some alternative, whether labour or leisure, has been sacrificed. Caring may also impose a 'burden' on carers that can affect the quality of their relationships with family or friends, or can affect their health. These costs should be considered when developing services for people with dementia and their carers. Research on carers and how caring affects them is therefore a necessary part of dementia policy.

This chapter examines some of the broad issues that arise in the measurement and valuation of the care provided by carers for dependent older people, particularly those with dementia and related cognitive impairments. The chapter begins with a discussion of the main characteristics of carers, including addressing the issue of who bears the main responsibility for caring? The characteristics of carers that are of interest include gender, age and relationship with patient. The nature of the caring process is also examined in this chapter. Three aspects of the caring process are particularly important: the decision to become a carer, the allocation of time in the caring role and the range of tasks completed by carers. Caring actions can be divided into three categories: direct care of the patient; communication with the formal care sector on behalf of the patient; and negotiation with other family members. The direct care of the person with dementia is the most important role performed by carers and the valuation of the time spent caring is critical to any economic evaluation. The costing of the care provided by families remains, however, the most difficult part of the exercise and depends on the approach taken by the researcher to the valuation of the time spent by carers with the person under their care. The 'burden of care' may also take the form of stress and sickness arising directly from the caring role. This non-monetary aspect of caring will also be considered in this chapter.

2.2 Who Cares and Why?

Studies from several countries (Stone *et al.* 1987; Ruddle and O'Connor, 1993; Orbell, 1996; Denton, 1997) indicate that the majority of people with dementia

living in the community are cared for by family members. The family member most likely to be responsible for the majority of care is the spouse, followed by adult children, mainly females, and then other family members. This hierarchy in family members may be one possible explanation for why women constitute the majority of carers. Generally, wives are younger than their husbands and it is more likely that the older spouse will develop dementia before the younger spouse, therefore wives are more likely to be carers. Or possibly because women live longer than men do, it is more likely that a wife will still be around to care for a husband than vice versa. The lower female labour force participation rate may explain why daughters are more likely to be carers than sons.

Why caring devolves mainly on women has been debated extensively in the literature and will not be repeated in detail here (see Ungerson (1983 and 1987), and Finch (1989)). Three main reasons have been put forward to explain why people care for older people. First, care may be provided for altruistic reasons encompassing feelings of love and concern on behalf of carers. Second, reciprocity and duty will likely influence the decision to care. Third, caring may arise from feelings of guilt and moral obligation, often linked to social norms and expectations. The latter motivation may explain why caring is largely done by women, particularly if combined with ideological and material forces mediated largely through the labour market experience of women. Traditionally, for women the financial opportunity cost of caring has been lower than for men, in terms of paid work foregone, making it more likely to find women in unpaid caring roles (Ungerson, 1983). In reality, the decision to care is likely to be influenced by a combination of the factors mentioned above. Moreover, the relative importance of these motivations is likely to change over the duration of the caring experience.

Much of the empirical research into motivation has been in the form of small-scale qualitative studies (Neilsen *et al.* 1996; Globerman, 1996; Cahill, 1999). Results show that wives are more likely to want to care, while in general daughters and daughters-in-law care because of kinship obligations and because nobody else was willing or available to do so (Cahill, 1999). In Globerman's (1996) study, daughters-in-law undertook the caregiver role out of a sense that their husbands had a kinship obligation, and since the husband generally doesn't carry out caring tasks the women do it, because 'someone has to do it'. The most cited motivation for caring in this study was 'relationship obligation' while the second most cited motivation was 'moral belief'. These motivations indicate that social norms have an impact on why individuals become involved in caring. Many women may feel obliged to undertake the caring role rather than rationally 'preferring it over all other activities'.

In many cases, irrespective of primary motivations, the caregiver, on taking on the role, may have little choice but to continue caring for as long as is necessary. Family carers are expected by the medical profession and social services staff to provide ongoing care irrespective of the level of social support available to them and changes in their own material, emotional and family circumstances. Family carers are frequently not consulted, or offered services, and are sometimes given only a few hours notice to take over a role that had previously been performed by many professional health workers (Oliver, 1983). Families are expected to provide ongoing care and, within families, women are expected to care more than men do.

It is important to make clear that carers are not a homogeneous group. For example, daughters may be married or unmarried and they may or may not have children. A small but significant proportion of carers are male with potentially different needs and expectations than female carers (Wells, 1999). Many carers are elderly and may themselves be dependent in one way or another. These differences must be reflected in the framing of policies to support carers in the caring role. The needs of carers are varied and complex reflecting the individual and particular nature of each caring relationship. The diversity of provision, relationships and needs will be confirmed later in the analysis of the data generated for this study.

2.3 The Nature of Care

The first task in estimating the cost of informal family care is to quantify the time commitment involved. There are two main problems that have arisen in estimating time spent caring. First, where there is an existing relationship between the older person and the carer it is necessary to ascertain how much time would have been spent together in the absence of disability. Where carers and older people live in the same household, time spent in social interaction need not result in any specific substitution of time, while caring tasks do result in time being given up. If no extra time is spent in providing companionship, then this should not be included as an opportunity cost. In the case of dementia, however, time spent in social interaction may be extremely stressful for the carer, because they often have to deal with problem behaviour, such as aggressiveness, repeated questioning, and wandering. Second, and related, is the problem of joint production. Joint production occurs when more than one commodity is produced in the household at the same time. For example, it may be difficult to separate own shopping time from shopping on behalf of the person with dementia. Similar attributability problems may arise with respect to meal preparation, washing and particularly companionship, which can be engaged in while the carer completes normal household tasks.

One method of overcoming the problems outlined above is to ask carers to keep detailed time diaries recording their daily activities and time specifically spent on caring. Time diaries, if diligently filled in, can be used to give an exact breakdown of the time spent in providing care. The problem is that time diaries take time to understand and to complete. And time is a scarce commodity for carers. In addition, time diaries are costly to administer and analyse, with more than one visit being necessary to the survey the household to ensure that the diary is completed and returned. As a result of these problems time diaries are only practical in small-scale surveys with a small number of cases, or in large-scale surveys with huge research budgets. The alternative to the time diary method is to ask people to estimate contemporaneous care provision through personal interviews. This approach may yield adequate information if the questionnaire is sensitive to the disaggregated nature of the caring process.

In general, while time spent caregiving is high, there is considerable variation in the total amount of time spent, due to different levels of dependency and different attitudes on the part of carers. For example, while Blackwell *et al.* (1992) found that on average carers of dependent older people spent 47 hours per week on caring duties, the average amount of care provided for persons at the highest dependency level was 85 hours per week. Many of the people at the highest level of dependency experienced significant mental health problems or had other problems associated with mental infirmity. Interestingly, there also seems to be a minimum threshold provision associated with caring. People with low dependency still required 38 hours of care per week according to Blackwell *et al.* (1992). This result is a powerful one because it suggests that once a caring relationship is established the time commitment is significant even for carers of people with low dependency levels.

The tasks that carers perform for people with dementia are many and varied. Tasks include activities such as assisting the person with dementia with activities of daily living, doing household tasks, going shopping, providing transport and maintaining the personal relationship with the person. Studies have examined the tasks performed by carers and the carers' feelings about the tasks undertaken. Two studies of general populations of older carers Stone *et al.* (1987) and Orbell (1996) examined the tasks performed by carers by the carer's gender and relationship to the patient. A common result from both studies is that women are more likely to perform personal hygiene tasks than men and the closer the carer is related to the patient the more likely they are to perform personal hygiene tasks. Although this result is based on studies of general populations of carers, it is probable that it is

applicable to carers of dementia patients given the consistency of the finding. This finding indicates that there may be differences between men and women in the tasks undertaken for people under their care, differences which may have implications for the range and quality of the care provided.

2.4 Caring and the Valuation of Time

Carer time has been valued in three main ways: replacement cost approach; transfer payment approach; and an opportunity cost approach.

(a) Replacement cost approach

This approach assumes that in the absence of the caregiver, the services provided by carers would have to be paid for by the State or hired through the market. A version of replacement cost was used by both Hay and Ernst (1987) and Hu *et al.* (1986) in their research on the aggregate cost of dementia in the United States. The latter based their estimate of the cost of carer input on the current (at the time) median wage of a 'replacement' nursing aide, valued at \$4.64 per hour. This approach is not ideal, however, since carers perform different activities apart from nursing, costs for each of which ought to be estimated. One study, which attempted to capture the variety of tasks associated with caring, is that by Harrow *et al.* (1995) on carers for the older people with disabilities in the US. They divided caring into different activities and used a weighted average wage based on the hourly rates for nurse's aides, cleaners, book-keepers and social workers. This weighted approach was also used by Max *et al.* (1995) in their study of informal care for people with Alzheimer's disease in California.

Theoretical work by Hawrylyshyn (1977) attempts to justify the replacement cost approach, on the basis that only the direct utility associated with caring should or can be measured. As a result, while the work is valued, in the sense of the gain to the person receiving care, the pleasure or indirect utility experienced by the carer is not valued. This approach ignores the fact that indirect utility seems to form a large part of people's motivations to care. Indirect utility is the satisfaction the carer derives from the perceived pleasure of the person receiving care. Even though a person with dementia may not be able to express satisfaction for care received, they may suffer increased levels of distress if they are not being cared for by someone they know, in their own homes. The knowledge that they are preventing such distress can be an important form of indirect utility for carers. Indirect utility may also include elements of reciprocity or repayment for care when the carer needed it in the past. Indirect utility may also be associated with an improved relationship

between the carer and the person being cared for, although this is not always obvious in the case of dementia. Indirect utility may also be associated with the satisfaction gained from providing the best possible care, from doing one's best in the circumstances. Indeed, when some people talk about caring they emphasise the transcendental or spiritual dimension of caring, which is difficult to capture under a conventional utilitarian calculus (Clifford, 1991).

Finally, the replacement cost approach does not capture certain aspects of caring such as the requirement to be constantly on call. Dealing with caring in terms of replacement does not capture the relentless nature of the caring role within the family, which is not there for paid employees, even where they might be carrying out the same caring tasks as family carers. Caring is a responsible and onerous task and many spouses find themselves taking on tasks previously performed by a team of professionals at high wage rates. Professionals do not usually carry the ongoing responsibilities and concerns associated with family relationships.

(b) Transfer payments

A second method of estimating the cost of care is to look at the amount of statutory benefit received by carers (Gray and Fenn, 1993). Caring is valued on the basis of what the State pays carers. There are three main problems with this approach. First, statutory allowances are not paid to all carers, since usually there are qualifying conditions associated with receipt of benefits. Second, transfer payments reflect the generosity of the State redistribution system at any particular time and are influenced more by political exigencies than by any consideration of the true worth or value of carers. Third, transfer payments bear no relationship to the effort or sacrifice involved in caring. This method underestimates the overall cost to a carer, since it does not account for the opportunity cost of lost working time, nor the cost of interrupted career paths if the carer has previously been in well-paid employment.

(c) Opportunity cost

A third method of valuation is to use the opportunity cost approach. This is the measure favoured by economists since it attempts to place a monetary value on the alternative use of carer time. In assessing the financial opportunity cost, different values are assigned to caring depending on whether the alternative use of time spent caring is paid employment or leisure time foregone. Work time is valued on the basis of what the carer might be working at if not involved in caring. Valuation will depend on the age, education and previous work experience of the carer. Leisure time is valued at a percentage of work time,

usually between 25 per cent and 33 per cent, since leisure is perceived to benefit the individual only, not society in general.

Some researchers have suggested modifications to the opportunity cost approach to take account of the complexities of the caring role. Wright (1987) suggests that different values should be assigned to time spent caring depending on the difficulties of the tasks involved. Caring would be weighted according to the unpleasantness of the task to be completed. However, establishing these weights would complicate the valuation process even more. For example, even though the task of surveillance or keeping an eye on a person with dementia is not difficult, or necessarily unpleasant, the need to be constantly on call can be both difficult and wearisome. Establishing a weight for keeping an eye on someone could prove a very difficult exercise. In any case, whether the carer enjoys the task is not the issue; the sacrifice made by the carer is the important point and should be the object of valuation.

Caregiving can also affect carers' work opportunities in a number of other ways outside the dichotomous decision to stay in paid employment or give up paid work in order to care. While some carers give up work in order to become caregivers others may reduce their working hours or reject opportunities for promotion, particularly if travel is required for the new post. All of these actions will have a number of short- and long-term consequences for carers. If carers leave the workplace at an early stage in their career, they may be unable to find employment again and/or career progression may be interrupted. They may also fail to build up occupational pensions. Rimmer (1983) suggests that focusing on the short-term loss of earnings fails to capture the most serious consequences of leaving the paid labour force in order to become a caregiver. Quitting paid work, reducing hours worked and forgoing career advancement will also have long-term impacts, affecting pension rights, career prospects and future earnings.

Netten (1993) suggests a formula to deal with the cost to the carer in this instance. The cost 'would be the difference in expected future earnings or unearned income resulting from caring responsibilities discounted back to the present time to give a weekly expected loss'. She suggests that the cost to the carer should include discounted future income from pensions as well as lost wages. This suggestion is entirely in keeping with the recommendations by Walby (1996), that one of the main sources of disadvantage in western society to women engaged in informal labour is their lack of direct access to a pension, which is dependent on having continuous periods of time in the paid labour

market. This, she argues, prevents them from access to economic security and full social citizenship in a way comparable with non-carers. A related cost to carers is the loss of non-material benefits such as the status, social contacts and sense of identity that being part of the paid labour force gives to people.

Family carers give up more than market-based work. It is not enough to only include time for which a wage is received, because this implies that other work is 'not productive'. Women carers may also sacrifice unpaid work in the home. This work is also productive and is a valuable contribution to the well-being of society. One proposed solution to this problem is to value non-waged time (e.g. time spent in retirement or childrearing) as a 'productive non-market activity'. Sometimes it is assumed that as most of this work is housework the hourly rate of general domestic help can be used in the valuation process as a proxy for housekeeping. Taking this approach is not, however, without controversy. Feminist critics argue that domestic work is traditionally undervalued by society; thus in using the rate for domestic help, such work is not valued highly enough. The market is not always a neutral mechanism in which price reflects the value of labour. Social norms influence the value assigned to particular skills and not others.

There is a series of related papers based on large-scale surveys (White-Means and Chang (1991); White-Means (1992); Chang and White-Means (1995); and White-Means (1997)) that examine opportunity cost issues for the carers of all types of frail older people. The first paper examines the factors affecting the hours spent on caring. The second paper also examines this issue and then examines the factors which influence the probability that carers decrease their leisure time and the probability that carers reduce paid work in order to care. The third paper focuses on the employment decision and first analyses whether the carer works or not and then, controlling for selection bias, looks at the factors that influence the number of hours worked. The fourth paper analyses the demand for formal health care services and the probability of decreased employment and decreased health status for the carer.

A basic premise behind these papers is that carers sacrifice something to spend time caring, whether the sacrifice is leisure time or time spent in employment, which in turn would mean decreased income. The fourth paper extends this basic premise to acknowledge that sacrificed leisure time may include time the carer would have spent on caring for themselves and which decreases the carer's health status. The economist's prediction is that factors which increase the value of what is being sacrificed will decrease the time spent on caring. For

example, a carer with higher wages would be expected to spend more time in employment and less time caring than a carer earning lower wages because the cost of caring is higher for the carer with higher wages.

There are some consistent results across the papers. In the two studies which examine hours spent caring, it was found that women and carers who were part of the patient's immediate family spent more hours caring. It was also found that the more other carers there were, the more hours spent caring by the carer. This result is interesting because it is contrary to the expectation that the presence of other carers would allow the carers to share the caring responsibilities, thereby decreasing the time spent caring for any one carer. This unexpected result may be due to extra time spent co-ordinating the other carers which would increase total caring time or perhaps families with several carers are also able and willing to spend more time with the patient. There was also evidence that carers with higher wages spent fewer hours caring as might be expected from theory.

When considering the employment decision, there was one consistent result across the three papers that looked at this issue. Carers were asked what they felt would happen if they were unable, for whatever reason, to perform their caring role at some time in the future. Carers who felt that a substitute would be available, should something unforeseen occur, were less likely to have changed their employment pattern in the past and were more likely to be currently employed. This result does not indicate that another carer is present and already sharing caring responsibilities so that the main carer has more time for employment. Rather, this result suggests that the knowledge that a substitute is available should anything unforeseen happen allows the main carer to accept more responsibilities. This raises interesting issues about the distribution of care responsibilities within households and the role of the State in promoting positive attitudes to sharing and substitution within households. The knowledge that the formal services of the State are also available to step in during an emergency may also allow carers to remain in employment.

2.5 Financial Costs of Care

While it is relatively easy to measure the financial costs of caring as opposed to the cost of time, there are some problems associated with measuring these costs. One approach is to simply ask the carer to enumerate money spent on items under various headings. Money spent on once-off capital items, for example, adaptations to bedrooms, bathrooms, providing locks and so on would be one heading. So also would money spent on medicines and any money spent on services such as Home

Helps, day care, or respite care. Similarly, money spent on aids such as incontinence pads, special mattresses, and so on would have to be monitored. There is no difficulty as long as the marginal cost of all of these items can be identified and linked directly to the caring role.

Sometimes, however, the estimation of marginal cost can be difficult. For example, if the carer is co-resident with the person with dementia it is often difficult to estimate how much extra money is spent to feed and heat the person being cared for. Sometimes less obvious items are omitted entirely from the analysis. For instance, some carers buy more expensive convenience foods, take taxis shopping, or pay for services such as decorating and dressmaking since they no longer have time to do their own due to the restrictions of the caring role. Qualitative studies have highlighted these areas of expenditure, which are often difficult to pick up in aggregate quantitative survey work.

2.6 Caring and Stress

It is generally accepted that the carers of people with dementia bear a heavy burden, depending on who they are and what they do (Eagles *et al.* 1987). The difficulties in conceptualising and measuring the burden felt by family carers have been discussed by researchers in many fields (George and Gwyther (1986); Pearlin *et al.* (1990); and Ramsey *et al.* (1995)). It is not necessary to explore measurement issues in detail other than to comment that there are many dimensions of a person's well-being that can be affected by caring and we will consider any impact as important. Drawing conclusions from the literature is nevertheless complicated by the variety of outcome measures and techniques used.

Donaldson *et al.* (1997) provide a comprehensive review of the literature on the impact of symptoms of dementia on carers. Their review highlights the difficulties in summarising the literature even though they consider the impact of a limited set of factors. They structure their review around the various outcomes measured which they grouped into seven categories: burden, impact on patient/carer relationship, restrictions on social activity, psychological distress, anxiety/stress, depression, and physical health. Despite large variation between the studies, Donaldson *et al.* (1997) draw three conclusions. First, non-cognitive features, such as hallucinations, depression, etc., are related to an increase in carer's burden, increased psychological problems in carers, an increase in anxiety, and a decrease in the patient/carer relationship. Second, cognitive problems in patients may affect carer burden but they felt more research was necessary before a strong conclusion could be reached. Third, activities of daily living (ADL) limitations do not appear to be related to psychological problems in carers.

There are three important and consistent results from the literature with respect to the relationship between burden and carer characteristics. First, the relationship to the patient and residency situation has an impact on carers. Second, help from others has a positive impact on carers. Third, the carer's perception of the degree of incapacity of their patient affects burden and stress levels. Gilhooly (1984) finds that the closeness of the relationship between carers and the person being cared for matters for burden levels; spouses have poorer mental health than children, who in turn have poorer mental health than other family members. Gilhooly also finds that living in the same household as the person being cared for is correlated with a lower morale for the carer. George and Gwyther (1986) find that spouses have a lower well-being than children and other family members, but they did not examine residency. O'Connor *et al.* (1990) found that co-resident children experienced higher levels of strain than spouses or non-resident children. Eagles *et al.* (1987) found no difference between spouses and children, although the issue of residency was not examined. It seems reasonable to suggest, however, that caring may have a stronger negative impact on the well-being of co-resident children (Gilhooly, 1984).

Gilhooly also finds that satisfaction with help from relatives has a positive correlation with the carer's morale and mental health. George and Gwyther find that a perceived need for social support is negatively correlated with most of their measures for well-being. Haley *et al.* (1987) find that a more developed and varied social network is correlated to higher levels of both life satisfaction and health status. Cohen *et al.* (1994) find that church attendance is the only social network characteristic to have a direct and positive effect on the carer's psychological well-being, but that most other social network variables have an indirect impact. At a minimum, the results indicate that positive interaction with others has a positive impact on carers along many dimensions such as decreased stress levels and improved mental health.

Eagles *et al.* (1987) and Jerrom *et al.* (1993) both find that the carer's perception of the severity of the patient's dementia is positively correlated with their reported level of strain as the more strain the carer feels the worse they believe their patient's condition to be. This result seems to contradict other studies that severity of dementia is not related to carer outcomes. The difference in the results is explained by the fact that it is how carers perceive their situation that matters. This result has implications for policy in the role education or information can play in assisting carers come to terms with the caring situation. If perception is what really matters then changing negative perceptions of dementia is of paramount importance. Carers need information on the condition itself, on primary and

community care services and on social support mechanisms for themselves. Providing more information is not likely to be costly but will have important long-run effects on both process and outcome in the home leading to improvements in the well-being of carers and people with dementia.

White-Means (1997) examines the possibility that carers sacrifice their own health status in the caring process. The two factors that were found to significantly increase the probability of decreased health status for the carer are constant care-giving and restricted social life. O'Connor *et al.* (1990) examined the impact of patients' needs on carers. In general, problems of physical dependence and disturbed behaviours were correlated with higher levels of stress in carers while apathetic behaviour was less stressful. Specifically, they examined which of the patient's needs were tolerated least well by carers. The top five of least tolerated behaviours were constant demands for attention, cannot be left for one hour, nosiness, falls, and personality clashes. These results suggest areas where policy intervention could be directed to best help carers.

2.7 Family Carers and the State

Caring involves interaction between family carers and the formal care sector. Several papers have suggested and tested possible models and relationships between the formal care sector and the family care system (Chappell and Blandford (1991); Denton (1997); and Vetter *et al.* (1997)). These models are attempts to explain how and why formal and informal services may, or may not, be used in conjunction. The first model is a task-specific model where the amount of care used from each sector depends on the tasks that are required to be completed. Second, a substitution model is suggested where use of formal services is accompanied by a similar decrease in the amount of family care and the opposite where the existence of family leads to minimal intervention by the formal sector. Third, and related to the previous model, the sectors could be viewed as compensatory where use of formal care would occur when other preferred alternatives are not available. Fourth, a supplementary model is proposed where formal care coexists with family care, especially when the demands of caring exceed the resources of the carer. Fifth, a complementary model is suggested that combines the compensatory and supplementary models. The papers that have tested these models suggest that the 'best fit' model is one of complementarity, wherein the formal sector is often turned to when the needs of the patient overwhelm the carer. These papers point out that carers turn to the formal sector when an 'overload' occurs, although there is less evidence of intervention to prevent such an 'overload' occurring in the first place.

In Ireland, stated public policy has been directed towards maintaining people with dementia in their own homes for as long as possible and practicable (Report of the

Working Party on Services for the Elderly, *The Years Ahead*, 1988). A number of policy recommendations were outlined in this report which would provide support to people with dementia and their carers. While some improvements in services have been made, the gap between the needs of older people and their carers and actual service provision, which was identified as far back as 1988, has not yet been bridged (Ruddle *et al.* 1997). While a number of health boards have recently put forward plans for new services for older people, it is too early to say if these plans will bring about new investment in community care. The lack of a match up between rhetoric and actual provision is indicative of the Government's attitude which is to regard the labour of family carers as a free good and a substitute service for government provision. This leaves families (and this generally means women) to cope with the onerous demands of caring with a minimum of support. This can result in either the complete physical and mental breakdown of the carer (who then has to be replaced with expensive residential care), or the provision of poor quality care to the person with dementia. These results are both inefficient and inequitable to the carer and to the person with dementia.

Family carers provide most of the support to people with dementia. However, their role is neither sufficiently acknowledged nor appropriately rewarded. Blackwell *et al.* (1992) found that what carers most wanted was some financial recognition for their efforts from the State. One way of doing this would be to increase and broaden the scope of the Carer's Allowance into a non-means-tested payment linked to the dependency of the person with dementia. This would increase the number of people eligible for the Carer's Allowance and would be a clear signal that society values the work being done by carers. Following a review of the Carer's Allowance, the Department of Social, Community and Family Affairs (1998) recommended the introduction of a new dependency-related 'continual care payment' for all carers who are providing the highest level of care. This new payment should be introduced without delay. Recent improvements in the scope of financial provision for some carers, arising largely as a result of the political fall-out from Budget 2000, are welcome and timely, but the changes announced do not go far enough in recognising the multifaceted and heterogeneous nature of the caring role.

Other policy changes are needed to provide more flexibility to carers with respect to work and caring choices. Paid leave for certain categories of carers for specified time periods should be considered. Specific certified training in dementia care would also be useful not only in providing a higher quality of care, but in providing the carer with a qualification to rejoin the labour force if they so wish. Another measure that should be addressed is the issue of pension provision and entitlements for full-time carers. Both of these measures could help offset some of the career disadvantages noted above.

Carers also stress the need for more information and for greater realisation by the formal sector of the carers' own physical and mental health. Carers not only want more information but they also want to be used as a source of information on the needs of the person with dementia and on their experience as a carer. Carers want information at the first contact with the formal sector (Keady and Nolan (1995); Ward and Cavanagh (1997)). Often, the first contact is made after symptoms have been observed for a long time and the carer feels that information is required immediately. There is also the lag between first contact and diagnosis, which can further delay the provision of information and further frustrate the carer. Information must be given as part of an ongoing process because dementia is a progressive disease and the demands on, and needs of, carers will change over time. Furthermore, carers expressed the wish to share information with either a general practitioner, counsellor, or other carers (Koffman and Taylor, 1997).

2.8 Conclusion

Family caring for people with dementia is an onerous task requiring levels of dedication and application, which if provided in other forms of work would be well rewarded. Family caring is, however, considered a free resource and very rarely are carers publicly rewarded for their endeavours. Carers give up many things to look after dependent family members, including both work and essential leisure. The monetary valuation of these sacrifices through an opportunity cost methodology suggests that the cost of family care is not insignificant. There may also be stress-related costs associated with caring for some carers. The evidence from the literature is that, although family care is difficult to measure, and controversy still exists with respect to its monetary valuation, to ignore it would seriously undermine the credibility of the subsequent cost analysis.

Chapter 3

Issues in Economic Education

Chapter 3¹

Issues in Economic Evaluation

3.1 Introduction

This chapter outlines the main issues that arise when estimating the costs of caring for people with dementia and related cognitive impairments. Particular attention is paid to methodological problems associated with economic evaluation and how they might be resolved. The main elements of resource use are considered in turn, in terms of the enumeration, quantification and valuation of all costs. There is also a discussion of benefits in the chapter, since the measurement of benefit is an important part of full economic evaluation. Even though benefits are difficult to measure and for that reason are not estimated in this report, they remain central to the discussion of services for people with dementia. It would be a travesty to equate efficiency with cost control. The quality of care and the outcomes associated with care also need to be explicitly recognised if not always measured.

Economics begins with the basic premise that resources are scarce and then studies how these scarce resources are allocated within an economy. This basic premise underlies any economic evaluation of health care programmes. An economic evaluation can serve two purposes. First, it can be used to simply determine the efficiency of a programme where a programme can be anything from the introduction of a new service for carers to a new drug treatment for patients. An efficient programme has outcomes the value of which are greater than the cost of its inputs. Second, an economic evaluation can be used to compare efficiency across programmes. Often decision-makers face not just the decision whether to implement a programme or not, but rather which programme to implement. An economic evaluation supplies a common reference point with which to compare programmes.

3.2 Economic Evaluation of Dementia Care

Following Knapp and Beech(1990) it is possible to set out four rules for the evaluation of health and social care services for people with dementia. First, costs should be comprehensive, meaning that inputs and outcomes should generally be measured broadly, covering both service provision and financial aspects, and the likely impacts on users, carers and society as a whole. The greater a patient's needs the broader the range of available services likely to be utilised. For example, people

¹Jennifer Stewart contributed to this chapter.

with severe dementia who are in contact with a health or social services agency tend to use a wide range of support services. The evaluation of dementia care programmes should include all service inputs, if the full impact on resources is to be assessed. Ideally, costs should also be measured in marginal terms, by looking at the addition to total cost attributable to the care of one more patient, or the production of one more unit of care. In practice, reliance is usually placed on average cost, given measurement difficulties and the absence of capacity constraints.

Second, it is necessary to recognise that there will be cost and outcome variations between patients, facilities and geographical areas. These variations should not be ignored as their examination yields valuable information for both policy and practice. The question as to whether it is possible within a broad organisational structure such as community care to identify and explain different utilisation patterns, or individual patient outcomes, has been raised. Instruments such as the randomised control trial (RCT) have been developed in order to remove the extraneous variation, but the use of RCTs has been limited because the conditions necessary to undertake the trial rarely prevail. Notwithstanding such difficulties, 'like with like' comparisons should be made if at all possible. The influence of extraneous factors should be removed, or qualifications made to ensure that comparable samples of patients or facilities are studied in comparable contexts. These are the only comparisons, which have full validity, and constitute the third rule for work in this area.

Finally, some effort must be made to link costs and outcomes. Cost information should not be explored in isolation from other information. Costs should be integrated with information on patient need, diagnostic category, and patient outcomes. The link between costs and outcomes is very important because it facilitates an analysis of the health production function. For instance, the issue of whether higher levels of spending lead to better outcomes for people with dementia is important for policymakers. Similarly, an exploration of the health and social gain associated with particular forms of intervention extends the analysis beyond a simple treatment of costs, and thereby reduces the likelihood that the consequences of low-cost treatment for people with dementia will be ignored.

It is generally recognised that most interventions in dementia care will have an impact along many different dimensions. To deal with this, researchers have constructed survey instruments that attempt to measure outcome along various dimensions. The dimensions that have been examined include physical function, ability to perform activities of daily living (ADL), mental health, social contacts and

networks. What needs to be measured can vary, and depends upon the objectives of the study, the expected impacts and past experience. Ramsey *et al.* (1995) provide an extensive review of available measures and conclude that the outcomes that are of interest when evaluating programmes for people with dementia and their carers are multi-faceted and sometimes can be difficult to identify, let alone quantify.

There has been much recent discussion about what characteristics an ideal instrument would possess (Clancy and Cooper (1997); Fortinsky *et al.* (1997); Higginson *et al.* (1997); and Hyde *et al.* (1998)). An ideal instrument should have four characteristics: validity, reliability, sensitivity, and feasibility. Validity refers to the ability of the instrument to measure the outcome of interest. For example, if researchers wish to measure the quality of life of patients then the instrument used should ask about social networks as well as ability to perform ADL. Reliability refers to how well the instrument measures the outcome. To determine reliability, an instrument may need to be tested alongside other instruments. Sensitivity refers to the instrument's ability to detect differences in the outcome between patients and over time. Often an economic evaluation of a programme will measure the outcome at the beginning of an experiment and wish to detect changes over time, for example, when a new drug is being tested. The instrument used will need to be sensitive to changes in the outcome over time. Feasibility refers to the ease with which the instrument can be used by users. For example, a research design may ask carers to use the instrument. The instrument must be designed so that carers have no difficulty in using it and are willing to use it. Factors such as the length of time to complete the instrument or repetition within the instrument need to be considered. Research into evaluating existing instruments has also begun (Ramsay *et al.* (1995) and Salek *et al.* (1998)). Both of these papers conclude that future work is necessary to further evaluate outcome measures.

3.3 Methods of Economic Evaluation

Within the framework outlined above, there are three basic approaches to the evaluation of care programmes for people with dementia: cost-effectiveness analysis (CEA), cost-benefit analysis (CBA), and cost-utility analysis (CUA).

3.3.1 Cost-Effectiveness Analysis

In a cost-effectiveness study the outcome or benefit of a treatment is measured in terms of uni-dimensional units such as life years gained, number of pain free days, or improved physical/social/emotional functioning. The measure of effect used depends upon the objective of the treatment programme being evaluated. For

example, if the objective of the treatment is to extend life, life years gained would be an appropriate measure of benefit. However, if the effect of treatment is to improve the quality of life rather than the quantity of life, the number of disability days avoided, cognitive improvement, or some combination, would be more suitable. Unfortunately, given that benefits are measured in uni-dimensional units it is not possible to measure the effect of a treatment on both the quantity and quality of life, nor can more than one aspect of quality be measured. Hence, important effects of a treatment may be ignored using this framework. Despite this limitation, cost-effectiveness analysis remains the most common, and probably the simplest, method of evaluation, particularly in the area of dementia care.

3.3.2 Cost-Benefit Analysis

The strength of cost-benefit analysis is in evaluations where the outcomes of different programmes are not identical and, therefore, cannot be expressed using the same physical measure. Cost-benefit analysis is useful in that it allows the policymaker to compare treatment costs with benefits using the same measure of value (usually money). Cost-benefit analysis determines the net social benefit (NSB) of the programme. The decision rule simply states that if $NSB > 0$, the programme should be implemented, and if $NSB < 0$, it should not. The analysis translates physical effects, such as disability days avoided, or life years gained, into monetary values using either market values or willingness-to-pay estimates. However, full CBA is rarely performed for specific health care interventions as measurement of certain less tangible costs and benefits are problematic.

A cost-benefit analysis attempts to put a monetary estimate on the value of the outcomes. There are different approaches to determining the monetary estimate. The human capital approach would value differences in years of future life by estimating the gain in productive ability associated with particular interventions. The problem with the human capital approach is that it only values productive years of life and ignores the value of leisure. For people with dementia it would be very inappropriate to judge programmes simply on the basis of their contribution to productive capacity given the nature of the disease and the age profile of people with dementia. The benefits of particular programmes for people with dementia may also be analysed using a willingness-to-pay approach. A survey might be conducted that asks respondents what is the maximum amount they would be willing to pay for particular programmes with particular outcomes for people with dementia and their carers. Willingness-to-pay estimates can be compared across programmes and can be linked to the characteristics of respondents. The willingness-to-pay approach has not yet been used in an analysis of programmes for people with dementia or their carers.

3.3.3 Cost-Utility Analysis

Cost-utility analysis is a special form of cost-effectiveness analysis in which the different dimensions of well-being are collapsed into a single measure such as quality-adjusted life-years (QALYs). A cost-utility analysis measures the value of current and future health relative to being in perfect health for a specified time period. The QALY equivalent of a year in the current health state represents how much of a year the patient would be willing to sacrifice to be in perfect health for the remaining time. A quality adjustment factor is first derived for a particular health state relative to death (rated 0) and perfect health (rated as 1). The survival duration is then multiplied by the quality adjustment factor to derive the number of QALYs produced by the programme. There are different processes that can elicit the relative value. The QALY is appealing because comparisons of efficiency, can, in principle, cover all the various forms of health care interventions that exist today. However, there has been criticism that QALYs discriminate against older people and for that reason should not be used to compare health and social care interventions for older people with interventions for younger age categories. While QALYs have not been used to rank the effectiveness of dementia programmes relative to other programmes (Gerard, 1993), there is a small amount of literature on the application of QALYs within the area of dementia for both carers and for people with dementia. Mohide *et al.* (1988) used a time trade-off technique to measure the relative value of different levels of well-being for carers of older people with different types and degrees of disability. In a time trade-off carers are asked to make a trade-off between length of life and quality of life. Carer respondents are presented with descriptions of two alternative states: one alternative is the reference (ideal) state and the other is a less than perfect health state for a set number of years of future life. They are then asked the maximum number of years of future life they would sacrifice in order to have the reference state for the remaining years. The ratio of the number of years in the reference state to the number of years in the comparison state is a measure of the relative value of the two states. For example, if a carer was told that they had twenty years of future life, at their current level of well-being and responded to the time trade-off question that they would give up five of these years if instead they could have the reference level of well-being for the remaining fifteen years then the ratio would be $15/20 = 0.75$. The relative value of the carer's current state is three quarters of the value of perfect health. These relative values can be used to convert years of future life in different states into a QALY. From the example, one year in the current state is equal to three quarters of a QALY.

The Mohide *et al.* study indicates that the time trade-off technique does discriminate between different states. When used to determine the value of the carer's current

state, the time trade-off does indicate a difference between carers with cognitively impaired patients, physically impaired patients, and well older relatives. Furthermore, there was a negative correlation between the scores produced by the time trade-off and the degree of stress reported by respondents. This study tested the feasibility and validity of the time trade-off technique to measure the well-being of carers. This process is one half of an economic evaluation and it is crucial that researchers are able to value the changes in well-being.

Neumann *et al.* (1999) use a health utilities index, the Health Utilities Index Mark Two (HUI: 2), to measure the health-related quality of life of people with Alzheimer's disease and their carers. There are two components to the HUI: 2. First, health status is measured along seven attributes-sensation, mobility, emotion, cognition, self-care, pain and fertility.² Second, there are preference weights attached to the different health levels in each attribute. These weights were determined by sampling a general population, not just Alzheimer's patients and their carers. To determine the weights, respondents were asked a standard gamble question. In its simplest form a standard gamble presents two alternatives to the respondent; one alternative is a less than perfect health state for certain and the other alternative is a gamble between perfect health for the same amount of time as the certain case and immediate death. Respondents are asked at what probability of receiving perfect health they would be indifferent between the certain alternative and the gamble. This probability is then their preference for the health state with less than perfect compared to perfect health. The HUI:2 can be used in various situations to measure an individual's health status relative to perfect health.

Neumann *et al.* (1999) test how well the HUI: 2 can measure a patient's health status when proxy respondents (such as carers) are interviewed and how the measured health status varies over the stages of the disease for both the patient and carers. They find that proxy respondents are willing and able to complete the survey. In addition, HUI: 2 does discriminate between the different stages of Alzheimer's disease for patients, although measured health status of carers is not affected by the stage of the disease. They were not able to test if the HUI: 2 could measure changes in the patient's health status over time. For the HUI: 2 to be useful in an economic evaluation, it would be necessary for it to be able to measure changes that occurred because of a programme intervention. Researchers are currently examining how best to construct health utility indices in this and other areas. These two studies show that health utilities are feasible even if not yet perfect, but there is evidence of a willingness to explore CUA in the area of dementia.

²Fertility was not considered by Neumann *et al.* (1999) to be applicable to AD patients.

3.3.4 Measuring Costs

Irrespective of the appraisal technique used in the evaluation of mental health care programmes, costs must be enumerated, quantified and valued in all three approaches. The distinction between public expenditure and opportunity cost valuation is particularly relevant in dementia care. An opportunity cost approach takes account of all resource use, irrespective of where the costs fall. In contrast, a public expenditure approach concentrates only on the costs and expenditures of the public agencies directly associated with caring. Costs that fall on agencies or individuals outside of the public sector are deemed irrelevant. The main difference between a conventional public expenditure notion of cost, and the economic concept of opportunity cost, is the explicit recognition of informal care in the latter. However, very few studies have documented, *let alone* put a value on, the involvement of the families in the care of dependent persons living at home. The costs for family members may be immense, particularly with respect to employment and leisure opportunities foregone, as well as fatigue and worry. The issue of family care has already been discussed in the previous chapter. For now, however, it is enough to highlight the major differences between public expenditure and opportunity cost approaches to comparing community and institutional options for older people (Table 3.1).

Capital is usually not treated as a resource use under a public expenditure approach to costing, for the reason that health boards or local authorities are rarely, if ever, required to pay interest on the monies used to build hospitals or health centres. On the other hand, transfer payments to people with dementia and their carers from the exchequer are usually included in the analysis, even though they do not directly affect productive resource use. A transfer payment is merely a transfer of income or wealth from one section of the community to another-there is no change in productive capacity as a result of receiving it (admittedly, there can be resource implications arising indirectly, through the taxes which are needed to finance redistribution).

Table 3.1: Two Approaches to Costing Care

PUBLIC EXPENDITURE COSTS

Community Care	Institutional Care
1. Social Security Payments	1. Social Security Payments
2. Council house rents/subsidies	2. Interest on capital cost
3. Service costs	3. Running costs (less patient contribution)

ECONOMIC OPPORTUNITY COSTS

Community Care	Institutional Care
Housing costs	Capital cost
Personal living expenses	Personal consumption
Care services costs	Care services costs
Family care costs	General services costs (e.g. heating, lighting, laundry, etc.)

Source: Wright, (1986).

Another example of the difference between the two approaches is their respective treatments of the personal consumption of people with dementia. Spending on consumption by people living in the community is included in the measurement of costs under an opportunity cost approach. A mentally ill person living at home uses up resources in the consumption of items such as food, heating, lighting, clothing, etc. If the same person were being looked after in a public institution, then the State would bear the cost of expenditure on these items. A public expenditure model would, however, only include the institutional component of personal consumption.

A particular difficulty to keep in mind is the difference between average costs and marginal costs. The cost that is of major interest is the additional cost of a programme. For example, when comparing two programmes or interventions, one of the differences may be that one day less is spent in the hospital. The cost of the last day in the hospital is not necessarily the same as the average cost of a day in the hospital. Generally, the first days in the hospital require the most intensive use of resources and the last days relatively less use. The cost associated with a decrease in the average hospital stay of one day is not equal to the cost of an average hospital day. The difficulty, of course, is that baseline data on health and social care costs are generally poor in Ireland, thereby making it difficult to estimate marginal costs with any degree of precision. In the majority of cases average costs are all that are available to the researcher.

3.4 Market Valuation of Costs

The use of a market valuation of inputs in the evaluation of health care programmes is based on the normative judgement that individual preferences should count, and

that these preferences should be weighted by the existing distribution of income. Both these judgements reflect what individuals would be willing to pay (sacrifice) to receive benefits or avoid costs. Pearce (1983) argues that such fundamental value judgements about market behaviour should not remain hidden in cost-benefit analysis. Rather they should be explicit; otherwise charges of 'subjectivity' may have some validity. Moreover, the use of market prices as a basis for valuing resource use should, ideally, be subject to the qualification that it is consumer surplus that should really be estimated. This is a facet of valuation that most analysts choose to ignore, mainly because of the difficulties of measuring consumer surplus.

Even when normative issues have been settled, market imperfections may still occur if the observed market prices do not reflect the true value of commodities and services. The deviation of market prices from their true opportunity costs may arise as a result of monopoly, externalities, government subsidies or taxation. A good example of how to deal with problems caused by the latter is a study by Wager (1972) on the cost of home care for old people. In this study fuel prices initially overstated their true opportunity cost because of the imposition of high indirect taxes. Since fuel is an important part of home nursing costs, Wager deducted the fuel tax from the estimates so as not to artificially inflate costs. Overall, the decision to adjust market prices to account for market imperfections (whatever their source) depends upon the following factors:

- the importance of the item itself in the overall evaluation,
- the extent to which its market price seems likely to deviate from its 'true' value,
- the time and trouble (cost) of obtaining and processing the information needed to make the adjustments (Drummond, 1980).

The service elements and information requirements for both in-patient and community care options for people with dementia are set out in Tables 3.2 and 3.3. Information on formal health board costs should be relatively easy to get. The reality is somewhat different. Data on service provision are not always routinely available in the form required by the researcher. Information usually has to be generated by a special survey of the patients included in the study. Truncated analyses of this type are unlikely to exhaust the total budget for the particular activity, which must then be allocated on an agreed pro rata to the study population (see Blackwell *et al.* 1992). This is unlikely to capture the specific nature of provision for patients with very different care needs but it may be the only way of making progress.

Table 3.2: Costing Facility-Based Services for People with Dementia

Items	Sources of Information
Buildings: location and size, equipment, furniture and fittings	Valuation of capital annuitisation procedures
Building-related expenses: power, rates, maintenance	Expenditure accounts
Staff: professions and grades	Payroll Expenditure accounts
Other service-related items: food, stationery,transport	Expenditure accounts
Ex-budget services: client and agency borne costs	Expenditure accounts

Table 3.3: Costing Community Services for People with Dementia

Items	Sources of information
Staff: professions, grades, hours	Payroll, salary scales, superannuation rates, travel and subsistence payments
Building-related expenses: power, rates, maintenance	Expenditure accounts
Office/clinic/equipment: location and size	Valuation of capital; annuitisation procedure
Service-related expenses: supervision and clerical support	Salary-related costs, expenditure accounts

The estimation of costs is very much affected by joint provision. Estimation problems may arise in quantifying care costs if, for example, caring resources and capital are shared among different categories of patients. This is especially true in the case of dementia where very few community care services are dementia

specific. Survey work will be necessary to provide a detailed breakdown of carer input into the care of people with dementia. Similarly, within residential care, resources (such as laundry, heating and lighting) are jointly consumed by many different departments and, therefore, are difficult to attribute directly to different categories of patients. The approach favoured by economists to apportioning the cost of these joint costs is marginal analysis. Drummond *et al.* (1997) have outlined some of the main approaches to allocating shared costs. The degree to which one needs to worry about ensuring fine distinctions depends, of course, on the importance of the items to the overall results. For that reason sensitivity analysis is always useful when presenting cost estimates.

3.5 Non-Market Valuation

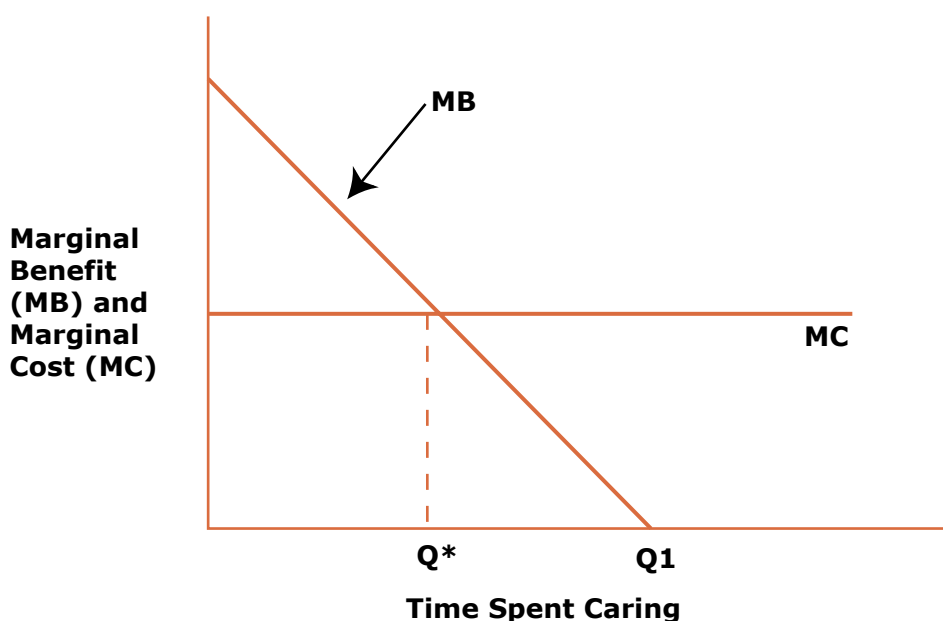
Not all costs in the care of people with dementia are market based. A major non-market resource use, especially in community care, is family involvement, as discussed in the previous chapter. If family members give up market work to look after a relative, a ready-made valuation of opportunity cost exists. Market valuations do not, however, exist for the lost leisure time of carers, or for the mental strain of having a person with dementia in the household. For both of these costs, market prices must be imputed if one is to remain faithful to the methodology of opportunity cost. Lost leisure time can, in theory, be valued on a continuum from zero through average earnings to average overtime earnings. Putting a money value on emotional costs is more difficult, since emotional problems do not always get translated into market transactions. While carers may sometimes visit the doctor or psychiatrist as a result of carer strain, more often than not they will suffer in silence.

Informal care may, of course, not always impose a net burden on carers; it depends on the relative size of the costs and benefits of caring (Smith and Wright, 1994). For most people there is likely to be a quantity of informal care below which marginal benefit exceeds marginal cost for the carer. It is only when the carer exceeds a critical amount of caring (Q^* caring hours in Figure 3.1) that marginal cost exceeds marginal benefit and the caring role becomes a net burden. At the limit (above point Q_1) the caring role may induce negative benefit or illness for the carer. The slope and position of these curves will depend on the particular circumstances, both personal and socio-economic, of the person with dementia and their family carers and their household living arrangements (Resource Implications Study, 1998).

3.6 Capital Costs

Economic evaluation studies, particularly those concerned only with public expenditure, have not usually concerned themselves with the valuation of capital. Capital usually represents a lumpy investment at a single point in time, which may explain why it is sometimes ignored. The opportunity cost relates to the funds tied up in the asset and the depreciation over time of the asset itself. Many approaches have been used to measure and value this cost. The most popular approach is to annuitise the initial capital outlay over the useful life of the asset, thereby producing an annual equivalent cost (Richardson and Gafni, 1983). Wright (1987a) has argued that capital can usually be valued in terms of the cost of new buildings, along with furnishings and fittings, i.e. at replacement cost. Sometimes, however, valuation at replacement cost may not be appropriate, particularly if institutions are being closed down and not replaced. The relevant cost in that case more properly relates to the re-sale value of buildings, land and equipment.

Figure 3.1: Subjective Marginal Costs and Benefits for Family Carers of People with Dementia



3.7 Conclusion

There will inevitably be imprecision in cost estimates for people with dementia. To some extent this can be tolerated, as long as the estimates are sufficient to enable broad conclusions to be drawn on the order of magnitude of costs in different

regimes of care. There are two different concepts of costs: opportunity costs and public expenditure accounting. The latter approach deals only with costs that fall on the exchequer. Underlying the opportunity cost approach is the following question: if this activity were not engaged in, how much resources would be saved for use in alternative activities? This is the key issue from the point of view of the allocation of resources. Opportunity cost allows one to focus on both formal and informal resource use. This, in turn, facilitates a comprehensive approach to costing care, one that includes current and capital elements, private and public aspects, and tangible and non-tangible items.

The simplest measures of benefit are those used in cost-effectiveness studies, where benefits are measured in uni-dimensional units. This is the approach that is used most often in the evaluation of dementia care programmes. In cost-benefit analysis, monetary values are assigned to benefits using either a human capital model or, preferably, a WTP approach. In cost-utility analysis, the effects of a treatment on the quality and quantity of life are incorporated into a single utility-based index such as a QALY. Neither WTP or cost-utility analysis have been used much in the appraisal of dementia care alternatives. In this study the analysis is confined to the measurement and valuation of costs, both formal and informal. No attempt is made to measure benefits or to compare different regimes of care for people with dementia. The resources were not available to allow us to do analysis of this kind.

4

Chapter 4

Methodology & Data

Chapter 4

Methodology and Data

4.1 Introduction

This chapter describes the main features of the survey data collected for this study. Methodological choices made at the beginning and during the course of the project's development reflect an attempt to reconcile the objectives of the study with the particular constraints which affect research into the prevalence of dementia, the nature of dependency for people with dementia and the reliable estimation of the costs of care. The methodological problem associated with the identification of carers for interview is the main issue considered in this chapter. The absence of a population frame for the carers of people with dementia is the most serious problem facing researchers in this area. Allied to this is the sensitivity attached to dementia and the reluctance of some people to discuss the issue with interviewers. Both of these problems limit the options available for the collection of the requisite data on resource use and hence affect the estimation of costs.

It is possible to estimate the number of people with dementia in the country using prevalence rates for other countries. However, knowledge of the number of people with dementia at an aggregate level is of little use for survey purposes without a list of the names and addresses of the carers of people with dementia. There is no comprehensive population frame from which a random sample of carers can be generated. The best way to generate a truly representative sample is to undertake repeated 'sifts' of the general population to identify possible carers of people with dementia. The 'sift' is based on identifying carers who are caring for a person with specified dementia-related symptoms on a regular or occasional basis. This approach is an expensive and time-consuming process, particularly if it is used as the sole mechanism to generate the numbers for the study. Moreover, using the symptoms method to identify carers of people with dementia is likely to result in significant numbers of both false positives and false negatives. Moreover, without asking people directly if the person under their care has dementia one cannot be certain that they are actually caring for a person with dementia. Even when potential carers are identified and subsequently interviewed, it may not be possible to get an accurate or precise definition of the condition of the person being cared for, not only because carers may not want to reveal a diagnosis of dementia but also because they may not know themselves.

The alternative approach is to interview the carers of known sufferers of dementia but this cannot be a randomised process because one is relying on existing lists of patients supplied by carer organisations. The difficulty with the list approach is the narrowness of the sample and the risk of self-selection. Carers who are members of The Alzheimer Society of Ireland, or known to the Society, may be different to other carers, thereby introducing bias into the selection process. This will almost certainly be the case since the number of carers linked to The Alzheimer Society of Ireland and the Western Alzheimer Foundation is small relative to the total number of carers of people with dementia in the country. The obvious advantage of using known dementia carers is the certainty that they are true carers of people with dementia. Allied to this is the low cost of identifying these carers. We used both a 'sift' approach and a 'list' approach to generate respondents for this survey.

4.2 The ESRI Sift

The purpose of the sift was to identify potential primary carers of people with dementia and related cognitive impairments in the general population. For the purpose of this research, the term 'primary caregiver' was defined as the person who had responsibility for the day-to-day care needs of a confused older person, whether that person lived in the same household or not (Stone *et al.* 1987). The first two questions in the sift simply asked if the respondent was caring for an older person either within the household or outside the household. If the respondent answered no to both these questions the interview was terminated. If the respondent answered yes to either of these questions they were then asked a question on the main symptoms or problems affecting the older person under their care. Potential carers of people with dementia and related cognitive impairments were identified on the basis of whether they were caring for people exhibiting one or more of the following symptoms on a regular or occasional basis: marked forgetfulness; wandering/losing way; restlessness/agitated behaviour; aggressive outbursts; confusion to the point of interfering with their everyday life; and disturbed sleep/wandering at night. These symptoms were successfully used by Ruddle and O'Connor (1993) to identify carers in their study on the carers of people with dementia. If any of the six symptoms was experienced on a regular or occasional basis the respondent was asked if they would be willing to participate in a survey on the needs of carers over the next few months. Respondents recruited on this basis will, of course, include false positives since these symptoms are merely indicative of dementia rather than proof of its existence. Similarly, it is likely we will have missed potential carers due to excluding false negatives. This is not surprising given the measurement difficulties in this area.

The one page questionnaire used in the ESRI sift was administered as a supplement to the ESRI's ongoing monthly EU Consumer Survey. The Consumer Survey has been carried out at the Institute since the mid-1970s on behalf of the European Commission. The purpose of that survey is to measure people's opinions about current economic trends and to assess consumers' short- and medium-term purchasing intentions. For the last fifteen years the survey has been used successfully as a vehicle for carrying out supplementary surveys on a wide range of issues. It was on this basis that it was used to collect preliminary information on the potential carers of people with dementia and related cognitive impairments. The sample design used in the monthly survey is based on a two-stage clustered sample using the electoral register as a population frame. A preliminary sample is selected using the ESRI's computerised random sampling system known as RANSAM.³The electoral register is used as the population frame for the Consumer Survey.

Initially, the sift was run for one month, December 1997, as a pilot to explore the potential of the procedure as a mechanism for identifying potential carers of people with dementia. Following encouraging results in the first month, two further surveys were undertaken in February and May 1998. No further sifts were planned, given the cost of the sifting procedure relative to the budget for the project. The survey was carried out by the ESRI's own panel of interviewers mainly by phone but also on a face-to-face basis. To ensure representativeness of the data, the composition of the effective sample was adjusted in such a way as to eliminate any identifiable bias, which may have arisen during the sampling process. This was achieved by re-weighting the data so as to ensure that the structure of the sample corresponded with the known structure of the population as derived from external independent sources. Accordingly, the combined data from the effective samples of the relevant rounds of the Consumer Survey were re-weighted at a household level on the basis of the following characteristics: number of adults in the household; principal economic status of the head of the household; and broad regional classification. This adjustment provided representative estimates of population totals.

4.3 Carer Estimates from the ESRI Sift⁴

Based on the data from the three months of the sift it was possible to generate estimates on the total number of carers in the country and on the number of people with the various dementia symptoms listed in the questionnaire. Table 4.1 presents details on the incidence of caring for a person aged 65 years and over within the carer's own home cross-classified by incidence of caring in another household. The percentage figures presented relate to the total population of all private households as a whole. The table indicates that in 91 per cent of all private households there is

³ For a description of this system see Whelan (1979)^o

⁴ This section draws heavily on data and analysis prepared by James Williams of the ESRI.

no one providing care services to an older person. In 4.7 per cent of households someone provides care to an older person in another household, but not in their own. In 3.7 per cent of households someone provides care within their own household, but not in other households. While in 0.4 percent of households (representing approximately 4,500 in the country as a whole) there is someone who provides care to an older person both within and outside their own household. This means, therefore, that an estimated 97,500 private households in Ireland have a carer who looks after an older person aged 65 years and over.

Table 4.1: Estimated number and percentage of households in which there is a carer of an older person aged 65 years and over

Carer in Other Household						
Carer in Own Household	Yes n	(%)	No n	(%)	Total n	(%)
Yes	4,500	(0.4)	41,000	(3.7)	45,500	(4.1)
No	52,000	(4.7)	1,012,500	(91.2)	1,064,500	(95.9)
Total	56,500	(5.1)	1,053,500	(94.9)	1,110,000	(100.0)

4.4 Presentation of Symptoms Amongst Older ‘Cared For’ People Aged 65 years and Over

Table 4.2 shows the number of private households in which there was a carer of an older person classified by the regularity with which that person suffered from each of the six symptoms listed. Essentially, this table represents a breakdown of the regularity with which each of the six symptoms occurred in the privately ‘cared for’ older population as a whole. The final column in Table 4.2 is consistent with the number of households in which there is a carer, as outlined in Table 4.1, allowing for some degree of non-response and missing information between the responses to the various questions. From the table, one can see, for example, that in approximately 19 per cent of private households, the ‘cared for’ older person suffered marked forgetfulness on a ‘regular’ basis, in 15 per cent of households this symptom was experienced on an ‘occasional’ basis, in 63 per cent of households it was experienced ‘rarely/never’ and in 3 per cent of households the respondent did not know the regularity with which this symptom was experienced.

Table 4.2: Number of households in which there is a carer of an older person aged 65 years or over classified by the regularity with which that person suffers from each of the six symptoms

Symptoms		Regular	Occasional	Rarely /Never	Resident Didn't Know	Total
1. Marked Forgetfulness	n	18,000	14,800	60,600	3,300	96,700
	%	18.7	15.3	62.7	3.4	100.0
2. Wandering /Losing way	n	3,000	5,600	83,100	4,200	95,900
	%	3.1	5.8	86.6	4.4	100.0
3. Restlessness/ Agitated Behaviour	n	9,000	22,300	61,100	3,700	96,100
	%	9.4	23.2	63.7	3.8	100.0
4. Aggressive Outbursts	n	3,100	11,100	76,500	4,900	95,600
	%	3.2	11.6	80.1	5.1	100.0
5. Confusion to the Point of Interfering with their Everyday Life	n	9,400	13,000	69,900	3,400	95,700
	%	9.8	13.6	73.1	3.5	100.0
6. Disturbed Sleep/ Wandering at Night	n	7,000	11,400	73,000	4,300	95,700
	%	7.2	11.9	76.3	4.5	100.0

While Table 4.2 shows the frequency breakdown of the symptoms in terms of the population, it does not present the frequency with which the symptoms were experienced in combination by the 'cared for' person. In many aspects it is of more interest to consider the complex or combination of symptoms experienced rather than the individual frequency distribution of each symptom in isolation as presented in Table 4.2.

Tables 4.3 and 4.4 present details on the combined experience of symptoms. As our interest lay with older people experiencing the symptoms on a 'regular' or 'occasional' basis, Table 4.3 provides a breakdown of all households according to whether or not an older person is cared for and also the regularity with which he/she suffers from at least one of the six symptoms in question. From the table, one can see that in 50,500 households (4.6 per cent of all households) the elderly 'cared for' person experiences at least one of the specified symptoms on a 'regular'

or ‘occasional’ basis. It was on these estimated 50,500 households that we focused in the supplementary questionnaire.

Table 4.3: Number and percentage of households in which there is a carer of an older person aged 65 years and over, classified in terms of experience and regularity of symptoms suffered by the older person who is being cared for

Experiencing at least one symptom	Number of households	Percentage of households
None	1,012,600	(91.2)
Rarely/Don’t know	46,900	(4.2)
Regular/Occasional	50,500	(4.6)
Total	1,110,000	(100.0)

Table 4.4 presents details on the combination of symptoms experienced by the ‘cared for’ population in the 50,500 households in which at least one of the symptoms was experienced on a ‘regular’ or ‘occasional’ basis. Each line in the table represents a combination of the symptoms. The top line (showing the six No’s) represents the 1.060 million households in which (a) no older person is being cared for or (b) is being cared for but where that person does not experience any of the symptoms on a regular or occasional basis.

The final column in Table 4.4 presents percentages based on the 50,500 households that contain members of the target population. One can see that the most frequently occurring symptom is marked forgetfulness (10.9 per cent). This was followed by restlessness/agitated behaviour (7.7 per cent); a combination of marked forgetfulness/ restlessness/agitated behaviour and confusion to the point of interfering with their everyday behaviour (7.3 per cent); and a combination of marked forgetfulness and confusion to the point of interfering with their everyday life (5.7 per cent).

Table 4.4: Number and percentage of households in which there is a carer of an elderly person aged 65 years and over classified by the combination of symptoms experienced on a regular or occasional basis by the elderly person who is being cared for.

Note: Experience of symptoms is defined in terms of regular or occasional basis only.

Marked Forgetfulness	Wandering/ Losing Way	Restlessness/ Agitated Behaviour	Aggressive Outbursts	Confusion to the point of interfering with their everyday life	Very disturbed sleep/ wandering at night	1 Estimated Number of Households	1 % of all Households	2 % of Households Caring for Elderly
N	N	N	N	N	N	1,059,600	95.5	-
N	N	N	N	N	Y	2,600	0.2	5.1
N	N	N	Y	N	N	1,400	0.1	2.8
N	N	Y	N	N	N	3,900	0.4	7.7
N	N	Y	N	N	Y	1,400	0.1	2.8
N	N	Y	Y	N	N	2,400	0.2	4.7
Y	N	N	N	N	N	5,500	0.5	10.9
Y	N	N	N	N	Y	1,000	0.1	2.0
Y	N	N	N	Y	N	2,900	0.3	5.7
Y	N	N	Y	N	N	1,100	0.1	2.2
Y	N	Y	N	N	N	2,600	0.2	5.1
Y	N	Y	N	N	Y	1,800	0.2	3.6
Y	N	Y	N	Y	N	3,700	0.3	7.3
Y	N	Y	N	Y	Y	1,400	0.1	2.8
Y	N	Y	Y	N	N	1,400	0.1	2.8
Y	N	Y	Y	Y	N	1,100	0.1	2.2
Y	N	Y	Y	Y	Y	1,400	0.1	2.8
Y	Y	Y	N	Y	N	1,900	0.2	3.8
Y	Y	Y	N	Y	Y	2,400	0.2	4.7
Other Combinations						10,600	1.0	21.0

¹ Based on all households in the country.

² This table is based only on an estimated 50,500 households in the country in which an elderly person is being cared for and in respect of whom at least one of the six symptoms was experienced on a regular or occasional basis.

4.5 Willingness to Participate in a Detailed Survey

Table 4.5 shows the actual number of private households interviewed in each round of the Consumer Survey plus a breakdown of these households by the following criteria:

- those which contained a carer of an older person,
- those where the carer cared for someone who experienced at least one of the six symptoms on a regular or occasional basis,
- those where the carer cared for someone who experienced at least one of the six symptoms on a regular or occasional basis and where the carer indicated a willingness to participate in the detailed survey.

Table 4.5: Numbers of carers and their willingness to participate in a detailed survey

Date of Consumer Survey	Total number of households interviewed	Number of households containing a carer of an elderly	Number of carer households where a carer cares for an elderly person who experiences at least one of the six symptoms on a 'regular' or 'occasional' basis	Number of carer households where a carer cares for an elderly person who experiences at least one of the six symptoms on a 'regular' or 'occasional' basis and where respondent initially indicated willingness to participate in more detailed survey
December 1997	1,400	127	86	46
February 1998	1,590	183	74	43
May 1998	1,390	112	48	30
Total	4,380	422	208	119

As evident from Table 4.5, a total of 422 households from the 4,380 interviews which were successfully completed in the initial three rounds of the sift said that they contained a carer of an elderly person. In just under half of these households the person being cared for experienced at least one of the six symptoms on a

'regular' or 'occasional' basis. Not all of these households were willing to participate in the detailed survey. Only 119 of the potential 208 carer households agreed to participate in the study. Moreover, only 40 per cent of these 119 cases were subsequently interviewed for a variety of practical reasons, including death of the person being cared for, death of the carer, institutionalisation of the person being cared for and inability to locate the carer household, or the carer herself. In order to increase the numbers of randomly identified carers, we ran the sift for three further months, in March, May and July 1999. From the second sift, a further 44 cases were eventually interviewed, though 11 of these could not subsequently be used in the analysis because they turned out not to have met the original screening criteria. This left the total number of respondents from the randomisation procedure at 80 valid cases, in terms of meeting the screening criteria, which is an unsatisfactory return from six months of sifting using the monthly EU Consumer Survey as the screening mechanism.

4.6 The Alzheimer List

We also experienced problems generating a response from dedicated carers known to The Alzheimer Society of Ireland. Our intention was to survey approximately 160 carers of people with dementia taken from a national list of Alzheimer day care users supplied by the Society. In addition, we hoped to survey about 80 carers (caring for non-day care users) generated from a national list of Carer Support Networks also organised by the Society. Initially, we received 211 names of carers from the Alzheimer Society of Ireland. However, in an effort to make the list of carers from the Alzheimer society as representative as possible we asked the Society to supply us with a complete list of carers known to them. This list would comprise anonymous cases broken down by region, age of person with dementia, sex of person with dementia, severity of condition of person with dementia, and the length of time the person with dementia was known to the Alzheimer Society. This would give us five variables from which a representative sample of Alzheimer Society carers would be drawn. Because of the confidentiality imperative, selected carers would be contacted by the Alzheimer Society asking for their agreement to participate in the study.

The total number of cases generated by this process came to only 322, with two thirds of these generated in two regions. Moreover, some of the carers were past carers; the person with dementia having died or having recently been admitted to residential care. These cases were not included in the study. We asked the Alzheimer Society of Ireland to contact all of the current carers on the list asking them to participate in the study. The process of getting consent from carers took time, but it was the only way to maintain the confidentiality, which is so important

for carers. Consent was obtained from just over 50 per cent of suitable cases. To increase the numbers further we also received additional names of carers willing to be interviewed from the Western Alzheimer Foundation.

The total number of known carers of people with Alzheimer’s disease interviewed from the Alzheimer list was 98, which when added to the sift cases makes up a completed sample of 178 carers out of a total of 297 potential respondents (Table 4.6). The overall response rate was, therefore, 60 per cent. Only 2 per cent of respondents refused to be interviewed. It was not possible to make contact with 9 per cent of the sample, while 3 per cent of households proved impossible to locate. Approximately one quarter of potential households were not interviewed for other reasons. This can largely be explained by changes in the caring situation: either the person being cared for had died before the interviewer called or the person being cared for was in hospital or in long-term care at the time the interviewer called.

Table 4.6: Total Response Rates for Carer Survey

Outcome	Alzheimer List +ESRI Sift (N)	Alzheimer List +ESRI Sift (%)
Completed	178	60
Refused	6	2
Unable to Contact	19	6
Temp. Absent	9	3
Unable to Locate	8	3
Other	77	26
Total	297	100

4.7 Patient-Based Measures of Dementia

The measures available for assessing people with dementia fall into two main categories: uni-dimensional measures and multi-dimensional measures. The most extensively used uni-dimensional measure is the Mini-Mental State Examination (MMSE) which covers the cognitive domain and can be administered by many health care professionals with appropriate training. Other uni-dimensional measures

include measures for functional assessment such as the Instrumental Activities of Daily Living (AIDL) scale, measures for mood disturbance such as the Geriatric Mental State (GMS-A), and measures for disruptive behaviour such as the Brief Psychiatric Rating Scale (BPRS). All of these scales contain advantages and disadvantages and the reader is referred to Ramsay *et al.* (1995) for a good discussion of the various measures under each of these headings.

From the point of view of this study a multi-dimensional measure of dependency for people with dementia was more attractive than a uni-dimensional approach given the emphasis on people living at home and the consequent resource implications of their care needs. Again there are many different scales available which assess the range of disability associated with dementia including cognitive elements, physical elements, functional elements, mood disturbance and disruptive behaviour. The scale chosen for this study is the Crichton Royal Behavioural Rating Scale (CRBRS), which was originally designed for use in institutions but has also been successfully used in community care. The scale has ten dimensions: mobility, orientation, communication, co-operation, restlessness, dressing, feeding, continence, memory and bathing (Table 4.7).

The important point about the scale is that it contains a confusion sub-scale within it comprising three dimensions: memory, orientation and communication. Tests done on the relationship between scores on the confusion sub-scale and diagnoses of dementia have shown that sub-scale scores of four or more were, in all cases examined, associated with clinical diagnoses of dementia (Evans *et al.* 1981).

Research by Blessed *et al.* (1968) showed that the confusion sub-scale had a correlation of -0.75 with the Abbreviated Mental Test and that a cut off score of 4 correctly classified 91 per cent of people with dementia. The confusion sub-scale is well validated both against clinical diagnosis of dementia and other simple tests of memory and orientation (Wilkin and Thompson, 1991) making it suitable for use in this study.

TABLE 4.7: Modified Crichton Royal Behavioural Rating Scale

DIMENSION		
A MOBILITY	Fully ambulant including stairs	0
	Usually independent	1
	Walks with supervision	2
	Walks with aids or under careful supervision	3
	Bedfast or chairfast	4
B ORIENTATION	Complete	0
	Disoriented in ward, identifies persons correctly	1
	Misidentifies persons but can find way about	2
	Cannot find way to bed/toilet without assistance	3
	Completely lost	4
C COMMUNICATION	Always clear, retains information	0
	Can indicate needs, understands simple verbal directions, can deal with simple information	1
	Understands simple information, cannot indicate needs	2
	Cannot understand information, retains some expressive ability	3
	No effective contact	4
D CO- OPERATION	Actively co-operative	0
	Passively co-operative	1
	Requires frequent encouragement or persuasion	2
	Rejects assistance, shows independent but ill-directed Activity	3
	Completely resistive or withdrawn	4
E RESTLESSNESS	None	0
	Intermittent	1
	Persistent by day	2
	Ditto, with frequent nocturnal restlessness	3
	Constant	4

TABLE 4.7: Continued

Dimension Continued			
F	DRESSING	Correct	0
		Imperfect but adequate	1
		Adequate with minimum supervision	2
		Inadequate unless continually supervised	3
		Unable to dress or retain clothing	4
G	FEEDING	Correct	0
		Adequate, with minimum supervision	1
		Inadequate unless continually supervised	2
		Constant	3
H	CONTINENCE	Full control	0
		Occasional accidents at night unless toileted	1
		Continent by day only if regularly toileted	2
		Urinary incontinence in spite of regular toileting	3
		Regular or frequent double incontinence	4
I	MEMORY	Complete	0
		Occasional forgetful	1
		Short-term loss	2
		Short- and long-term loss	3
J	BATHING	Washes and bathes without assistance	0
		Minimal supervision with bathing	1
		Close supervision with bathing	2
		Inadequate unless continually supervised	3
		Requires washing and bathing	4

Source: Wilkin and Jolly, 1979.

The scale has the advantage that it is a relatively simple and economical measure of dependency that is capable of being administered by non-health care personnel. While interviewers must be familiar with the detailed notes on classification, they do not have to be health care professionals. The scale emphasises actual behaviour rather than ability, making it easier for interviewers to administer the questionnaire. Information for the scale can also be obtained from third-party informants who in the case of people with dementia living at home will usually be the main carer. Carers are likely to have the detailed and intimate knowledge of the people to be assessed that is necessary for the scale to work well.

There are, of course, limitations to the scale. The major weaknesses of the scale are the arbitrary nature of the scaling and the restricted range of items. The scale constructs an additive index from what are essentially ordinal rankings on each of the dimensions. The scale is therefore not cardinal in the proper sense of the word, since if one person has twice as many points as another, this cannot mean that the person is twice as disabled as the other. Different combinations of disability may also result in the same score but with different and profound implications for both the person with dementia and the caring services. There is, therefore, no basis for assuming that a score of 10 implies twice as much dependency as a score of 5 or that two individuals scoring 10 are equally dependent, since their scores may be derived from different items (Wilkin and Thompson, 1991). These limitations are less relevant for this study given the fact that the scale is not used to assess outcome, either at a point in time, or over time.

The CRBRS includes measures of function and physical ability, both of which are likely to be affected by the onset of dementia symptoms, although causation cannot be inferred from the data. The CRBRS scale is augmented with both cognitive and instrumental functional measures, which seek to assess the whole range of dependency for people with dementia living in the community. Carers are also asked to describe in general terms the main complaint that the person under their care is suffering and to indicate if that complaint has been medically confirmed.

Carer attitude to, and experience of, stress is measured by the Carer Strain Index (Robinson, 1983) and by the General Health Questionnaire (GHQ) (Goldberg, 1972), both of which are widely used instruments in the literature. Both of these instruments have been used before in studies of carer needs and outcomes (Blackwell *et al.* 1992), thereby allowing comparisons over time and across different types of dependency in older populations. Ideally, one would like the following domains to be covered in outcome measures for the carers of people with dementia: physical health, psychological well-being, social resources, satisfaction, knowledge/skills, and co-ordination/communication (Ramsay *et al.* 1995). In that respect, the carer strain index, which focuses quite specifically on the generation of stress among carers, is likely to miss other important outcomes if used on its own. For that reason we also use the more generic GHQ instrument which captures a broader set of activities and hence outcomes, even if not all of the ideal set of outcomes are covered. Both of these scales have the added advantage that they can be administered by trained interviewers and do not require the use of health care professionals in the interviewing process.

The original version of the GHQ consists of 60 items (Goldberg, 1972) but the version used in this study is the shorter 12-item version (Goldberg and Williams, 1988). The 12-item scale, although slightly less valid and sensitive than the long version (60 items), is more suitable than the longer version(s) for use with frail older people (Bowling, 1997). The GHQ consists of a checklist of statements asking respondents to compare their recent experience to their usual state on a four-point scale of severity. The 12-item version consists of six positive and six negative statements which were administered to respondents in the study in the order shown in Table 4.8.

Table 4.8: General Health Questionnaire Items

1. Been able to concentrate on whatever you are doing
2. Lost much sleep over worry
3. Felt that you were playing a useful part in things
4. Felt capable about making decisions about things
5. Felt constantly under strain
6. Felt that you couldn't overcome your difficulties
7. Been able to enjoy your normal day-to-day activities
8. Been able to face up to your problems
9. Been feeling unhappy or depressed
10. Been losing confidence in yourself
11. Been thinking of yourself as a worthless person
12. Been feeling reasonably happy, all things considered

The negative items are numbered as follows: 2, 5, 6, 9, 10 and 12 with the following set of response categories:

Not at all then GHQ equal to zero

No more than usual then GHQ equal to zero

Rather more than usual then GHQ score equal to one

Much more than usual then GHQ score equal to one

The positive items are numbered as follows: 1, 3, 4, 7, 8 and 11 with the following set of response categories:

More so than usual then GHQ equal to zero

Same as usual then GHQ equal to zero

Less so than usual then GHQ score equal to one

Much less than usual then GHQ score equal to one

The overall GHQ is the sum of the item scores. The 0-0-1-1 scoring scale is simply a count of the symptoms, but avoids the problems of middle-user bias response (Bowling, 1997). The normal threshold score for a case is 2 on the 12-item scale (Goldberg and Williams, 1988), above which individuals are at risk of mental health problems.

Conclusion

There were two main problems associated with generating data for this study. The first and most important was the size of budget available for the study. The small budget restricted the numbers of people we could generate via the sift randomisation process. We eventually ran the sift for six months, which was longer than intended but was necessary due to the low response rate among carers identified in the initial sifts. The second and related difficulty was the unwillingness of some carers to be interviewed, even within the supportive environment of The Alzheimer Society of Ireland. While the latter went to great trouble to identify possible respondents, many carers known to the Society did not want to be interviewed. This reduced the potential of the list survey and made it even less reliable due to bias inherent in this form of self-selection. It is difficult to know why people did not want to be interviewed for the study but certainly people worried about the confidentiality of the process, even though it was guaranteed, the emotional aspect of the interview, and the time costs of the interview. Despite all the limitations, however, we did succeed in identifying enough carers for us to undertake meaningful analysis with respect to both the resource and cost implications of caring for people with dementia and related cognitive impairments in the community.

Chapter 5

Dependency, Carer Characteristics & Care Provision

Chapter 5

Dependency, Carer Characteristics and Care Provision

5.1 Introduction

In this chapter we consider dependency, socio-demographic and care provision issues associated with caring for people with dementia and related cognitive impairments living in the community. The chapter begins with a discussion of the nature of dependency among the people being cared for in the Alzheimer list group and in the ESRI sift group. The Crichton Royal Behavioural Rating Scale and the confusion sub-scale contained therein are the main instruments used to measure dependency in this study. The discussion on dependency is followed by a description of the main socio-demographic features of family carers in the two groups. The provision of care for people living at home in the community is then discussed, together with carer demands for additional services from statutory sources. The chapter then goes on to explore the level and form of family care provision to older people in both groups. Included in this analysis are details of care provision by individual activity, including surveillance, as well as aggregate estimates of family involvement in the caring process

5.2 Dependency Issues.

Dependency, as measured by the Crichton Royal Behavioural Rating Scale (CRBRS), is higher for the Alzheimer list than for the ESRI sift (Table 5.1). In the Alzheimer list two thirds of people being cared for by respondents to the survey score over 21 points on the CRBRS scale. In contrast, two thirds of people in the ESRI sift score less than 21 points on the scale.

While one must be careful not to read too much in to the CRBRS measure, in that the scale is not literally cardinal, the differences between the two groups are so large and consistent at either end of the scale that they do point up real differences in dependency. These differences in dependency, although crudely measured here, have implications for need and, hence, resource allocation. People with higher levels of dependency will need more of all types of care.

Table 5.1: Crichton Royal Behavioural Rating Scale

Score Point	ALZHEIMER LIST		ESRI SIFT	
	N	%	N	%
0-5	1	1.0	16	20.8
6-10	7	7.2	19	24.7
11-15	5	5.2	16	20.8
16-20	16	16.5	14	18.2
21-25	27	27.8	8	10.4
26-30	28	28.4	2	2.6
31-35	12	12.4	2	2.6
36-39	1	1.0	-	-
Total	97	100.0	77	100.0

We also test for differences in dependency between the two groups using more general indicators of cognitive impairment first used in the sift to identify potential carers of people with dementia (Table 5.2). On each of the six symptom indicators the people on the Alzheimer list fare worse than the people on the ESRI sift. In particular, the vast majority of people being cared for on the Alzheimer list experience marked forgetfulness and confusion on a regular basis, at 83 per cent and 69 per cent respectively. The corresponding proportions of people on the ESRI sift experiencing these two symptoms on a regular basis are 33 per cent and 26 per cent respectively. There are also differences between the two groups with respect to the two symptoms of wandering/losing way and restlessness. Once again these differences point to higher levels of need in the Alzheimer list group

Table 5.2: Percentage of People Experiencing Symptoms of Mental Disorder on a Regular Basis

Symptoms Experienced	Alzheimer list (%)	ESRI sift (%)
Marked Forgetfulness	83.1	33.3
Wandering/Losing way	49.3	9.9
Restlessness	45.1	18.3
Aggressive Outbursts	12.7	8.5
Confusion	69.0	26.4
Disturbed Behaviour	19.7	16.9

Not surprisingly, the number of people from the randomly generated list scoring 4 or more on the confusion sub-scale is much less than in the Alzheimer list (Table 5.3). Close to 90 per cent of the Alzheimer list group have a score of 4 or more on the confusion sub-scale incorporating the items memory, orientation and communication. Fifteen patients, or 16 per cent of the Alzheimer list group, have the maximum score on the confusion sub-scale. Less than half of people in the sift group score 4 or more on the confusion sub-scale. Only one person in the sift group scores maximum on the confusion sub-scale.

Table 5.3: Confusion Sub-scale (Memory, Orientation, Communication)

Score Point	ALZHEIMER LIST		ESRI SIFT	
	N	%	N	%
<4	9	9.2	44	55.7
4	5	5.2	8	10.1
5	11	11.3	10	12.7
6	12	12.4	5	6.3
7	11	11.3	5	6.3
8	17	17.5	3	3.8
9	8	8.2	2	2.5
10	9	9.3	1	1.3
11	15	15.5	1	1.3
Total	97	100.0	79	100

In a separate question carers were asked to describe the main complaint suffered by the person under their care. Just under one half of all carers on the Alzheimer list describe the main complaint suffered by people under their care as 'Alzheimer's disease'. A further 30 per cent mention dementia or dementia-related conditions as part of the main complaint suffered by the person under their care. The remaining carers list complaints which may have dementia links such as loss of memory, acute confusion, and stroke. On the other hand, only one fifth of carers from the ESRI sift describe the main complaint suffered by people under their care as 'Alzheimer's disease' or dementia. However, one quarter of sift respondents describe the main complaint of the person being cared for using general terms such as old age or forgetfulness, both of which are likely to be linked to the onset of dementia. A further 25 per cent mention stroke or heart problems to describe the main complaint of the older person. The remaining cases are mainly described in general medical terms, with depression being the most likely complaint mentioned in this category.

These results confirm the prevalence of dementia in the Alzheimer list group and justify the approach taken in the study to identify potential dementia sufferers in the general population. The data on main complaint generated through the survey instrument correlate highly with the confusion sub-scale from the CRBRS scale. Where it is appropriate we will use the CRBRS sub-scale cut-off score of 4 or more to separate potential dementia and non-dementia cases in the sift group. For the most part, however, the comparison will be between the Alzheimer sift group and the more representative, albeit more diverse, cognitive impairment elderly population generated through the ESRI sift.

Respondents were also asked to make a judgement on the functional abilities of the people they were looking after across five basic activities: sorting out own affairs, general housekeeping, preparing meals, laundry and ironing and shopping or going for groceries. The inclusion of these measures reflects a desire to collect information on the more important daily and social activities of older people. The focus is on instrumental activities of daily living and is not meant to be exhaustive. The measures are adapted from the domestic tasks section of Townsend's Disability Scale (Townsend, 1979) which is frequently used in community surveys of older people in the UK (Bowling, 1997). Carers were asked to rank the five activities along four basic dimensions: independent, slightly dependent, fairly dependent and very dependent. Most people were very dependent on each of the five activities, with only small differences in the two groups in terms of the proportion of people experiencing severe difficulty with each activity (Table 5.4). The results show that carers in both groups have to provide high levels of support for older people with respect to administration, housekeeping, meal preparation, laundry and ironing, and shopping.

Table 5.4: Percentage of People Who are Very Dependent on Selected Instrumental activities of Daily Living

Activities	Alzheimer list (%)	ESRI sift (%)
Sorting out affairs	98.6	79.2
General housekeeping	93.0	78.9
Preparing meals	97.2	76.1
Laundry and ironing	98.6	84.7
Shopping/going for groceries	95.8	86.1

5.3 Socio-Demographic Characteristics of Carers

Table 5.5 shows the main characteristics of carers from the survey. The data confirm previous survey work on the carers of people with dementia by Ruddle and O'Connor (1993). A typical carer of a person with Alzheimer's disease in Ireland is female, married, aged between 40 and 54, and engaged in home duties. The number of female carers outnumbers the number of male carers by 3 to 1 in the Alzheimer list and by 4:1 in the ESRI sift. The majority of carers are married: 76 per cent in the Alzheimer list and 85 per cent in the ESRI sift. Almost half of all carers from the Alzheimer list are involved in home duties, that is, not involved in paid employment, while just under two thirds are engaged in home duties from the ESRI sift. Approximately 20 per cent of carers remain attached to the paid labour force, either through full-time or part-time employment. A small but significant number of carers from the Alzheimer list are retired from the labour force (15 per cent), while 8 per cent of respondents from the ESRI sift classify themselves as retired.

Just under two thirds of carers are looking after a parent or parent-in-law in the Alzheimer sample while the corresponding figure from the ESRI sift is similar at 63 per cent. Nearly one third of carers from the Alzheimer list are looking after a spouse or partner. The corresponding figure for the ESRI sift is just under 20 per cent. Only a very small number of older people with cognitive impairment of any type, are looked after by a friend or neighbour. The vast majority of carers from the Alzheimer list (91 per cent) live in the same household as the older person with dementia. This is not the case for carers drawn from the ESRI sift where just over half of the carers live in the same household as the person being looked after. The difference here may reflect the higher level of dependency in the Alzheimer sift

Table 5.5: Characteristics of Main Carer

		Alzheimer List	ESRI Sift
Gender		%	%
	Male	28.9	16.0
	Female	71.1	84.0
	Total	100.0	100
Marital Status		%	%
	Married - Living Together	76.3	85.2
	Single	21.6	11.1
	Widowed	2.1	2.5
	Divorced	-	1.2
	Total	100.0	100.0
Current Employment Status	%	%	
	Full-time Paid Employment	12.9	7.4
	Part-time Paid Employment	9.7	12.7
	Unemployed	4.3	2.5
	Temporary Leave from Job	3.2	-
	Retired	15.1	7.6
	Home Duties	49.5	63.3
	Other	5.4	6.3
	Total	100.0	100.0
Relationship of Main Carer to the Person Being Cared For		%	%
	Spouse-Partner	30.9	18.5
	Daughter	45.4	40.7
	Son	12.4	7.4
	Daughter-in-Law	7.2	14.8
	Sister	-	4.9
	Friend / Neighbour	-	3.7
	Other	4.1	9.8
	Total	100.0	100.0
Main Carer lives in the Same Household		90.7	54.3

group, many of whom may not be able to live apart from their main carer. All of the people on the Alzheimer list are known to have dementia, unlike respondents from the ESRI sift for whom there is no such certainty.

Over half of all carers are aged between 40 and 54 in both groups of carers (Table 5.6). Fifteen per cent of carers are aged between 60 and 69 in both samples while 13 per cent of carers from the Alzheimer list are aged 70 years or over.

Table 5.6: Age of Main Carer

Alzheimer List		ESRI Sift
Age Ranges	%	%
Less than 30	1.1	-
30 - 34	2.2	5.9
35 - 39	6.7	8.8
40 - 44	18.0	14.7
45 - 49	18.0	22.1
50 - 54	19.1	19.1
55 - 59	5.6	8.8
60 - 64	9.0	11.8
65 - 69	6.7	4.4
70 - 74	6.7	4.4
75+	6.7	-
Total	100.0	100.0

It is clear from the data that a significant number of carers are themselves older people. The age distribution of carers raises very interesting questions about the viability of the family caring system in Ireland. Caretaker potential, which is the ratio of women aged between 45 to 69 to all people aged 70 years and over, has fallen more slowly in Ireland than in most other European countries. This is likely to change from the second decade of the new century when the proportion of people aged 70 years and over will begin to increase significantly in this country. An increase in the labour force participation rate of women, particularly for married women, will also affect the availability of women for full-time caring duties, since the opportunity cost of engaging in home care will increase in line with market opportunities. While these effects will influence future caring arrangements the high proportion of elderly carers is a more immediate worry since older carers may have special needs, particularly with respect to the physical dimensions of caring.

Just under 30 per cent of carers from the Alzheimer list receive their main source of income from wages, salaries and profits (Table 5.7). The corresponding market-based income from the ESRI sift is 36 per cent. Approximately, one fifth of carers from the Alzheimer list receive income from a State pension, while only 12 per cent of carers from the ESRI sift receive a State pension. Three in ten carers from the Alzheimer list rely on the Carer's Allowance as their main source of income. The corresponding figure from the ESRI sift group is two in ten carers receiving Carer's allowance. The low take-up of the Carer's Allowance confirms the restrictive nature of this particular transfer, despite recent changes in the eligibility criteria for the award.

Table 5.7: Sources of Income of Main Carer

Alzheimer List		ESRI Sift
Source	%	%
State Pension	17.5	12.3
Disability Pension	3.1	1.2
Rental Income	2.1	1.2
Occupational Pension	10.3	2.5
Wages, Salaries, Profits	28.9	35.8
Unemployment Benefits	3.1	6.2
Carer's Allowance	29.9	21.0
Other	9.3	13.6

Over two thirds of households in both surveys experience varying degrees of difficulty in making ends meet (Table 5.8). The data are very similar between the two groups and also broadly correspond to the recent ESRI data on the risk of poverty for all household types in Ireland (Layte *et al.* 1999). Approximately one in ten respondents say that they have great difficulty in making ends meet; just under 20 per cent of respondents say they have difficulty in making ends meet; while between 36 and 38 per cent say that they can make ends meet, but with some difficulty. Less than 10 per cent of respondents in both groups say that they have no financial difficulties at all.

Table 5.8: Ability of Household to Make Ends Meet

		Alzheimer List %	ESRI Sift %
Ability to make ends meet			
With great difficulty	9.3	12.5	
With difficulty	17.5	18.8	
With some difficulty	38.1	36.3	
Fairly easily	25.8	23.8	
Easily	7.2	8.8	
Very Easily	2.1	-	
Total	100	100	

Not surprisingly, the vast majority of people being cared are covered by a medical card (Table 5.9). However, only 30 per cent of carers from the Alzheimer sift are covered by a medical card, with 44 per cent of ESRI sift carers similarly covered. Just over one half of Alzheimer list carers have private insurance, while 40 per cent of ESRI sift respondents have private insurance. Between 15 and 24 per cent of people being cared for are covered by private insurance between the two surveys. This insurance covers health care needs only. People are not insured for community care services or for care in long-stay institutions.

Table 5.9: Medical Card and Insurance Coverage

Type of Cover	% covered Person being cared for		% covered Carer	
	Alzheimer List	ESRI Sift	Alzheimer List	ESRI Sift
Medical Card	88.7	84.7	29.9	44.4
VHI	23.7	14.8	51.5	39.5

5.4 Service Provision

Carers were also asked to provide information on the type and amount of home-based social care, including any out-of-pocket expenses associated with the various services (Table 5.10).

Table 5.10: Home-Based Social Care for People with Dementia and Related Cognitive Impairments

Service	% Using		Average hours per week		£ average weekly out- of-pocket payment	
	Alzh. List	ESRI Sift	Alzh. List	ESRI Sift	Alzh. List	ESRI Sift
Home help	24.7	17.3	10.4	8.9	6.4	9.1
Home care attendant	27.1	3.7	8.0	16.3	9.7	50.7
Personal assistant (private)	17.5	4.9	23.2	31.2	111.2	85.7
Private nurse	1.0	1.2	8.0	48.0	-	-
Meals on wheels	-	6.2	-	-	-	5.5
Laundry	-	-	0	0	0	0
Voluntary visits	4.1	1.2	9	2	0	0
Other	9.3	-	8.2	0	53	0

The proportion of people receiving home-based services is small. This is not surprising and corresponds to what we know from other accounts of community-based provision of health and social care services in Ireland (Ruddle *et al.*1997). The most commonly used service by carers on the Alzheimer list is home care attendant, followed closely by home help, but even here coverage is only 27 and 25 per cent of households respectively. Coverage is even lower in the ESRI sift group, with home help highest at 17 per cent; a home care attendant is received by only 4 per cent of households. Home care attendant provision, where it exists, is likely to be specific to people known to The Alzheimer Society and the figure for the sift group is more representative of the true level of provision from this source. Similarly, nearly one fifth of households on the Alzheimer list employ a private personal assistant to assist in the caring process, at an average cost of £111 per week for people receiving the service. The figure of 5 per cent take-up from the sift survey is likely to be more representative of overall personal assistant use in the general population.

The provision of health-related services is equally sparse, with the exception of general practitioner and public health nurse provision (Table 5.11). Nearly three quarters of people being cared for on the Alzheimer list are seen by a public health nurse in their own home, with an average length of visit of 25 minutes. The corresponding proportion of people receiving public health nurse visits in the ESRI sift sample is 62 per cent. Just over 50 per cent of people on the Alzheimer list receive visits from their GP at home; the corresponding proportion for the sift group is 65 per cent. Just under 30 per cent of people in both groups have visited a consultant or have gone for a general medical check-up in hospital.

Table 5.11: Health-Related Care Services for People with Dementia and Related Cognitive Impairments

Service	% Receiving		Time spent		% making		Time spent	
	at home		per home		visits to		per visit to	
			visit		service		service	
			(mins.)				(mins.)	
	Alzh. List	ESRI Sift	Alzh. List	ESRI Sift	Alzh. List	ESRI Sift	Alzh. List	ESRI Sift
General Practitioner	50.5	65.4	18.6	18.6	47.4	61.3	21.8	19.0
Public Health Nurse	73.2	61.7	25.2	24.7	-	-	-	-
Physiotherapist	1.0	2.5	10.0	65.0	-	-	-	-
Chiropodist	23.7	17.0	26.7	26.3	18.8	27.2	32.0	28.1
Social Worker	3.1	1.2	22.5	22.5	-	-	-	-
Dentist					13.5	4.9	33.3	30.0
Consultant					28.1	29.6	33.3	25.3
General Medical Check-up in Hospital					25.0	29.6	36.0	50.3
Other	7.2	3.7	30.0	21.7	4.1	4.2	43.3	30.0

Chiropody was the only other service availed of to any significant degree in both groups with visits to and from the chiropodist ranging between 17 and 27 per cent of people in the two groups. Very few people were visited by a social worker mainly because a community-based service for older people does not exist in most places in the country, with a few notable exceptions. The absence of variety in community care provision is noteworthy from the data. People do not have many choices when it comes to community-based services. The Public Health Nurse remains the main bulwark in meeting the needs of vulnerable older people living at home.

Table 5.12: Day Services for People with Dementia and Related Cognitive Impairments

	Service			
	Day Care		Day Hospital	
	Alzh. List	ESRI Sift	Alzh. List	ESRI Sift
% Regularly using	49.5	12.3	3.1	1.2
% of Users making weekly visits	93.8	50.0	-	-
Average time in hours spent per visit	5.6	5.5	8.0	3.0
Average out-of-pocket cost per visit	£7.7	£2.8	-	-

Fifty per cent of people on the Alzheimer list make regular use of day care services, with 94 per cent of people using services making weekly visits, at an average cost of £8 per visit (Table 5.12). Not surprisingly, the percentage of people using day care in the ESRI sift group was much lower at 12 per cent, with only 50 per cent of users making weekly visits. The Alzheimer Society of Ireland is the main provider of day care services for people with dementia so one would expect usage to be high among people known to the society. Day hospital services are not used in any major way by people in either group. For people on the Alzheimer list, 26 per cent had spent at least one night in a hospital or nursing home for medical reasons in the past year. The corresponding figure for the ESRI sift group was 31 per cent. A combined total of 50 per cent of people from the Alzheimer list had spent at least one night in hospital or a nursing home for respite reasons during the same period. The figure for respite care among people from the ESRI sift was only 16 per cent (Table 5.13). Once again, even allowing for double-counting, this reflects higher levels of social need among the Alzheimer list respondents.

Table 5.13: Medical and Respite Care Services for People with Dementia and Related Cognitive Impairments

	Medical Care				Respite Care			
	Hospital		Nursing Home		Hospital		Nursing Home	
	Alzh. List	ESRI Sift	Alzh. List	ESRI Sift	Alzh. List	ESRI Sift	Alzh. List	ESRI Sift
% Spending at least one overnight stay	25.8	30.9	2.1	1.2	22.7	9.9	28.1	6.2
Average number of nights in past 12 months	11.3	16.5	31.5	14.0	19.0	12.4	22.0	15.0

We also tested whether a CRBRS sub-scale score of 4 or more in the ESRI sift group led to a higher usage of community care services relative to people with a sub-scale score of less than 4. The following services showed up as significant: general practitioner care, chiropody and respite care. Just over 77 per cent of people with a score of 4 or more were receiving GP care at home compared to 57 per cent for people with a score of below 4. The corresponding usage rate for chiropody was 29 per cent in the 4 or over sub-group and 9 per cent in the below 4 sub-group. Almost one quarter of the 4 or more sub-group had used respite care compared to 9 per cent of the below 4 sub-group.

Respondents in both the Alzheimer list survey and in the ESRI sift were also asked questions about their health and social care requirements. The questions were designed to elicit the demand for additional visits and hours per week from existing services (Table 5.14).

For some services, like meals on wheels and laundry, no one responded to the question on additional services, while only three people responded to the question on additional social worker visits. Whether the low response rate reflects a genuine lack of need for these services is difficult to tell. If people have never received these services they may not realise the benefits to be gained from the services, but the low level of interest, reflected in the overall poor response for some services, is food for thought for those who would purport to know instinctively what carers want.

Respite care generated the highest response levels from both groups in terms of answering the question and indicating a desire for more services. The emphasis on respite care is in keeping with what we know from other surveys about the services that carers value most (Blackwell *et al.* 1992; Ruddle and O’ Connor, 1993) and in line with the recommendation for increased investment for respite care set out in the recent *An Action Plan for Dementia* (O’Shea and O’ Reilly, 1999). On average, people wanted an additional 29 to 31 respite days per year across the two groups. Predictably, the other services most in demand were the services already being received by people, notably public health nurse services, Home Helps, home care attendants and chiropody. Additional day care places were also high on the agenda for both groups. For those wanting additional day care services the overall demand in the Alzheimer list was for an additional 2.3 days per week, which was higher than the 1.5 additional day care days demanded by people in the ESRI sift group.

Table 5.14: Percentage of Respondents Requiring Extra Health and Social Care Visits

Services	Additional Visits			
	% Requiring Extra Health Care Visits			
	Alzheimer List		ESRI Sift	
	%	N	%	N
Respite Care	56.8	95	40.3	77
Public Health Nurse	31.7	63	40.5	42
Day Care	56.3	48	40.0	10
GP	22.0	36	18.6	43
Home Care Attendant	80.0	25	33.3	18
Home Help	66.6	24	78.0	14
Chiropodist	30.0	20	33.3	12
Personal Assistant	62.5	16	25.0	16
Social Worker	50.0	2	100.0	1
Physiotherapist	-	1	50.0	2
Private Nurse	100.0	1	-	-
Meals on Wheels	-	-	-	-
Laundry	-	-	-	-
Voluntary visits	50.0	2	-	-
Other	50.0	6		

5.5 Family Care Provision

The provision of family care for people with dementia is shown in Table 5.15. The overall mean daily provision of care for carers on the Alzheimer list is 11.6 hours, which is in keeping with the results from other surveys on care provision for people with dementia and is the figure used in the burden of illness estimation in Chapter 7. The median figure for this group at 10 hours per week is lower than the mean reflecting the fact that a small number of people reported the maximum score for each item listed which inflated the overall mean score for caring. The mean daily hours of care for people from the ESRI sift is 6.4 hours per day reflecting the lower level of dependency amongst this group. The mean score for surveillance is shown separately for the two groups and amounts to around 20 hours per day for both groups. The high figure for surveillance reflects the fact that many people responded to this question by citing the constant nature of care for people with dementia and related cognitive impairments. When we split the ESRI sift group into those scoring below 4 on the CRBRS confusion sub-scale and those scoring 4 or more there were no significant differences between the two sub-groups with respect to personal care provision. People in the 4 or over category did, however, receive significantly more housekeeping hours.

Table 5.15: Hours of Care on Various Activities (per day)

Type of Care/Activities	Alzheimer List			ESRI List		
	Mean	Median	St.dev.	Mean	Median	St.dev
Personal Care Morning	1.9	2.0	1.1	1.6	1.0	0.9
Personal Care Day	2.3	2.0	1.9	2.2	2.0	1.7
Personal Care Evening	2.5	2.0	2.0	2.2	2.0	1.2
Personal Care Night	3.1	2.0	2.9	2.0	1.0	2.2
Accompanying	2.0	1.5	1.4	2.0	1.5	1.2
Extra Housekeeping	3.8	2.5	3.8	2.7	2.0	1.7
Administration/Sorting Out Affairs	1.4	1.0	2.6	0.6	1.0	0.5
Total Specified	11.6	10.0	8.2	6.4	4.0	5.6
Optimal Specified	8.2	5.7	6.5	4.8	3.4	4.5
Surveillance	19.6	21.0	10.5	21.7	15.0	14.4

People were also asked to specify their preferred, or optimal, time spent caring, given the choice. For carers on the Alzheimer's list the optimal caring day is just over eight hours, equal to what most people consider a normal working day, but only 70 per cent of what they are being asked to do at present. For people in the ESRI sift group the optimal caring day is just under five hours, or 75 per cent of what they are doing at present. It is clear from the data that while people are willing to care for dependent kin they would prefer if they could reduce their involvement to reflect more freely chosen levels of provision. Optimality depends on the level of support that carers receive from the State, both financially and through service provision. Currently, carers receive a relatively low level of support from the State. The Carer's Allowance is still restricted despite recent improvements, while community care support remains narrowly focused and fragmented. Improvements in State support would alter the supply of caring hours by family carers.

5.6 Conclusion

In this chapter we have examined the dependency of the people being cared for in the two groups under review. The CRBRS confusion sub-scale confirms the presence of dementia in the Alzheimer list group. Dementia appears to be less prevalent in the ESRI sift group but still accounts for 45 per cent of the cases in that population, with many of the remaining cases suffering related cognitive impairments. The sift data also confirm the difficulty of finding true dementia cases through randomly-generated means without any medical assessment of potential sufferers. While people may exhibit some of the symptoms of dementia this will, in many cases, be put down to old age, or confusion, or will be linked to a specific medical condition such as stroke. It is impossible to know the true diagnosis without more refined measurement procedures, but these are costly and time-consuming to undertake.

We have also explored carer characteristics in this chapter and confirmed findings from other studies, namely that carers are mainly women, married, aged between 40 and 54, and engaged in home duties. A significant number of carers are also elderly themselves. The data on care provision confirm the paucity of community care provision for vulnerable older people living in the community. Services are largely confined to the core areas of general practitioner and public health nurse provision, with lower provision in the areas of home help, home care attendant and chiropody. Day care services are more prevalent in the Alzheimer list group than in the ESRI sift group. When asked to nominate services that they would like to see expanded, respite care was the service most in demand by carers.

This chapter also considered care provision by families. Family involvement was substantial with the main bulk of care provided by family members. Carers were mainly involved in providing personal care and in doing additional housekeeping chores. Carers also reported high levels of surveillance, or time spent keeping an eye on the older person, leading, in many cases, to care being described as a 24 hour-a-day job. There is, however, a strong indication from the data that optimal provision for carers is below actual levels of provision. This is not surprising given the weakness of official support mechanisms for carers, who, by and large, are left to cope with inadequate levels of support from the State.

6

Chapter 6

The Cost of Care in the Community

Chapter 6

The Cost of Care in the Community

6.1 Introduction

This chapter considers the cost of care in the community using both an opportunity cost approach and a public expenditure approach to estimate the relevant costs. Information on service provision outlined in the previous chapter is combined with unit cost data estimated from a number of different sources to provide the estimates of the cost of care in the community. Costs are calculated for the following elements of community-based provision: family care, community care services, therapeutic aids, house adaptations, drugs and any additional carer costs. The chapter begins with a discussion of the stress and psychological costs of caring for people with dementia and related cognitive impairments. The Caregiver Strain Index and the General Health Questionnaire are used to measure stress and psychological well-being among carers.

6.2 Carer Stress

There are a number of research instruments that can be used to measure the stress associated with caring for people with dementia and other cognitive impairments. One of them is the Caregiver Strain Index validated by Robinson (1983) and used by Blackwell *et al.* (1992) to explore stress among carers in their nationally representative sample of carers of dependent elderly people. Strain as used in this context is defined by Pearlin and Schooler (1978) to mean 'those enduring problems that have the potential for arousing threat, a meaning that establishes strain and stressor as interchangeable concepts'. The items used in the Caregiver Strain Index were derived inductively from a series of open-ended interviews with adult children caring for elderly parents (Robinson and Thurnher, 1979).

The application of the Caregiver Strain Index in this survey suggests that caring for people with dementia and related cognitive impairments takes a heavy toll on carers (Table 6.1). Strain is higher for respondents from the Alzheimer list than for respondents from the ESRI sift for each item on the list. Differences between the ESRI sift and the results from Blackwell *et al.* (1992) on the level of strain among the carers of all types of dependent elderly people are not as marked, but still show strain to be lower in the latter than in the sift survey, with the exception of the 'inconvenient' variable.

Table 6.1: Carer Strain Index: Percentage of Carers who Experience Strain as Carers

Items	Alzheimer List	ESRI Sift	Blackwell <i>et al.</i> (1992)
Disruption of sleep	72.9	37.0	20.3
Inconvenient	39.5	31.7	34.3
Physical strain	79.2	48.2	46.5
Confining	90.6	76.6	64.6
Adjustment for Family	84.4	74.0	36.9
Change in Personal Plans	87.5	63.0	34.3
Demanding because of other demands on time	67.3	60.5	32.8
Emotional Adjustments	78.1	44.5	28.3
Upsetting because of elderly persons behaviour	75.0	44.4	34.3
Upsetting because of changes in elderly person	95.8	58.0	43.4
Adjustment to work	60.5	34.6	18.7
Financial strain	69.5	48.1	36.9
Completely overwhelming	64.6	56.8	37.9

Two thirds of carers from the Alzheimer list reported that they felt completely overwhelmed by caring. Over half the ESRI sift group found caring completely overwhelming. The corresponding proportion in the Blackwell *et al.* (1992) sample was 38 per cent. The vast majority of carers experienced feelings of confinement due to caring. Similarly, most carers in both groups of the current survey reported adjustment for the family as a result of caring, much higher levels of family adjustment than reported in the Blackwell *et al.* (1992) survey. Almost all of the respondents from the Alzheimer list reported upset because of changes in the person under their care. More than three quarters of this group also reported emotional adjustment due to caring, while the same proportion reported upset due to the behaviour of the person under their care. Caring for people with Alzheimer’s disease/dementia takes a heavy toll on carers.

Significantly, in terms of the opportunity cost implications, respondents in both groups of the current survey reported adjustment to work as a result of caring, 35 per cent in the ESRI sift and 61 per cent in the Alzheimer list. The latter figure is in contrast to the low figure of 19 per cent for adjustment to work reported in Blackwell *et al.*(1992). Nearly two thirds of carers also reported financial strain in the Alzheimer list group. The corresponding percentage for the ESRI sift was just under 50 per cent, while only one third of carers in the Blackwell *et al.* (1992) study reported financial strain. The results on income-related strain from the Caregiver Strain Index confirm earlier data shown in Chapter 5 on the difficulty some carer households have in making ends meet (Table 5.8).

When we divided the ESRI sift group into the carers of people with a CRBRS confusion sub-scale score of 4 or more and a CRBRS confusion sub-scale of below 4 there were only two items on the Caregiver Strain Index where there were significant differences in terms of people experiencing strain. Almost two thirds of carers from the ESRI sift group looking after someone with a confusion sub-scale score of 4 or more experience upset because of the elderly person's behaviour compared to 31 per cent of carers looking after someone with a confusion sub-scale score of below 4. More than three quarters of carers from the ESRI sift group looking after someone with a confusion sub-scale score of 4 or more find the changes in the elderly person upsetting compared to 40 per cent of carers looking after someone with a confusion sub-scale score of below 4. Both of these items are behaviour specific and are likely to be related to the onset of dementia symptoms. Both sub-groups of the ESRI sift find caring confining, with 72 per cent of respondents below the cut-off sub-scale score of 4 reporting strain. The corresponding percentage for the 4 or more sift sub-group is 83 per cent. What this suggests is that caring is restrictive irrespective of the degree of confusion exhibited by the person being looked after in the household.

The General Health Questionnaire (GHQ) was also used to explore the level of stress among carers in both the ESRI sift and the Alzheimer list groups. Table 6.2 shows that 74 per cent of carers from the Alzheimer list score above the cut-off point in the GHQ, while 52 per cent score above the cut-off point in the ESRI sift.

Table 6.2: Distribution of General Health Questionnaire Scores

GHQ Scores	Alzheimer List %	ESRI Sift %
0	10.3	27.2
1	9.3	8.6
2	7.2	12.3
3	6.2	12.3
4	11.3	8.6
5	7.2	11.1
6	15.5	3.7
7	12.4	1.2
8	8.2	1.2
9	7.2	6.2
10	5.2	4.9
11	-	1.2
12	-	1.2
Total	100	100
N	98	80

These figures are well above those found by Blackwell *et al.* (1992) for a nationally representative sample of carers of mainly physically dependent older people, where 30 per cent of carers scored above the cut-off point. The overall mean score on the GHQ is 4.8 for the Alzheimer sift group and 3.3 for the ESRI sift group, both of which are significantly above the mean score of 1.8 for carers in the Blackwell *et al.* (1992) study (Table 6.3).

Table 6.3: Percentage of Carers Who Score Above the 'At Risk' Score on the General Health Questionnaire (GHQ) and Overall Mean Score on the GHQ by Survey Category

General Health Questionnaire	Alzheimer List	ESRI Sift	All	Blackwell <i>et al.</i> 1992
Percentage above cut-off	73.2	51.9	63.5	29.5
Mean score	4.8	3.3	4.2	1.8
S.D on GHQ	3.0	3.3	3.2	2.4

These findings indicate a worrying level of psychological distress among carers and confirm consistent results from the literature that GHQ morbidity in carers is closely associated with patient psychopathology. Non-cognitive features of dementia comprising psychotic symptoms, depressive features and behavioural disturbances in patients, both separately and together, are highly correlated with GHQ scores (Eagles *et al.* 1987; Draper *et al.* 1992; LoGiudice *et al.* 1995). The literature review by Donaldson *et al.* (1997) of 17 studies in this area suggests that non-cognitive features are positively related to caregiver burden and psychological disturbance and may be associated with anxiety in caregivers and deterioration in the patient-carer relationship. Quite significantly, in view of the above findings on the differences in GHQ score between the present study and the findings of Blackwell *et al.* (1992), activity of daily living (ADL) limitations appear unrelated to psychological outcomes in caregivers.

6.3 The Cost of Family Care

We know from the previous chapter (Table 5.15) that family care is the most important source of care for vulnerable older people living in the community. Carers drawn from the Alzheimer list provide 12 hours care per day while carers from the ESRI sift provide approximately six hours care per day. The next issue is how to value the care provided by families to people with dementia and related cognitive impairments. The methodological issues arising in the valuation of unpaid family care in the home have already been discussed in an earlier chapter. The reader is also referred to Blackwell *et al.* (1992) for a detailed discussion on weighting the valuation according to the source of the opportunity cost: paid work, leisure, housework and voluntary work. The information collected for this study is not as comprehensive as that collected by Blackwell *et al.* (1992). This means that we will have to be more eclectic in how we value family care, meaning that a number of

different estimates will be provided, beginning with what carers themselves feel they should be paid for what they do.

Table 6.4: Financial Arrangements between Carer and Person Being Cared For

	% Yes		% No	
	Alzheimer	ESRI	Alzheimer	ESRI
	List	Sift	List	Sift
Existence of financial arrangement	4.1	9.9	95.9	90.1
Desirability of financial arrangement (i.e. weekly payment)	83.9	75.0	16.1	25.0

There are very few private financial arrangements between people with dementia and related cognitive impairments and their carers (Table 6.4). Only 4 per cent of carers from the Alzheimer’s list had a financial arrangement, such as a weekly payment, between themselves and the person being cared for, despite the fact that 84 per cent of carers would like to see such an arrangement in place. The vast majority of carers in this group felt that any money received for caring should be paid for by the Government rather than by the person under their care. Ten per cent of ESRI sift carers had a financial arrangement with the person under their care. Three quarters of carers in this group would like to see an arrangement in place, once again paid for by the Government rather than by the person with dementia.

When asked how much of a weekly payment would be appropriate, a roughly equal proportion of Alzheimer sift carers (69 per cent) and ESRI sift carers (68 per cent) would be happy with between £50 and £150 (Table 6.5). Basing the valuation of family care on the upper limit of the range of financial demands of carers implies a subjective net monetary valuation of carer time of £150 per week. On the basis of an estimated 80 hour week for the Alzheimer sift group and an estimated 40 hour week for ESRI sift carers this translates into an hourly rate of £4 per hour for the latter and £2 per hour for Alzheimer list carers. The latter figure is less than half of the current government proposal for a national minimum wage of £4.30 per hour.

Table 6.5: How Much of a Weekly Payment Would be Appropriate

Category of Payment	Alzheimer List	ESRI Sift
	%	%
Less than £50	5.2	11.1
£50 - £99	33.8	33.3
£100 - £149	35.1	35.2
£150 - £199	11.7	11.1
£200 - £249	9.1	3.7
£250 - £299	3.9	3.7
£300 - £349	1.3	1.9

Asking carers to put a market value on their worth is a difficult exercise since their perception of self-worth may be conditioned by what family and society expects of them. Not caring is not an alternative for some carers since not to engage in the act of caring may be an act of betrayal, either real or perceived, and prove too difficult for the carer to bear (Himmelweit, 1996). A more fundamental issue is whether payment for care undermines the caring relationship. Folbre and Weisskopf (1998) suggest that as wages move from zero upwards so does motivation run in the opposite direction, from love, to love-and-money, to finally money alone. The suggestion is that money undermines the true value of the caring relationship. Nelson (1999) disputes this claim arguing instead a major part of the reason for the low monetary value placed on caring by society is because caring is considered in some sense 'natural' and unimportant. It is difficult in this context for carers to have very positive feelings about their true worth.

The second approach to valuing family care is to use an opportunity cost approach. Carers made significant changes to work patterns as a result of caring (Table 6.6). One in three carers from the Alzheimer list stopped work completely, while nearly one in four carers from the ESRI sift stopped work completely. Almost 20 per cent of respondents from both surveys worked fewer hours, while 12 per cent of carers from the Alzheimer sift took early retirement or temporary leave. As a result of caring, almost two thirds of carers from the Alzheimer sift who had previously been involved in paid employment made changes to their work pattern and as a result experienced a loss of income, while a further 12 per cent were denied career advancement or promotion. The corresponding combined figure from the ESRI sift was 45 per cent.

For the people on the Alzheimer list who gave up work or worked fewer hours as a result of caring (63 per cent), the mean weighted weekly net loss of income for these people was £156. The corresponding loss of income for ESRI sift carers who gave up work or worked fewer hours as a result of caring (43 per cent) was significantly lower at £92 per week.

Table 6.6: Changes to Work Patterns as a Result of Caring

Change	Alzheimer List	ESRI Sift
	%	%
Stopped work completely	33.3	22.5
Worked fewer hours	18.6	17.5
Took early retirement	6.2	1.3
Took temporary leave	5.2	1.3
Denied career advancement or promotion	12.4	2.5
Mean weighted weekly loss of income	£156.3	£92.2
Median weighted weekly loss of income	£150.0	£70.0

When averaged across all carers in the respective groups, this translates into a weekly net work-related opportunity cost of £99 and £39 respectively. Given that these estimates of opportunity costs are incomplete in that they only deal with paid work foregone they must be augmented by opportunity cost valuations that include leisure time foregone, unpaid work time foregone and voluntary activity foregone.

One way of doing this is to refer back to Blackwell *et al.* (1992) and their baseline estimates of carer opportunity costs in Ireland. Based on the averaging of responses from a national random sample of carers, of all types of dependent older people, Blackwell *et al.* (1992) were able to break down the alternative use to which one hour of caring would be put as follows: 24 per cent would go to paid work; 37 per cent to unpaid work in the home; 7 per cent to voluntary work; and 32 per cent to leisure activities. Applying these weights to money estimates for each of these alternative activities yielded an overall opportunity cost of £1.21 per hour. When the calculations upon which this figure is based are uprated to 1999 money terms, the opportunity cost estimate increases to £1.60 per hour. Multiplying the hourly cost of care by the number of hours provided by carers yields an opportunity cost for

Alzheimer list carers of £130 per week and an opportunity cost for ESRI sift carers of £72 per week.

The alternative to using an opportunity cost approach to the valuation of family care time is to use a replacement cost valuation to reflect what the Government or health board would have to pay if family care was absent. For instance, valuing carer time on the basis of an hourly home help rate of £3 per hour would lead to a replacement cost valuation for Alzheimer list carers equal to £244 per week. The corresponding replacement cost valuation for ESRI sift carers would amount to £134 per week. Alternatively, valuing family care on the basis of the national average hourly earnings rate for women in industry, which is currently close to £6 per hour, would lead to weekly replacement values for Alzheimer list carers and ESRI sift carers of £487 and £269 respectively. In a joint report on financing long-term care in Ireland, The Irish Association of Pension Funds (IAPF), The Irish Insurance Federation and The Society of Actuaries in Ireland (IAPF *et al.* 1998) also used a £6 per hour valuation for the purpose of estimating the value of family care. The rationale for choosing £6 per hour was not explained in the report, but it may be related to average hourly earnings for women in industry.

The range of monetary estimates for family care is presented in Table 6.7. Weekly estimates range from £99 to £487 for carers on the Alzheimer list and from £39 to £269 for carers on the ESRI sift survey. The above estimates refer to the involvement of main carer only in the caring process. The main carer is taken as the person principally involved in making decisions regarding the person who is being cared for. Although about half of the respondents in each group receive support from other members of the family in the caring role we have not included any monetary estimates for this additional care. The reasons for not doing this are that the amount of additional care is small relative to the contribution of the main carer and information on opportunities foregone is absent on the providers of this additional care. In addition, help from other sources is difficult to measure accurately because of the low response by main carers when they were asked to document the support received from family and friends. When additional care from family and friends is averaged across all respondents in the Alzheimer list it amounts to just under one hour per day. The corresponding figure for additional care averaged across all respondents in the ESRI sift group is higher at 1.5 hours per day.

Table 6.7: Valuing Family Care

Source of Valuation	Rationale	Weekly Mean Values (£)	
		Alzheimer List	ESRI Sift
Current Survey	Opportunity cost (work only)	99	39
Blackwell <i>et al.</i> (1992) (uprated)	Opportunity cost	130	72
Current Survey	Carer's own estimate: upper limit	150	150
Home Help Hourly Rate	Replacement value	244	134
National Average Hourly Earnings For Women	Replacement value	487	269

6.4 The Cost of Community Care Services

The weakness of community care services in this country has been well-documented (Ruddle *et al.* 1997; O’ Shea and O’ Reilly, 1999). The data on service usage from this survey, which were discussed in the previous chapter, confirm the under-provision of community care services in this country. The task in this section is to provide a monetary estimate of community care provision for the two groups of people under discussion. Table 6.8 gives the main costs or prices per unit which are applied either to the number of caring hours or to the usage of services in order to obtain the total costs of community care for the two groups. Costs are estimated for the main elements of community care provision. Community care services where the level of provision is low or negligible, such as social work, meals-on-wheels or physiotherapy, are not included in the calculation of costs. The weekly per capita cost for each service for each group is shown in the final two columns of Table 6.8. The weekly per capita cost of community-based services, public and private combined, comes to £69 per week for the Alzheimer list group and £32 per week for the ESRI sift group.

Table 6.8: The Weekly Cost of Community Care Services

Service	Source of Activity	Unit Cost Data	Source of Unit Cost Data	Weekly Per Capita Cost of Care: Alzheimer List (£)	Weekly Per Capita Cost of Care: ESRI Sift (£)
Home Help	Table 5.10 (Per Week Use)	£3.00 per hour	(Lundstrom and McKeown, 1994) uprated	7.71	4.62
Home Care Attendant	Table 5.10 (Per Week Use)	£6.30 per hour	Health Board Communication	13.66	3.80
Private Personal Assistance	Table 5.10 (Per Week Use)	£4.83 per hour	Market Rate	19.61	7.38
Private Nurse	Table 5.10 (Per Week Use)	£9.90 per hour	Table 5.10 Market Rate: Personal communication	0.79	5.70
General Practitioner	Table 5.11 (Per Month Use)	£20 per visit	GP opportunity cost	2.53	2.67
Public Health Nurse	Table 5.11 (Per week/Month use)	£12.10	Health Board Communication	4.72	3.73
Chiropodist	Table 5.11 (Per Month Use)	£9.49	Health Board Communication	0.56	0.40
Day Care	Table 5.12 (Per Week Use)	£22 per day	Based on estimates for one day centre in EHB	10.21	1.35
Respite care	Table 5.13 (per year use)	£45 per night	Blackwell et al. (1992) uprated	9.09	1.86
Total				68.88	31.51

The weekly per capita costs of disposable and non-disposable therapeutic aids are shown in Table 6.9 along with data on house adaptation costs and drugs. Disposable therapeutic aids include items such as incontinence pads, napkins and bandages. Weekly per capita costs come to £6.00 for the Alzheimer list group and £2.50 for the ESRI sift group. Non-disposable items are also costed. These include items such as special beds, special mattresses, toilet chairs and personal alarms. The equivalent weekly cost of these items is estimated using an annuitisation procedure based on a five-year life at a discount rate of 5 per cent spread across all people in the sample. House adaptation costs are estimated using an annuitisation procedure based on 10 years and a 5 per cent discount rate. Weekly adaptation costs come to £3.85 for people on the Alzheimer list and £2.37 for people on the ESRI sift.

Drug costs are also calculated, but only for the ten most used drugs. Carers were asked to list all of the drugs taken by the person under their care but it was only practical to cost the most commonly used drugs given the variety of drugs listed. Selecting only the top ten will undoubtedly lead to an under-estimation of drug costs in the study. The three most commonly used drugs in the Alzheimer list are aspirin, aricept and melleril. The three most commonly used drugs in the ESRI sift are aspirin, lanoxin and frumil. Usage is calculated on the basis of recommended dosage as given in the Monthly Index of Medical Supplies (MIMS, 1999). Costs are calculated on the basis of trade prices given in MIMS and do not include the pharmacist dispensing fees. Per capita drug costs for older people on the Alzheimer list are £3.98 per week, while for people on the ESRI sift costs are £1.60 per week.

Table 6.9: Therapeutic, House Adaptation and Drug Costs

Activity	Basis of Calculation	Alzheimer list:	ESRI sift:
		weekly per capita estimate (£)	weekly per capita estimate (£)
Therapeutic aids. (Disposables e.g. napkins, incontinence pads)	Basic data on consumption from questionnaire by market prices	6.00	2.50
Therapeutic aids. (Non-disposables e.g. special chairs, beds, alarms)	Annuity factor of 5 years at 5 per cent rate of interest equal to 4.3395.	0.26	0.19
House adaptations	Annuity factor of ten years at 5 per cent rate of interest equal to 4.3395.	3.85	2.37
Drug Costs	Only the ten most used drugs are costed. Trade price calculation (MIMS)	3.98	1.60

Table 6.10 shows the main additional costs that fall on carers as a consequence of caring. Heating is the main additional cost for respondents on the Alzheimer list, while transport is the main additional cost for people in the ESRI sift group. Transport also features highly as an additional cost for carers on the Alzheimer list group. In total, the carers of people with Alzheimer's disease spend an extra £21 per week as a direct result of caring, while people in the sift group spend an extra £9 per week. These additional costs are not insignificant given the level of financial

strain experienced by carers. One fifth of Alzheimer list carers report heavy financial strain, while 55 per cent report some strain. In the ESRI sift group 13 per cent of carers experience heavy strain, while 50 per cent report some strain. In such circumstances £20 per week additional spending, even £9 additional expenditure, can have serious consequences for carer households.

Table 6.10: Weekly Carer Costs Arising as a Direct Consequence of Caring

Additional cost item	Basis of Calculation	Alzheimer list: weekly per capita estimate (£)	ESRI sift: weekly per capita estimate (£)
Transport	Total weekly cost (TWC) = £387 for list group. TWC=£288 for sift group	3.94	3.6
Own health care	TWC= £98 for list group. TWC=£80 for sift group	0.61	0.97
Own personal care	TWC=£288 for list group. TWC=£63 for sift group	2.93	0.78
Training	TWC= £15 for list group. TWC=£0 for sift group	0.15	-
Heating	TWC= £971 for list group. TWC=£232 for sift group.	9.91	2.91
Other	TWC= £377 for list group. TWC=£74 for sift group.	3.85	0.92
Total		21.39	9.18

6.5 Conclusion

The overall costs of community care are shown in Table 6.11. Costs are calculated on the basis of a full opportunity cost valuation of family care provision and a replacement cost valuation for that provision, based on the average industrial earnings rate for women. On the basis of an opportunity cost valuation the overall cost of community care for people on the Alzheimer list is £234 per week, while the cost of community care for people in the ESRI sift group is equal to £120 per week. These estimates are baseline opportunity cost estimates and should be seen as preliminary in nature given the difficulties with the data. Having said that, the differences between the two groups are consistent across all items of resource use and overall estimates are in line with the results of previous research in the broad area of care of older people (Blackwell *et al.*1992). When the cost of family care is estimated on the basis of a public expenditure replacement cost valuation, community care costs are much higher, rising to £591 for people on the Alzheimer list and £317 for people in the ESRI sift group. Costs would rise even higher if personal consumption and capital costs for people living in the community were included in the analysis. These costs would have to be estimated if comparisons were being made between community care and residential care provision for people with dementia and related cognitive impairments.

Table 6.11: Community Care Estimates: Weekly Cost of Care (Opportunity Cost and Replacement Cost Valuation)

Cost Item	Alzheimer list: Opportunity* cost valuation £	ESRI sift: Opportunity* cost valuation £	Alzheimer List: Replacement** cost valuation £	ESRI sift: Replacement** cost valuation £
Family Care	130	72	487	269
Community Care Services	69	32	69	32
Therapeutic Aids	6	3	6	3
House Adaptations	4	2	4	2
Main Drugs	4	2	4	2
Additional Carer Costs	21	9	21	9
Total	234	120	591	317

*Based on Blackwell *et al.* (1992) updated.

** Based on national average hourly earnings for women.

Caring for highly dependent people can also be a source of major strain and psychological distress for carers. These are real costs even if they cannot be valued in monetary terms. The results of this survey show a very high level of psychological distress among the carers of people with dementia and related cognitive impairments. Carers are currently providing high levels of care, at a huge personal cost in terms of time, money and emotional distress. When the data on stress are combined with the opportunity cost data the picture that emerges is of the immense sacrifices involved in caring. Carers need more support than they are currently receiving, both for themselves and for the people whom they are looking after. The next chapter extends the analysis to explore the overall burden of care in society for people with dementia and related cognitive impairments.



Chapter 7

7

The Economic & Social Cost of Dementia in Ireland

Chapter 7⁵

The Economic and Social Cost of Dementia in Ireland

7.1 Introduction

The objective of this chapter is to estimate the overall economic and social cost of dementia in Ireland and to discuss the major policy implications arising from the findings. The previous chapter provided survey-based estimates of the cost of family care and community care for people with dementia and related cognitive impairments. This chapter builds on that analysis by providing an overall burden of illness study for dementia only, incorporating other important areas of provision such as residential care, psychiatric care and acute care. The main focus of the chapter is on the distribution of the overall burden of dementia rather than on the overall burden itself. The chapter is a study in its own right and provides an important framework for planning services for people with dementia in the future. While the focus of this report is primarily on the cost of home care for people with dementia and related cognitive impairments, generating information on the distribution of the overall costs of dementia in society is also important. A burden of illness approach is a cost-effective way of exploring the sectoral costs associated with the care of people with dementia.

The economic burden of dementia has been assessed in only a small number of studies for a handful of countries (Huang *et al.* 1988; Ostbye and Crosse, 1994; Wimo *et al.* 1997a). Some studies have focused only on the cost of Alzheimer's disease in different countries (Hay and Ernst, 1987; Ernst and Hay, 1994; Rice *et al.* 1993; Gray and Fenn, 1993), while others have estimated dementia costs within a much broader cognitive impairment framework (Kavanagh *et al.* 1993; Schneider *et al.* 1993). There has also been variation with respect to the coverage of costs in the literature. For example, some authors have put a monetary valuation on family care (Stommel *et al.* 1994), while others have not (Gray and Fenn., 1993; Smith *et al.* 1995). The fact that different authors have used different methodologies and different approaches to costing care makes it difficult to compare studies, or to establish an overall comparative framework for the evaluation of policies for dementia across countries.

Given the absence of a common approach to estimating costs, it is little wonder that serious reservations exist with respect to cost of illness studies (Drummond, 1992). The reservations are methodological and are concerned with measurement issues,

⁵ Siobhan O'Reilly contributed to this chapter

particularly the measurement of indirect costs. Concern has also been expressed about the practical value of cost of illness studies for decision-makers (Davey and Leeder, 1993). Cost of illness studies may lead to incorrect decisions because of poor data, no consideration of outcomes, and the absence of marginal analysis (Shiell *et al.* 1987). Decision-makers may simply respond to the size of the problem without giving much consideration to the efficiency of the response. Notwithstanding these criticisms, the value of a cost of illness approach to dementia research in Ireland lies in the valuable information it provides in an area where there has not been any work at all with respect to the resource implications of the disease. This study shines the spotlight on current resource use, highlighting where, and on whom, the burden of dementia currently falls. The chapter also provides important additional and baseline data on epidemiology, current resources, and unit costs, which is built upon in later chapters of the report. What this chapter does is to provide an important overall 'top-down' framework for the more detailed 'bottom-up' analysis of community and family care costs later in the report.

7.2 Methodology

The economic burden of a disease on society is essentially the value of all resources used to prevent, diagnose, treat and generally cope with the disease. In this chapter, the economic and social impact of dementia is assessed using the burden of illness framework suggested by Rothstein *et al.* (1996), incorporating direct and indirect, formal and informal, costs. Six main areas of burden are covered in the analysis as follows: mortality and life years lost, in-patient acute care, in-patient psychiatric care, family care, primary and community care and residential long-stay care. Direct and indirect costs are estimated for both statutory and family care resource use. Problems with the data mean that we are not able to estimate all costs. The most notable omissions from the analysis are day hospital services, both medical and psychiatric, research costs and the psychological distress of caring for some families. Sensitivity analysis is used to deal with some of the measurement difficulties in this area, particularly with respect to the valuation of family care and acute care costs.

Table 7.1 shows the data sources for the calculation of burden of illness for dementia in Ireland. Costs can be calculated using either national data, the so-called top-down method, or local/survey data extrapolated to a national level, the so-called bottom-up method. Very often both approaches are used, as is the case in this study. Similarly, costs can be calculated on a gross or net basis. Ideally, costs should be calculated on a net cost basis where the emphasis is on the costs for the disease of interest only (Manton *et al.* 1993). For that to happen, co-morbidity costs

and hotel costs in acute and institutional care settings must be estimated. This is a difficult, and sometimes impossible, task given existing hospital and residential care accounting systems. The analysis in this study is confined to gross costs mainly because of the estimation difficulties presented by a net cost analysis. Finally, although the sources of data in this study are mainly dementia-specific, there are instances where the estimation of costs is based on generic, mainly elderly-related, data. In particular, the estimation of family care costs and residential care costs is partly based on data from non-dementia sources.

Table 7.1: Data Sources

Cost Category	National Data	Survey Data	Gross Data	Net Data	Generic Data	Dementia Specific Data
Mortality	✓	—	—	—	—	✓
Acute Care	✓	✓	✓	—	✓	✓
Psychiatric Care	✓	—	✓	—	✓	✓
Family Care	✓	✓	✓	—	✓	✓
Primary and Community Care	—	✓	✓	—	—	✓
Residential Care	✓	✓	✓	—	✓	✓

Mortality statistics are a useful way to look at the impact of a particular disease on different populations. Crude and age-adjusted mortality rates are, however, an incomplete measure of the impact of particular diseases, since they give equal weight to a childhood or young adult death, and a death in old age. A complementary measure, potential years of life lost, weights life lost at younger ages more heavily than deaths occurring later in life. This measure estimates years of remaining life-expectancy at the time of death and is the approach used in this study. The data on deaths were provided by the Central Statistics Office (CSO) and relate to deaths under the International Classification of Diseases (ICD) code 290 (senile dementia) and ICD code 331 (Alzheimer’s disease). The data on deaths from dementia are problematic due mainly to differences in the approach to certification by local medical practitioners (Flaten, 1989). One in five people may become demented before death. This is not reflected in the mortality data leading one to

suspect serious under-reporting of dementia as a cause of death. Under-reporting may occur for a variety of reasons, but the main one is related to sensitivity about the categorisation of mortality as dementia-related. Unfortunately, there are no other sources for deaths from dementia other than the official data from the CSO.

Life expectancy at various ages was calculated from Life Tables supplied by the CSO. Life years lost from dementia were calculated for both males and females by combining the mortality and life expectancy data. No attempt is made to estimate a monetary value for the life years lost in productivity terms. Mortality from dementia is largely confined to people in the 65+age category who are retired from market-productive work. Although these people may be involved in some form of non-market productive activities, either in a private or voluntary capacity, the monetary valuation of this activity is difficult, and hence is not attempted in the baseline estimation of costs.

Information on the number of admissions of dementia patients to acute hospitals and their average length of stay was obtained from the Hospital In-Patient Enquiry⁶ for 1996. Given the general absence of published data on cost in the Irish health care system, the cost of acute care services is calculated using information supplied by the Department of Health on overall average cost per in-patient week across the thirty hospitals participating in the Department's case-mix modelling exercise. Unfortunately, specific cost information by dementia diagnostic category is not available from this source-hence the reliance on average case-mix related costs. While averaging across all diagnostic categories is not ideal, it allows us to make some progress with respect to costs. In addition, a significant number of old people in acute care for other reasons may also suffer from dementia. Unfortunately, the calculation of the marginal costs of dementia in acute elderly populations is a difficult exercise and is not attempted in the baseline estimate, although a tentative estimate is provided in the sensitivity analysis.

Information on long-stay patients in psychiatric hospitals and units is available from the National Psychiatric In-Patient Reporting System (NPIRS)⁷ for 1994. Data on average length of stay for people with dementia in psychiatric hospitals were provided by the Health Research Board and are based on the figure for all discharges (including deaths) in 1996. Once again, costs are based on average data estimated across all patient types in psychiatric care. The total budget for psychiatric care is divided by the total number of in-patients to yield the average cost estimate. Again, this is not ideal but is the only estimate available to us.

⁶ The Hospital In-Patient Enquiry (HIPE) system collects data on all admissions to acute general hospitals. Coverage of the Enquiry is around 90 per cent.

⁷ The National Psychiatric In-Patient Reporting System collects information from private and public psychiatric hospitals and units around the country, with a 96 per cent coverage rate.

Families provide the bulk of care for dependent older people living in the community and that contribution should be acknowledged and documented. We draw on a number of sources for material on the care provided by families, including our own analysis. In the first instance, we use data on prevalence generated by Lawlor *et al.* (1994) using AGECAT,⁸ which estimated that 5.5 per cent of older people living in the community were suffering from dementia. There are no data on the prevalence rates for people aged less than 65 years, so these people are not included in the analysis. Overall, the data suggest that just under 23,000 people living in the community, and aged 65 years or over, are affected by dementia. Estimates from Ruddle and O' Connor, (1993) suggests that about 60 per cent of these require full-time care. For estimates of care provision and costs we rely on the estimates generated in the previous chapter. Estimates of primary and community care resource use are also drawn from the analysis in the previous chapter. Monetary estimates for the psychological distress and loss of quality of life that some carers experience looking after people with dementia are not included in the analysis.

Residential care costs are estimated for five residential types: health board geriatric homes, health board welfare homes, health board district hospitals, private nursing homes, and voluntary homes. Estimates of the number of people with dementia are available for each type of care (Department of Health, 1995), although there is a view that the official figures are significantly underestimated due mainly to the poor system of recording dependency data in long-stay care (Browne, 1996; O'Neill *et al.* 1991). Notwithstanding this caveat, they are the best available estimates, and for that reason are used in this study. Costs per patient in residential care are based on the results of extensive case-study work done on average costs by Blackwell *et al.* (1992) on public long-stay institutions in the early 1990s. Typically, long-stay institutions in Ireland cater for both physically dependent older people and people with dementia and data relating to specific dementia costs in long-term care are not routinely available. Neither are there any estimates of the cost of care for people with dementia in private nursing homes, which is why the figure for public long-stay care is also applied to the private sector.

7.3 Results

7.3.1 Mortality and Life Years Lost

The data refer to deaths recorded as due to dementia in 1996, with the number of female deaths equal to 198 and the number of male deaths coming to 113 (Table 7.2). Within each age group, life years lost are calculated by multiplying mortality figures by remaining life expectancy for both males and females. Female life years

⁸ AGECAT is a computerised diagnostic system with demonstrated reliability and has been validated against diagnoses made by psychiatrists using DSM-III criteria.

lost amounts to 1,299 years, while male years lost totals 727 years, reflecting the fact that female deaths are higher than males in all age categories over 65, and, of course, the longer life expectancy of females. It is possible to develop this analysis to consider the potential years of working life lost before the normal age of retirement and provide a monetary estimate of the years lost. We did not do this in the baseline analysis, however, mainly because most deaths occur in this disease classification after retirement age, making a calculation of this type redundant in this case. Overall, deaths from dementia account for 0.73 per cent of all life years lost across all diseases. Deaths from diseases of the circulatory system and neoplasms account for most of life years lost, accounting for approximately two thirds of the total.

Table 7.2: Mortality and Life Years Lost from Dementia

Age category	Male deaths	Female deaths	Male life years lost	Female life years lost	Males & female life years lost as % of total (all causes) life years lost
45-49	0	1	0.00	32.60	0.20
50-54	0	0	0.00	0.00	0.00
55-59	1	0	19.29	0.00	0.08
60-64	3	2	46.52	38.93	0.24
65-69	8	10	97.41	156.12	0.58
70-74	18	14	167.94	169.74	0.71
75-79	25	34	174.10	306.54	1.08
80-84	32	60	162.12	384.96	1.84
85+	26	77	59.79	209.66	1.73
Total	113	198	727.17	1,298.55	0.73

7.3.2 Acute Hospital Care

Some people suffering from dementia may end up in acute care hospitals, or as day patients attached to general hospitals. There were 1,635 patients diagnosed as suffering from dementia in acute hospitals in 1996. The vast majority of these were aged 70 years and over (88 per cent), with 44 per cent aged between 81-90. The average length of stay for these patients was 17 days, with patients in the age categories 41-50 and 51-60 having the longest stays at 26 days (Table 7.3). The overall cost burden for dementia in acute hospitals is calculated by combining the unit costs, based on an average case-mix (minus mental disorders) cost per in-patient week, with the in-patient data on dementia generated by HIPE. Although day-patient cases are shown in Table 7.3, no attempt is made to estimate costs for the service because of the absence of any base cost reference point. Similarly, although day hospital provision is growing, it too has been omitted from this study due to the absence of appropriate information. The absence of cost estimates for both of these activities will not alter the final estimates that much, as they are likely to be small relative to total provision. The total annual cost of caring for patients suffering from dementia in acute hospitals is just over £5 million (Table 7.3).

Table 7.3: Annual Cost of Acute In-patient Care for People with Dementia by Age Category

Age group	No. of in-patients	Average length of stay (days)	Day-patient cases	Average cost per acute in-patient week (£)	Total annual cost (£)
< 21	0	0.00	0	1,283.71	0
21-30	2	14.50	0	1,283.71	5,318
31-40	3	10.00	0	1,283.71	5,502
41-50	10	25.60	0	1,283.71	46,947
51-60	31	25.55	0	1,283.71	145,252
61-70	149	18.28	11	1,283.71	499,495
71-80	646	16.10	30	1,283.71	1,907,336
81-90	712	16.51	36	1,283.71	2,155,738
90+	82	18.65	5	1,283.71	280,454
Total	1,635	16.83	82	1,283.71	5,046,042

7.3.3 Psychiatric Care

Table 7.4 shows the data used to estimate the costs of psychiatric hospital care for people with dementia. First admissions make up just under 50 per cent of all admissions. Approximately one third of patients spend less than a week in hospital while a further 50 per cent spend less than three months as in-patients. A small number of people spend a long time in psychiatric hospitals. Approximately 10 per cent of people spend more than one year in care, while 3 per cent of patients stay longer than five years. Based on the most recently published data on expenditure and beds (Department of Health, 1995), uprated to 1998 prices, the average weekly cost per in-patient bed is just over £650 per week. Total cost is obtained by multiplying average cost by length of stay by discharges. The data on discharges closely mirrors the available information on the number of in-patient dementia cases (561 cases) as given by the most recent Irish Psychiatric Hospitals and Units Census (Keogh and Walsh, 1995), but has the advantage of being current, as well as being broken down by age category. The estimated total cost of care in psychiatric hospitals is highest for people aged 75 years and over, with these costs accounting for 71 per cent of the total cost. This reflects the fact that this group spends the longest time in care. The total cost of psychiatric care for people with dementia is just under £14 million.

Table 7.4: Annual Cost of Psychiatric Hospital In-Patient Care for People with Dementia

In-patient data	< 65	65 - 69	70 - 74	75 - 79	80 - 84	85+	Total
Annual admissions	239	96	129	115	141	65	785
First admissions	73	42	65	64	74	44	362
Average weekly cost per in-patient bed (£)	652.71	652.71	652.71	652.71	652.71	652.11	652.71
Average length of stay by discharge (days)	43.85	269.82		285.39			247.53
Number of discharges (including deaths)	84	146		366			596
Total cost (£)	343,456	3,673,239		9,739,621			13,756,316

7.3.4 Family Care

Data generated by Ruddle and O’ Connor (1993) suggest that the average care provision for people with dementia is 11 hours per day. Blackwell *et al.* (1992) also estimated an average family care provision of 12 hours per day for people in the highest category of physical dependency, as measured by an activities of daily living (ADL) scale. Almost two thirds of people in the highest ADL category had associated mental problems (Blackwell *et al.*,Table A5.13) though not necessarily dementia. These estimates are validated by the analysis of the data from this study which shows that the average daily hours of family care for people with Alzheimer’s disease is 12 hours per day.

Table 6.7 in the previous chapter provided a range of estimates for the valuation of family care provision. The estimate used in this chapter is the opportunity cost valuation of £130 per week associated with the carers of people with dementia on the Alzheimer list. For an 81 hour week this amounts to only £1.60 per hour in money terms. This is the most appropriate rate to use in the calculation of family burden as it is a measure of what carers sacrifice in order to care. Multiplying the hourly cost of care of £1.60 by the number of hours provided to people in each age category yields a total cost for family care of £154 million (Table 7.5). Given the high levels of family care provision for people with very low dependency (Blackwell *et al.* 1992), it seems reasonable to include all people with dementia in the calculations of aggregate family care.

Table 7. 5: Annual Cost of Family Care for People with Dementia

Age category	%	Number	Care hours per day	Opportunity cost per hour (£)	Total annual cost (£)
65-69	1.6	1,998	11.6	1.60	13,535,251
70-74	4.8	5,390	11.6	1.60	36,514,016
75-79	2.1	1,796	11.6	1.60	12,166,822
80-84	10.4	5,814	11.6	1.60	39,386,362
85+	22.9	7,763	11.6	1.60	52,589,667
All	5.5	22,761	11.6	1.60	154,192,118

7.3.5 Primary and Community Care

This section combines data on primary and community care to provide an overall estimate of the cost of formal community care services for people suffering from dementia. Estimates of the number of people with dementia receiving the various services are based on the weighted average take-up rates for people on the Alzheimer list and in the ESRI sift group in this study, as shown in Tables 5.10 to 5.13. Basing the estimates only on take-up rates for people on the Alzheimer list would have exaggerated community care provision, since people on the list are more likely to receive some community care services due to their contact with The Alzheimer Society of Ireland. The absence of other services from the calculations reflects the paucity of their provision in the community referred to earlier in the report. The data on service use are combined with estimated hourly rates of pay for each of the service providers to yield an overall cost of care. Unit cost data for each service are based on the weighted averages for people on the Alzheimer list and in the ESRI sift group shown in Table 6.8. The overall cost of care in the community, including respite care and some private provision such as private personal assistance and private nurse, is £16 million (Table 7.6).

Table 7.6: Primary and Community Care for People with Dementia

Service	Weekly Per Capita Cost of Care	% Using the Service	Number of People with Dementia Using the Service	Total Annual Cost (£)
Home Help	6.32	21.3	4,848	1,593,247
Home Care Attendant	9.23	16.9	3,847	1,846,406
Private Personal Assistance	14.11	11.8	2,686	1,970,772
Private Nurse	3.00	1.1	250	39,000
General Practitioner	2.59	57.2	13,020	1,753,534
Public Health Nurse	4.28	68.0	15,478	3,444,784
Chiropodist	0.49	20.7	4,711	120,036
Day Care	6.22	32.8	7,466	2,414,803
Respite care	5.84	35.4	8,058	2,447,053
Total				£15,629,635

7.3.6 Residential Care

Table 7.7 shows the total costs by residential type, based on 1998 prices. The total cost of all residential care is estimated at £82 million. The weekly cost of care is assumed to be the same for all types of public and private accommodation. Highest annual costs are recorded in private nursing homes where the majority of people with dementia who need residential care are located. Direct public funding of residential care for people with dementia accounts for £21 million, or only 25 per cent of total costs of residential care. There may, however, be some indirect public subvention of private provision for people with dementia, though we have no way of estimating the extent of subvention involved.

Table 7.7: Annual Cost of Dementia in Residential Care

Category of Visit	Number of patients over 65 years	Number with dementia	Average weekly cost of care (£)	Total Annual cost of Care (£)
Health Board geriatric home/hospital	5,082	950	312	15,412,800
Health Board welfare home	1,200	133	312	2,157,792
Health Board district /community hospital	1,560	224	312	3,634,176
Private nursing home	6,200	1,470-3,700	312	41,939,040
Voluntary geriatric home/hospital	2,936	478-1,800	312	18,479,136
				81,622,944

The overall baseline cost estimate for dementia in Ireland is £328 million (Table 7.8). If we accept that the total population of people with dementia in Ireland is just over 30,000 people, then the cost of care spread across people affected by the disease is just over £9,000 per person per year. Annual costs per patient as reported in the literature (Wimo *et al.* 1997b), expressed in 1993 money terms, range from a low of around \$6,660 (Smith *et al.* 1995) to a high of approximately

\$46,700 (Ernst and Hay, 1997; Ernst *et al.* 1997). Our estimate comes at the lower end of the range of published estimates. These differences reflect methodological differences in the calculation of costs and system differences in the organisation and funding of care for people with dementia.

Table 7.8: Total Annual Costs of Dementia Care in Ireland (1999)

Care Type	Annual cost per patient (£)	Number with dementia	Total annual baseline cost of care £m	% of total cost	Annual cost based on Sensitivity analysis (£)	% of total based on sensitivity analysis
In-patient acute care	3,059	1,635	5	2	52	11
In-patient psychiatric care	23,490	596	14	5	14	3
Family care	6,766	22,761	154	57	289	64
Primary and community Care	703	22,761	16	6	16	4
Residential care	16,299	5,031	82	30	82	18
Total	9,026	30,023	271	100	453	100

7.3.7 Sensitivity Analysis

Given the absence of data on some variables, and uncertainty with respect to the estimates generated for other variables, there are a number of valuation issues that can be briefly raised through sensitivity analysis. Primarily, sensitivity analysis can be used to take account of different views on the value of the work that carers do for their dependent kin. For instance, valuing carer time on the basis of an hourly home help rate of £3 per hour would lead to a replacement cost valuation of £289 million per year. Valuing family carer input on the basis of the national average industrial wage for women of approximately £6 per hour would more than triple the cost of family care.

Including an estimate of the marginal cost of dementia in acute care elderly populations would increase the cost of dementia in this setting. Dementia and other forms of cognitive impairment are common in older people admitted to hospital for other reasons. The difficulty lies in estimating the additional costs, in terms of service use and length of stay, associated with dementia in this group. A major element of the additional cost of care is associated with patients awaiting transfer to more appropriate forms of care. The problem is that we do not have data on the extent to which dementia increases the waiting time for patients awaiting transfer. If we assume a dementia prevalence rate of 20 per cent in acute care elderly populations (Hickey *et al.* 1997), and that 18 per cent of all bed days are additional dementia-related days⁹ then acute care costs could rise by £52 million.

Valuing family care on the basis of home help rates, when combined with new estimates for acute care costs increases the overall cost of dementia in Ireland to £453 million (Table 7.8). However, it must be acknowledged that both baseline and sensitised estimates produced in this chapter reflect actual levels of provision, not optimal levels of provision. The recent An Action Plan for Dementia identified a major gap in Ireland between the needs of people with dementia and existing provision (O'Shea and O'Reilly, 1999). Thus, their suggestion of a cash injection of £46 million, over a three-year period, to begin the process of bridging the gap between need and existing provision for people with dementia. Whether this money will be allocated in the future will, ultimately, be a political decision, but the fact that the need for such an allocation is universally acknowledged by people working in the area should serve as a warning not to confuse actual and optimal estimates of resource use.

7.4 Conclusion

This study has used a variety of different indices to estimate the resource implications of dementia in Ireland, including information on the following items: mortality and life years lost, acute in-patient care, psychiatric in-patient care, family care, primary and community care, and residential care. While the analysis suffers from the usual problem associated with cost of illness studies—the lack of good quality data—the distribution of the burden of care is clear enough. Family care accounts for 57 per cent of the overall burden of care (Table 7.8). That proportion rises to 64 per cent if family care is valued on the basis of home help replacement cost. The contribution of family members to the caring process is a consistent finding in the literature where such costs have been measured. The contribution of family care is in contrast to the relatively low provision of community care for people with dementia. Only 6 per cent of the cost of dementia is attributable to community care services.

⁹ This estimate has been provided by Dr. Desmond O'Neill

The results point to very important balance of care issues between community care and residential care. Community support services for people with dementia and their carers are underdeveloped and fragmented. Generally, people with dementia do not come into contact with the health and social services until a crisis occurs, involving the person with dementia, their carer, or both parties. Late intervention is, in turn, more likely to lead to institutional care, when the carer decides that she cannot provide the level of care needed. Currently, long-stay residential care accounts for one quarter of the burden of dementia care. There is a need to examine the effectiveness of different regimes of long-stay care for people with dementia, and to compare the results to different community care options. We need more information on process and outcomes if we are to improve decision-making at the margin between care in the community and long-stay care (Kavanagh *et al.* 1995). Cost of illness studies are not designed to evaluate effectiveness, but the results presented here do highlight the potential and need for such studies. However, before we can move towards cost effectiveness analysis and cost utility analysis of dementia care programmes we must first of all document and understand the current approach to resource allocation in the area and the distribution of existing burdens. The cost of illness approach used in this analysis is an important first step on the road to full economic evaluation of dementia care programmes in Ireland.

8

Chapter 8

Developing the Social Economy in Dementia Care

Chapter 8

Developing the Social Economy in Dementia Care

8.1 Introduction

The motivation for this study arose out of concern about social care provision for people with dementia and their carers. The gap between existing social services provision and need is confirmed in the data generated for the study. Services are inadequate for the level of need that exists in community care. For people with dementia, need exists in relation to home care services, community-nursing services, respite facilities, and day care services. The public policy issue is how best to encourage new and flexible forms of service provision to meet the needs of people with dementia at a local level (O'Shea and O'Reilly, 1999). On the supply side, we need to consider the limits of public and private sector provision and consider how innovative community-based responses can be encouraged at a local level to deal with multi-faceted access problems. On the demand side we have to consider how need can be transformed into effective demand for people with dementia and their carers. Thinking must extend beyond conventional State provision of services if the problem of inadequate provision of community care is to be addressed.

The gap between the needs of older people with dementia and the public and private resources available to meet those needs has focused attention on the possibilities of bridging that gap through the development of the social economy. The social economy is difficult to define, with different groups using different definitions depending on the particular context at any given time. Most definitions include some combination of the following to describe social economy activity: community ownership; local control and benefit; decentralised, people-centred, models; and social objectives. The social economy is the space between purely private production and purely public production. It is most relevant where market failure exists, but the State cannot, or will not, intervene. In such circumstances, needs and demands arising from the market failure are met through community, voluntary, or co-operative forms of organisation, rather than through conventional public sources. Latent needs are transformed into effective demand through local, community-based, innovative responses to the problem of provision. Thus delineated, the social economy is related to the concept of the 'third sector', which comprises the voluntary, non-profit, and co-operative sectors.

The need for increased investment in community care services is widely acknowledged. The likelihood of this investment coming from conventional public sources is low, however, given the increasingly binding constraints on public expenditure, linked to our commitment to Economic and Monetary Union within the European Union. New forms of social enterprise will, therefore, be required to bridge the gap between what the State is currently providing and what people with dementia and their carers need. The social economy contains the potential to address some of the social care problems facing local communities in Ireland today. The social economy is the place where the needs of people with dementia might be addressed, while at the same time generating additional income for the providers of services. The task is to develop a model for social entrepreneurship, which will provide the catalyst for local groups to address their own problems, with the support of statutory agencies. This task will be made easier if funding issues are addressed at the same time, with particular attention given to new ways of financing community care consumption. While the State will continue to provide the bulk of services and financing for the care of people with dementia, the emphasis in this chapter is on developing local social economy solutions to support existing levels of provision.

8.2 The Nature of the Social Economy

For some people the social economy is synonymous with voluntary activity. However, while voluntary provision comes within the broad ambit of social provision it is only one part of the social enterprise spectrum. Social economy production is usually located between purely voluntary activity and purely commercial activity (Table 8.1). For Pearce (1993) the 'community business continuum' covers the following activities:

- voluntary enterprises [defined by Pearce as projects which provide a local service and are run in a business-like fashion but which use for the most part volunteer labour],
- social enterprises [defined as a business providing a social or commercial service which requires some special ongoing contract arrangement, or subsidy, usually from the public sector, or from within the community enterprise group, or in the form of some unpaid labour input],
- community businesses [defined by Pearce as a business which should become viable and sustainable without any ongoing external assistance, beyond that which is generally available as part of small business support schemes].

Pearce (1993) describes how movement along the continuum will and should happen, but it is important not to set up as a community business something that can never be more than a voluntary enterprise. For example, most thrift shops and community cafes are likely to be voluntary enterprises but some may become a social enterprise and, in exceptional circumstances a community business. Projects like these, and others, like community launderettes, may operate in different ways at different times: sometimes paying staff, sometimes dependent on volunteers, sometimes breaking even, sometimes not. It is important to be realistic about the potential of a project when planning it and target aspirations accordingly. Thus, the continuum must be dynamic and permit shifts along it by projects and people in both directions at different times. In development terms the capacity to learn in one category and move on to another is a vital part of the process. In economic terms, according to Pearce (1993) all types of business along the continuum are trading organisations and make an important and valuable contribution to the community economy.

It is widely argued that it is a mistake to view social enterprises as businesses or as vehicles for job-creation. For example, Mallaghan *et al.* (1996) conclude that some may have measurable outputs in training or job creation, but arguably the greatest long-term benefit will be the creation of organisations that are enterprising in that they bring together the resources from a range of public sector agencies and local markets to ensure that local needs are addressed. For the most part the activities cannot be justified on current commercial criteria but are nevertheless needed and there are people who are willing to provide them. The most important considerations, and measures of success, should be the achievement of the mission-related objectives in meeting social need as set by the social enterprises themselves. Services for people with dementia and their carers are ideal for development by the social economy since they require skilful financial management and are best delivered at the local level (Grimes and Maxwell, 1997).

Local responses through the social economy sector in Ireland have been quite substantial and varied. The level of voluntary activity in dementia care has been acknowledged, particularly the work done by the Alzheimer Society of Ireland and the Western Alzheimer Foundation (O' Shea and O' Reilly, 1999). Less is known about other forms of local provision for people with dementia and their carers. In recent years, there have been a number of general reports detailing experiments that are taking place in the social economy, and speculating on the potential for further developments in many different areas, including social care provision for dependent older people. (Mallaghan *et al.* 1996; Fitzpatrick and Associates, 1997; PLANET, 1997). Generally speaking, social care services for older people are suited to the social economy approach. Many of the current initiatives are funded through

pilot programme grants from both national and EU sources and, as a result, tend to come and go as these initiatives start and finish. The majority of social care initiatives depend almost entirely on Community Employment (CE) schemes, which by definition are transitory and uncertain. There is also a lack of continuity and consistency across areas and regions in how initiatives are supported and developed (Mallaghan *et al.* 1996). Many of the urban-based initiatives tend to focus on enterprise linked to problems of long-term unemployment, on trying to integrate people back into mainstream employment through new forms of work. In rural areas there are more serious limitations on economic activity and employment opportunities because of smaller markets and therefore the initiatives tend to have more social objectives.

Table 8.1. The Social Enterprise Spectrum

Purely Voluntary <-----> Purely Commercial			
Motives, Methods and Goals	Bridging gaps between local need and provision. Local Capacity Mission driven Social Value	Mixed Motives. Mission and Market driven. Social and Economic value	Market derived opportunities. Appeal to self-Interest. Economic Value
Key Stakeholders *Beneficiaries	Pay nothing	Some willingness to pay subsidised rates or mix of full payers and those who pay nothing	Market rate prices
*Capital	Grants Donations/gifts.	Below market capital mix of donations and market rate capital	Market rate of return
*Employment	Volunteers	Community Employment Below-market wages. Mix of volunteers and fully paid staff	Market rate wages
*Statutory agencies	Some informal relationship	Negotiated but temporary relationships	Full contracts

Source: Modified after Dees (1998)

The concept of the social economy has received increasing attention in recent years, mainly through the published reports of a wide range of agencies including the PLANET network of area-based partnerships, Area Development Management, the National Economic and Social Forum, the Community Workers Co-operative and the Tallaght Social Economy Unit. Many of these reports have been written to inform the deliberations of the Social Economy Working Group which was set up to honour a commitment in Partnership 2000 to undertake a detailed examination of the potential of the social economy. Much of the recent literature on the social economy in Ireland has, therefore, been produced to inform the Report of the Working Group. The Partnership 2000 agreement contains a further commitment to establish appropriate support mechanisms to facilitate the achievement of the full potential of the social economy in light of the recommendations of the Working Group (Report of the Partnership 2000 Social Economy Working Group, 1998).

These recent Irish reports signify the emergence of consensus on a working definition for the social economy, based on that proposed in the 1997 Planet document Building the Social Economy. The social economy has been broadly defined as that part of the economy between the public and the private sectors, which engages in economic activity in order to meet social objectives. (Report of the Partnership 2000 Social Economy Working Group, 1998). Social objectives include the creation of employment in disadvantaged communities, the provision of new personal and social services, the economic empowerment of communities, and the development of social entrepreneurship (ADM 1998). Three categories, or subsets of social economy activity, have been identified in order to clarify the discussion on the development and potential of the sector. These have been identified as community business, deficit demand social enterprise, and enterprises based on public sector contracts. While community businesses and enterprises based on public sector contracts would be expected to attain commercial viability soon after their establishment, deficit demand social enterprises may require a certain amount of ongoing public support. Social care services would be categorised under deficit demand enterprises.

A review of existing State supports to the social economy is undertaken both in the most recent ADM report (1998) and in the Report of the Partnership 2000 Social Economy Working Group (1998). Both reports conclude that the State already provides a significant amount of support to the social economy, albeit in an incomplete and uncoordinated manner, through a range of labour market integration and enterprise development schemes. However, since none of the schemes was designed to support the development of services within the social economy, they are inappropriate and difficult to access. The lack of an appropriate support scheme

and the diverse range of potential sources of funding can, and often does, result in a high degree of complexity and bureaucracy, which can stifle the development of services by community organisations. Furthermore, it is acknowledged that the evaluation criteria applied under current schemes can result in a distortion of the objectives of social economy project promoters.

Many of the schemes that offer the most appropriate support to the development of the social economy, such as the FÁS Community Enterprise Programme, are underresourced and limited to projects perceived as commercially viable. The main (and often only) form of State support for social enterprise has been in the form of labour subsidy through the Community Employment scheme. Unfortunately, these schemes may not always cover important categories of workers who have traditionally provided the bulk of unpaid social care services. Women between the ages of 45 and 69 make up the majority of those who provide social care for people with dementia. Even though many of these women come from low-income households, they may not be receiving social welfare benefits in their own names and therefore do not qualify for some of the schemes. More flexibility with regard to the eligibility criteria for participation in social economy programmes would allow for greater participation by those currently engaged in the provision of unpaid care for people with dementia.

The Social Economy Working Group (1998) recommended that any new State financial support for the development of the social economy should be funded 'to the greatest possible extent from existing resources'. The 1998 Report also recommends that existing local government and local development structures, including health boards, be charged within existing policy frameworks with developing more active and strategic supports for the social economy. Even though enterprises based on public sector contracts were identified as a legitimate and commercially viable category of social economy activity, concrete discussion of the development of this category is almost entirely absent from the Report. A strong case can be made for the awarding of public sector contracts to established deficit demand social enterprises with a proven capacity to produce high quality services in the area of dementia care. Awarding of health board contracts to established community groups would certainly not amount to a displacement or replacement of existing public sector services, since a vacuum currently exists regarding the provision of home care and social care therein.

8.3 Social Entrepreneurship

On the assumption that real gaps in social services provision will not be met by either the public sector, or the private sector, there is an imperative to explore ways

to grow the social economy in the years ahead. This is not to say that the social economy is the only answer to the problem of inadequate social provision but in the absence of developments elsewhere, it may be an important source of additional funding and provision. When markets fail, or are thinly provided, and when the resulting public sector response is inadequate, social innovation is necessary to deal with the resulting impasse. Social entrepreneurs are an important source of social innovation. They identify social needs, but more importantly they identify new ways of addressing these needs. Social entrepreneurs are likely to be complex, multi-dimensional people, who are driven by a need to do something about the social problems in their immediate areas. They find ways and means to address these problems through using under-utilised resources, mainly people, but also buildings and equipment and putting all of these to good effect to solve problems. They identify sources of funding for particular projects and find new ways of delivering services to people in need. Leadbeater (1997) describes the core assets of social entrepreneurs in terms of social capital, meaning relationships, networks, trust and co-operation, which gives them access to physical and financial capital.

The concept of social capital is a useful way of dealing with the contribution social entrepreneurs make to social development. Social capital is associated with shared values, trust, networking and co-operation (Putnam, 1993). The more extensive the social contacts, the more complex the networking, the greater the co-operation, then the more likely it is that social needs can be addressed in an effective way. Social entrepreneurs harness and develop social capital for social productive purposes. Communities with well-developed social capital are able to respond to problems and deal with threats and opportunities in equal measure.

Unfortunately, social entrepreneurs are in scarce supply, particularly the variant that can transform communities through an innovative supply of social services. This is not to deny that many communities have people who care about social problems and who try to do something about these problems. The reality is, however, that many communities do not get beyond the documentation of problems, and, even when they do, their response is often too isolated, too narrowly focused, too poorly funded, with poor internal links within the community they wish to serve, and no links to outside communities, or agencies. The desire to effect change is there, but the social capital necessary to transform social life is under developed, or, worse still, absent entirely. We must also recognise, of course, that many communities have shown no response at all to the problems that affect their local area.

Enduring social entrepreneurship is about creating what Leadbeater (1997) calls the virtuous cycle of social capital, whereby physical capital, financial capital, human

capital and organisational capital all grow rapidly to the point of generating social dividends which can be used to create more social capital and the cycle begins again. In very few places in Ireland is there evidence of such virtuous social capital cycles in operation. The main reasons for this are the absence of a comprehensive and consistent public policy for the creation of social entrepreneurs, the lack of an institutional framework to support social entrepreneurs, and a poor general understanding of the concept of social capital and its importance in both economic and social development. Moreover, while there are things that government and other agencies can and should do to develop more social entrepreneurs, nobody should underestimate the inertia that exists in some communities with respect to taking action to bring about social change.

The major question, therefore, is how communities can be encouraged and facilitated in the development of social entrepreneurial skills. The first point to make is that entrepreneurial skills are difficult to teach. There is a vast literature on what makes an entrepreneur in the conventional economic sense, but not much on the nature of social entrepreneurs. The promotion of a volunteering ethos in society may be an important pre-requisite for the development of social entrepreneurs. If voluntary effort and community action are not seen as important, or are not highly valued by society, then it is unlikely that entrepreneurs will be attracted to social production. Voluntary effort is still highly valued in Ireland, so a general framework does exist for social entrepreneurship. Paradoxically, the existence of a voluntary ethos may also undermine an enterprise culture among potential social entrepreneurs. Voluntary effort in this country has largely been associated with unpaid, often religiously motivated, provision of service, and this legacy can make it difficult to generate new forms of innovation linked to quasi-commercial objectives within a social economy framework. Training in management and business-oriented skills may be necessary to encourage potential entrepreneurs and embryonic community groups to think in social enterprise terms, and ultimately develop sustainable socially-oriented projects. Genuine partnership between the State and social economy producers will be necessary for initiatives to succeed.

There is a general absence of specific public funding for organisations operating in the social economy, particularly for those involved in social services provision. Social housing provision is the only area where dedicated financial support is available covering at least 90 per cent of the total costs. Funding in other areas, where it exists, tends to be piecemeal and idiosyncratic, making it difficult to engage even in medium-term planning. Funding to community bodies tends to be allocated on an annual basis thus making it difficult to plan beyond this time frame. Moreover, funding is often allocated retrospectively, with the result that community groups

must commit to projects without knowing when dedicated funding for that project will arrive. The absence of long-term contracts for social economy producers further undermines the planning process.

There is a strong case for the capital funding of social enterprise projects from public sources. The most successful social economy projects tend to be those that have initial access to physical capital. The availability of a building, or buildings, provides a secure basis for future activities and increases the likelihood of statutory support for current activities. Very often, particularly in the area of social care, the provision of a building provides the foundation for a whole range of outreach community activities. Buildings are the visible manifestation of community action that allow less tangible forms of activities like home services to grow and prosper. In some cases, opportunism and luck play a major part in projects having access to physical capital. For example, buildings are sometimes donated by individuals, or by religious orders, or monies are donated by generous benefactors, which allow old buildings to be renovated. In the absence of such benevolence, community groups face a long struggle in generating funds to meet their physical capital needs.

Private funding of the physical capital needs of community groups engaged in social economy activity is entirely absent. Banks do not get involved in social economy projects, particularly in the field of social care, because of the low return, high-risk nature of activity in this area. The fact that banks do not lend to community projects geared to social provision does not mean that they shouldn't be encouraged to do so under new social responsibility-type tax schemes. The creation of a small social fund through the nominal taxation of bank profits would be an important public statement on the importance of social objectives in this society. Credit unions might also play a more direct role in funding community activities. The presence of specialised banks for agriculture and industry in Ireland only serves to highlight the absence of any coherent strategy towards the achievement of social objectives in the country. The amount of money necessary to gear-up the social economy, particularly with respect to social care activity, is very small and may not require the introduction of a dedicated credit agency. It does, however, require increased support from existing lending agencies, either freely given, or on a compulsory basis.

The private sector has an important role to play in developing the social economy. The idea that social objectives can be separated from economic or commercial objectives is an anachronism, with a consensus now emerging on the importance of social capital for economic progress. This idea is, of course, not new and one can find plenty of examples, especially in the pre-welfare state past, of companies

recognising their social responsibilities through the provision of social housing and social services for workers. While much of this involvement was based on paternalistic motives, it did provide important social investment at a time when public spending in the area of social protection and social care was low, or non-existent. The opportunity now exists for private sector involvement of a different type and on a different scale to support community groups involved in social economy activity.

Companies should be encouraged to think strategically about their social policies. Currently, many private companies are providing ad hoc support for social enterprises—a small donation on an occasional basis, sponsorship, unwanted equipment now and again, services in kind—but nothing on a strategic basis. There may be opportunities, however, for more formal arrangements, including initiatives in the areas of joint ventures, mentoring, venture capital alliances, and for the transfer of important commercial and technical skills between the private sector and the social enterprise sector. These new relationships will not happen automatically, and may require an imaginative taxation policy to reward companies who wish to become involved with social enterprise. Some form of brokerage may also be required to facilitate the involvement of private enterprise in social enterprise.

8.4 Demand-Side Issues

Supply-side measures can only achieve so much in the development of the social economy. They must be complemented by demand-side initiatives which encourage consumers and clients to purchase the services produced by community groups engaged in social production for the care of older people. Public sector agencies, such as health boards and local authorities, must also be encouraged to purchase the services produced by community groups. The critical issue, therefore, is the existence of a market for social economy output. The absence of any tradition of a private market for social care in this country will make any transition to a social economy problematic and difficult. It is particularly difficult to introduce charges, even minimal ones, for services that are currently provided free of charge by voluntary groups. The issue of payment for services seems to create fewer problems when it is built into the service from the beginning.

There will have to be a great deal of work done on building up the demand side of the market if the social economy in the area of social care provision is to become a viable commercial proposition. Partly the problem is one of persuading people that paying for additional social care is justified, given the general view that services should be provided by the State free of charge to all recipients. For the social economy to work however, in the absence of expanded public provision, care

recipients will have to pay for new services. This immediately focuses the spotlight on the ability of older people to pay for care. It is one thing to say that older people shouldn't pay, but quite another to say that they cannot pay. The former is a normative view, about which one can do very little, if that is the view prevailing at any particular point in time. The proposition that older people cannot pay is essentially an empirical issue, about which one can do something, if it turns out to be true.

The ability of older people to participate meaningfully in economic and social life is determined by their access to financial resources. There is general agreement that the incomes of older people improved significantly during the late 1970s, and in the first half of the 1980s. During this period, a disproportionate share of State subsidies, both cash and in-kind provision were concentrated on older people. Many positive changes in public pension policy have also occurred during these two decades. New schemes were introduced, the age at which pensions were payable was reduced, and real increases in payments took place. Improved and more widely available occupational pension schemes also helped to raise incomes.

The general improvement in the income position of older people has not continued into the nineties. Current cash incomes among older people are generally low with the result that about 30 per cent of older people have incomes below 50 per cent of the national average (Layte *et al.* 1999). Even with improvements in the value of the old age pension in the 1999 and 2000 budgets, the relative income position of older people in society may deteriorate due to the expected higher rate of growth in average national household income in the short to medium-term. Moreover, the problem of income polarisation among older people is not one that has received much attention in Ireland. Yet, there is evidence of income differences between some categories of older people, for example, the risk of poverty increases for older women on non-contributory widow's pension, especially those living in rural areas (Layte *et al.* 1999). These women are much less likely to be receiving income from occupational pensions, or to be covered by social insurance and, therefore, have to rely on social assistance for the bulk of their income.

For all the improvements in the value of the old age pension, a significant number of older people cannot afford to contribute much to the social economy in the way of payments for care. Recall that between 22 and 31 per cent of carers interviewed for this study reported serious difficulties with making ends meet. One solution to the deficient demand problem is to expand the potential social economy market through the use of designated vouchers for social care which could be cashed in return for care from dedicated social economy providers. Home care services, for

example, might be provided by a community organisation on the basis of local demand supported by designated home care vouchers from the State. As well as developing the potential of the social economy, designated social care transfers to older people would encourage consumer choice in this area, something which is absent under current provider-driven arrangements. We might find that older people prefer to spend their vouchers on satisfying social and psychological needs rather than on medical or residential forms of care. This, in turn, might stimulate an appropriate supply-side response within the social economy. The use of vouchers presupposes a commitment by a third-party funding agency to provide the necessary finance to support their general introduction.

The question of family responsibility for community care financing has not been the subject of very much discussion in this country. Presumably this is because community care services are generally free across the country, and are so under-developed that they are not an issue in the way nursing home costs are for the State. There are two main issues with respect to family involvement in financing arrangements for care of the older people. The first issue is normative and concerns the degree to which invoking the moral obligations of family in this area conflicts with the norm of adult independence and personal responsibility. This is a philosophical question that cannot be addressed in the present study, for all its importance. The second issue is a positive one and concerns the willingness of families to financially support the purchasing power of older family relatives in the area of social care. There are no data on the willingness of families to pay for care. There is, however, a lot of evidence that older people in this country are not neglected, either emotionally, or financially, by their families. Family carers are providing high levels of care for relatives with disabilities, with inadequate support from the State. The likelihood is that they would also be willing to purchase appropriate social care if given the opportunity. The absence of much publicly funded support for carers is currently a problem which may only be resolved by the development of social economy type production. At the very least, with new forms of supply, carers might get offered the services they actually need, rather than what doctors and Public Health Nurses think they should have, which is currently the case.

8.5 Institutional Relationships

The opportunity now exists to develop the relationship between investment in local communities and innovation in social production. The main obstacle to the development of greater social innovation is the institutional rigidities associated with existing forms of community care provision. Currently, social care production is, by and large, controlled by the State, and particularly by the health boards. This

control exerts a powerful conservatism on the organisation of social care for people with dementia and serves to dampen any sustained attempts at innovation and development in this area by local and community groups. Any sustained attempt by local people to address social need requires the endorsement of the board, since ultimately funding for any new initiatives is likely to come from this source.

Official Department of Health policy is to maintain older people in dignity and independence at home and to encourage and support the care of older people in their own community by family, neighbours and voluntary bodies in every way possible (Department of Health, 1994). However, these central policy objectives are not matched by a coherent support structure for voluntary bodies and community groups involved in social care provision at local level. The allocation of funding for social economy production is very arbitrary, and operates on an ad hoc basis, leading to frustration among community groups seeking to integrate their services with existing statutory provision. The degree of support available for locally based social care projects varies between health boards and even within health boards. While there are good examples of positive relationships between health boards and local providers, for example in the North Western Health Board, more could be done to expand the overall level of support from official circles.

Many of the problems experienced by community groups stem from the fact that social care tends to cross traditional functional and administrative boundaries and is not comprehensively dealt with by any one statutory body. Community groups trying to develop social care provision have to deal with a myriad of different organisations: the health board, the local authority, the county council, FÁS, the Department of Social Welfare, the Department of the Environment, the National Lottery etc. Moreover, any funding received at a given point in time does not necessarily imply that further funding will be forthcoming in the future. This limits the capacity of community groups to plan the development of their social care services. For the majority of community groups, getting money and support for social care projects is almost always a battle and, therefore, is enormously time consuming.

The lack of support structures, allied to the absence of dialogue between the statutory and the social enterprise sector, clearly inhibits the development of community-based social care for people with dementia. A platform is needed whereby the community sector can formally engage statutory bodies as an equal partner in both the formulation of social care policy and in the delivery of locally-based social care services. The response to the problem of dementia must be both local and immediate if people are to receive the support that they need quickly and

effectively. The development of care management schemes can also provide an important structure to facilitate the integration process, but on its own care management is not enough. Services need to exist before care managers can access them and this is where a fully developed social economy becomes important. Local community groups can meet some of the most basic needs of people with dementia, but they require consistent and medium-term funding arrangements in order for services to develop in the first place. Community-based social economy producers also need training if the services are to be developed in a professional and consistent manner across the country. Indeed the development of the social economy depends upon the introduction of a regulatory structure designed to ensure that appropriate standards are set and met in the provision of social care to people with dementia.

8.6 Policy Innovation

Social entrepreneurship is the key to the future development of community and social care services for people with dementia. Structures will have to be developed to regulate, support and nurture social entrepreneurship in the coming years. This process does not have to start from scratch as a pool of potential entrepreneurs already exists in many areas of the country, mainly working in the voluntary sector. Support for entrepreneurs will involve the following commitments:

- the provision of seed capital for potential entrepreneurs to investigate local social need and to explore new models of delivery to meet that need, particularly for people with dementia,
- investment in specific business and management courses for potential entrepreneurs which would include information on the legal aspects of any new organisations,
- the provision of basic start-up capital grants for projects meeting specific social economy criteria as follows: local job creation, provision of community-owned and controlled local services, providing designated benefits, using any profits for community benefit, and providing a focus for local social development,
- design of regulatory framework and dedicated training programmes for social economy workers and volunteers with a view to expanding the abilities of groups and individuals to respond to the challenges posed by caring for people with dementia.

An opportunity now exists for the health boards to become directly involved in supporting social enterprise in community care provision. The development of the social economy requires the existing brief of the health boards to be widened to include a designated social enterprise dimension. A new and specific unit for social enterprise should be established within each board. The brief of this unit should be to facilitate and support the development of social entrepreneurs in all areas of social care, including services for people with dementia. The primary aim of the unit would be to develop the capabilities of local communities to respond in a professional and employment-creating way to the social needs of local communities. The unit would also be involved in providing seed funding, advice and information on all matters relating to the establishment of social care projects. The unit could also provide training and education for community groups, as well as acting as a clearinghouse for information on social economy projects in the broad area of social care. The unit would also have a regulatory role in the development of the social economy. This would be necessary to ensure that standards of operation and provision are high and consistently applied across the country.

8.7 Conclusion

The State should continue to provide the bulk of care and funding for people with dementia through new investment in community care services and facilities. However, the social economy can be used to support the State in the delivery of innovative, local and flexible forms of provision. The social economy is currently an under-utilised source of support for people with dementia and their carers. What is needed now is the resolve and the commitment to build on the important contribution of the voluntary sector in this area and provide a local and comprehensive response to the problems of dementia. More public funding is required to deal with current inadequacies in community care services and, ultimately, we may need to think about a social insurance financing structure for long-term care. In the meantime it is time to take advantage of the goodwill that exists in the community for locally-based responses to the problem of dementia. We need to expand the capacity of the social enterprise sector to provide appropriate services and we must ensure that the services that are provided are used when and where they are needed.

9

Chapter 9

Care Management for People with Dementia & Related Cognitive Impairments

Chapter 9

Care Management for People with Dementia and Related Cognitive Impairments

9.1 Introduction

The policy emphasis on community care is based on two assumptions: that older people prefer to live at home and that care can be provided at lower cost for people living in the community. There are difficulties with both of these assumptions. While it is true that the majority of older people prefer to live at home, it is important not to confuse optimality of provision and the preference of older people for living at home. The fact that dependent older people like living at home is of little practical value if community care services are inadequate or inappropriate relative to the needs of older people. What the earlier analysis has revealed is the paucity of community care provision relative to other forms of provision. The cost advantage associated with community care may, therefore, have more to do with an over-reliance on family care provision and fragmented formal provision than any inherent cost advantage of home care over institutional care. Costing actual provision rather than optimal provision, while ignoring family care involvement is bound to show a cost differential in favour of community care.

The key issue, therefore, is not the simple dichotomy between community care and some form of institutional care for dependent older people but the development of an adequately resourced, needs-led, community-based service focusing on assessment, enhanced individual choice and the support of carers. It is difficult to see much progress being made in this direction within the current structures of community care in this country. A key recommendation of the recent *An Action Plan for Dementia* (O' Shea and O' Reilly, 1999) was the need to develop care management structures for the delivery of services to people with dementia in Ireland. The objective of this chapter is to explore the most appropriate model of care management for this country in the light of evidence of good practice from other countries and taking into account existing structures, organisations and relationships in the provision of services for people with dementia and their carers. If the previous chapter was about generating additional community care services for people with dementia, this chapter is concerned with ensuring that people get the services that they need, when and where they want them.

The basic philosophy of care management is to facilitate more flexible and individualised packages of care for vulnerable older people living at home in the community. The origins of care management lie in the fragmented nature of community care delivery and the subsequent need to co-ordinate the provision of services to individual clients. Care management can be the catalyst for a new form of community care delivery, client specific, and geared to meeting the changing needs of older people and their carers. Care management can be provided in many different settings and for different target groups. There are so many different models that it is difficult to talk about standard care management practice (Davies, 1992). The basic objective is, however, to ensure that the needs of vulnerable older people are met by the optimal use of the resources available in the community. To achieve this objective care managers must develop the capacity of existing services to respond to client need, nurture and encourage new forms of provision and promote service efficiency and effectiveness. The core tasks are case finding and screening, assessment, care planning, implementing and monitoring the care plan (Challis, 1994). For care management to be successful sufficient resources must accompany any new forms of organisation and delivery of services.

The basic distinction in care management models is between the broker and service manager models. In the broker model the care manager co-ordinates care and refers older people for needed services but does not control a budget to pay for these services. In contrast, the service management model gives budgetary control to the care manager (Applebaum and Austin, 1990). Outside this basic distinction care management can vary according to the choice of care manager, the setting for care management, the selection of clients for care management, the overall budget for care management and the duration of care management schemes. While the implementation of care management in other countries has not been without controversy, there is evidence that properly constituted care management schemes carry the potential to improve the well being of older people living in the community. In a commentary on care management schemes in the UK Challis (1993) suggested that schemes have led to improved morale and reduction in care needs for older people, improvements in the well-being of carers compared with non-recipients of the service, and a much improved chance of people remaining in their own homes without a significant increase in costs.

The recent *An Action Plan for Dementia* (O'Shea and O'Reilly, 1999) identified a variety of services that need to be developed to support people with dementia and their carers in the community. These include an increase in specialist domiciliary care, enhanced use of professional home-based services and respite care, and improved integration between primary and secondary sectors. What is clear from

the Plan and from the published literature in this area is that the provision of the standard range of services, even if provided early, is necessary but not sufficient to significantly improve the well-being of people with dementia and their carers. An 'intensive care management model' providing substantially different services both in quality and quantity, may also be required, particularly if targeted on people in need of extra support (Knight *et al.* 1993; Challis, 1994).

9.2 Framework for Care Management

Care management is mainly about enhancing the potential of people with dementia to remain in their own homes for as long as possible. Care management is particularly important for people on the margin between community care and continuing care in hospital or long-stay institution, given the importance of targeting care management schemes on specific client groups. The optimal placement of people with dementia between community and residential care is essentially an allocative efficiency problem. In the public sector, allocative efficiency is concerned mainly with whether the level and mix of services provided is what the public wants. Optimality is achieved when net social benefits (social benefits less social costs) are maximised. In dementia care, the optimality question hinges on whether there exists an identifiable dependency cross-over point above and below which some regimes of care are more efficient than others and whether, with care management, it is possible to influence that cross-over point to allow more people to remain in their own homes. Figure 9.1 is an attempt to simplify the identification of net benefit opportunities in moving between care in long-stay settings to community care settings.

Estimating the precise nature of the costs and benefits of dementia care programmes in Ireland is not an easy task. One of the main difficulties is the absence of published information on the numbers likely to benefit from policy changes emanating from innovations in community care. The key issue with respect to care management is to identify the categories of older people who are likely to benefit most from the new service. We have very poor data on both the extent and adequacy of existing community care provision for people with dementia. The absence of good data makes the evaluation of the costs and benefits of major policy changes in the area of dementia more difficult than it should be. It may also lead to biased results if resource use in community care is under-estimated relative to institutional care, due to incomplete or inadequate data.

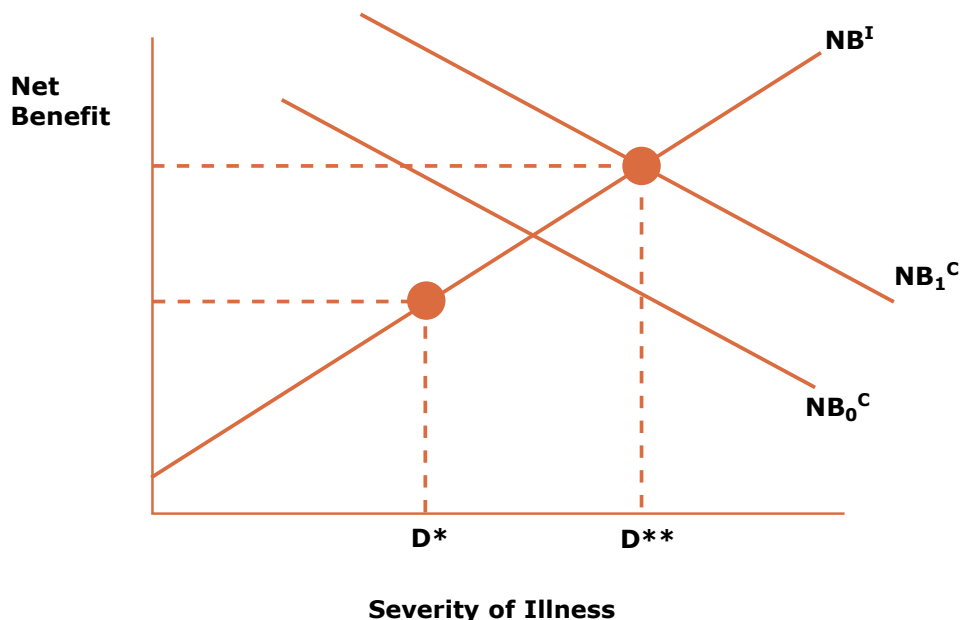
Fig .1: Net Social Benefits for Community and Institutional Care



Most theoretical models in this area are characterised by the assumption that the cost of care increases linearly with severity of illness. It is further assumed that marginal costs are lower for community care at low levels of severity, while institutional care is cheaper for people with advanced dementia. For people with less severe dementia, community care is cheaper, while for people with severe illness residential care may be cheaper. People with intermediate levels of dependency are, therefore, the most important group from a policy perspective. This is due to concern about whether community or residential care is less costly in the immediate vicinity of the cross-over point.

When analysing choices, costs and benefits must be considered simultaneously. The critical theoretical relationship is between marginal net benefit (marginal benefit less marginal cost) and the severity of illness in both regimes of care. Figure 9.1 shows hypothetical net benefit schedules for community and in-patient care based on the assumptions discussed above. The 'cross-over' point is that level of severity of illness where alternative regimes of care change, at the margin, from having a lower (higher) net benefit to having a higher (lower) net benefit. Below level of severity D^* the efficient placement is community care- benefits are greater and costs are lower; above D^* in-patient care is more efficient.

Figure 9.2 Net Social Benefits for Community and Institutional Care Following an Increase in Community Resources



The model can be adjusted to allow for consideration of the effects of the introduction of care management programmes in community care. If care management increases the benefits of living at home without significantly affecting the cost, then the net benefit schedule for community living shifts to the right, reaching a new equilibrium at D^{**} (Figure 9. 2). This means that community care is now also the most efficient placement for people with higher severity ratings between D^* and D^{**} . Now, only people with a level of severity above D^{**} should be admitted to in-patient care. As a result of the investment in care management more people can now live at home.

The balance of care model is, of course, overly deterministic in terms of the precision that can be achieved in allocative decision-making. In practice, there is a wide margin within which decisions about placement are made. Placement procedures are not so well developed as to allow people with dementia to be slotted easily into the most efficient regime of care, except between broad parameters. The model is, however, a convenient way of thinking about the returns from investment in care management in community care.

There are a number of important conceptual issues associated with the development of care management schemes. The first issue is the concern among policymakers over the potential expansion of home care services associated with care management initiatives. Additional resources for home care may lead to more needs being met rather than to the substitution of one form of care for another (Davies *et al.* 1990; Jamieson, 1991). Funders worry that a significant proportion of care packages may be accessed by people who do not need services. This may result in a funding crisis in community care, which may undermine progress made under the initial care management scheme.

This is akin to the concerns that private insurers have about selling insurance for community care services. Insurers worry that without proper controls costs may become unsustainable due to the so-called 'woodwork effect' of an expansion in community care cover (O'Shea and Hughes, 1994). Allied to this is the concern that there may also be substitution away from family-based care as a result of care management initiatives, thereby putting more strains on public provision. Not surprisingly, therefore, the development of mechanisms for achieving effective case finding and targeting is a continuing preoccupation of care managers in providing alternatives to institutional care in countries where schemes exist (Challis, 1999). Legitimate concerns about controlling demand should not, however, be allowed to undermine progress in the development of community-based services, which, as we have seen, are grossly underdeveloped in this country. Neither should concerns about budgetary control blind us to the fact that families need more support as witnessed by the carer stress levels reported in Chapter 6.

The second issue is the source of public funding for the development of care management schemes. Ideally, community-based care management should be paid for from savings generated in residential settings associated with a lower admission rate to the latter. This does not necessarily mean bed closures; it can also mean avoiding expansion of long-stay facilities (Gibbins *et al.* 1982). The problem is that closure, or even reduced capacity, are difficult to achieve, or take a long time, and it will be necessary to invest in care management before any facilities are closed down. Investment in care management can be difficult to justify in such circumstances but the long-term effect is likely to be reduced overall expenditure, all other things being equal.

Of course, conditions do not always remain the same. If the residential space made available, particularly in acute care settings, is not left idle but is filled with other

patients then overall expenditure may not fall. It may even increase given the fact that the marginal cost of new non-elderly patients is likely to be higher than for people with dementia. Similarly, as mentioned above, if care management succeeds in identifying more needs than were anticipated in the community then overall costs are also likely to rise. The reality is that funding will have to be provided on a prospective basis before any savings generated from bed closures occur. Otherwise, progress will be slow or, more likely, non-existent. For care management to work there will have to be an increased investment in community care facilities and services.

The third issue concerns the primary objective of care management schemes. Care management schemes have often been ill defined and, as a result, have not always delivered on either potential or promise. For some people care management is primarily about increased investment in community-based services with a view to keeping more people living at home with a better quality of life; for others care management is synonymous with cost containment and nothing else. The expectation with respect to the latter is that through better co-ordination of existing services care management will facilitate a degree of downward substitution from residential care to home-based care. For co-ordination to succeed, however, there must be services to co-ordinate. Therefore, with the best will in the world, care management cannot succeed if resources are not adequate in the first place. Indeed, perversely, care management can be used to deflect attention from the problem of insufficient resources by highlighting the co-ordination problem as the main constraint on achieving home-based care (Rothman, 1992).

If care management is used primarily to control costs it is likely that access and quality of care issues will be relegated to second place. Therefore, the primary focus of care management should be that of improving the quality of life of people living at home in the community. The critical issue is one of maximising benefits rather than simply controlling costs. This is the only approach that will guarantee an improvement in well-being and quality of life for people with dementia living at home. This is not to deny the importance of budget constraints, simply to acknowledge that the constraints must be realistic. Care management schemes must be properly resourced if they are to improve the quality of life of older people living in the community.

The final issue is the role of care management in the empowerment of clients and consumers. Care managers act as intermediaries between consumers and providers of care, drawing down services on behalf of clients and consumers when and where the need arises. Their role is one of needs assessment linked to case history

interpretation followed by the organisation of a response to meet the needs identified in an appropriate way. Sometimes care managers have control of budgets and can allocate services directly; other times their role is one of co-ordination only. Whether budget holders or not, care managers act as de facto consumers, standing in for older people and their carers in the demand process. This is acceptable, from an optimal point of view provided that care managers act as the client would, if the client were in possession of the same information. However, third-party care management is likely to complicate the demand process, creating an interdependence between demand and supply, particularly if care managers are also suppliers, that would not be there if clients were making their own decisions on what services to purchase, when and where.

This raises the question of whether the interests of people with dementia and their carers might be better served by giving money directly to carers to purchase what they need, in effect empowering them to be their own care manager. From the point of view of autonomy and choice, for both carers and the person with dementia, there are strong theoretical arguments for giving people money directly and letting them make their own decisions on what services to buy. These issues are rarely discussed however, mainly because of general absence of concern about consumer choice and autonomy in social care provision. When the identification of the care manager is being discussed, it is usually with a view to identifying the most appropriate professional group to act as manager. The argument that professionals know best rules in both health and social care services. This view needs to be challenged in any future development of care management in this country.

9.4 Models of Care Management

There are many different kinds of care management, so many that it would be impossible to outline in detail the whole range of schemes that are available. Instead, following Sturges (1995) it is easier to describe general categories or types, which are relevant at this time to Ireland. It is important to point out that the models described below are stylised accounts of the various models available and do not capture the full complexity of provision. In addition, models are not so neatly separated as the account here suggests. Care management structures are often idiosyncratic and there has been an element of learning-by-doing associated with the implementation of care management in other countries.

9.4.1 Clinical versus Administrative

The broadest distinction is between clinical and administrative models of care management. Within clinical models, the emphasis is on process and outcomes, as well as on co-ordination and integration concerns. In administrative models, the role

of the care manager is primarily that of a broker with a focus on service arrangement to the exclusion of more clinical concerns. Administrative models are likely not to be seen as the province of professional workers, in contrast to the clinical approach. There is a clear separation between co-ordination and assessment, provision and delivery. In administrative models, the role of the care manager is to make sure that services get to the people who need them most as assessed by the relevant health care professional. The care manager is not involved in the assessment, provision and delivery of services. In reality, the needs of effective practice may not always allow such organisationally neat solutions. On occasions, in work with people with dementia, part of the ongoing assessment function may be most effectively undertaken by the 'administrative' care manager, because of their proximity to the older person over a considerable period of time. Such workers may also be crucial in undertaking other core tasks, such as monitoring health and well-being, maintaining diet, or giving medication, especially for people living alone. Thus, effective care management for people with dementia may necessitate close links between those formally designated as providers of services and those formally designated as care managers.

9.4.2 Broker versus the Service Manager Model

The broker model is where the care manager refers people for needed services but does not have a budget to purchase these services. The broker is aware of the needs of clients but depends on co-ordination and integration skills to get services to people who need them. In contrast, the service manager does have a budget and can use this budget to purchase services on behalf of clients. The likelihood of appropriate services being delivered to people is higher when the care manager has a budget, although the administration burden is also likely to be higher than in the broker model (Kemper, 1988). This suggests that the introduction of a service manager model of care management may require significant clerical support for optimal effect. Training in the handling and administration of budgets may also be an important pre-requisite for the service manager model to work effectively. It is important to distinguish both broker and service manager models from a key worker model. The latter is usually associated with the co-ordination of a single service usually on a short-term basis whereas care management, whether broker or service manager model, is concerned with the co-ordination of multiple services to meet multiple needs on a long-term basis.

9.4.3 The Generalist versus the Specialist Model

A critical issue is whether the care manager should be a generalist or specialist in terms of the skills needed for the population being served. In a specialist model the care manager will concentrate on particular client groups, such as older people,

people with dementia, and people with mental illness. In a generalist model the care manager will serve a range of people with different types and degrees of disability and incapacity. There is an increasing tendency towards specialisation in many health care professions and this is reflected in the development of client-specific services for people with dementia. Dealing with a complex condition such as dementia may require an intimate knowledge of the condition, which can only be obtained through specialist education. On the other hand, particularly in less populated areas, the number of cases of dementia seen by care managers is likely to be so small as to make specialisation an expensive option. Ultimately, the generalist/specialist decision may be a pragmatic one linked to population size and the availability of suitably qualified specialist staff in an area.

9.4.4 Targeting versus Non-Targeting Model

This issue revolves around whether care management should be focused on certain categories of people within a client group or whether schemes should be more universal in orientation. The targeting problem has been to effectively identify the characteristics of individuals who are likely to gain most from care management. The PSSRU care management projects in the UK were carefully targeted services, focused upon people with considerable needs and a high probability of entry to institutional care (Challis, 1999). The debate about targeting is closely linked to costs. By preventing the admission to long-stay care of a person with dementia on the margin of long-stay care, overall costs are likely to be reduced, subject to the qualifications raised earlier. Under a non-targeted care management approach rising average costs could occur. This is because individuals whose needs currently fall just below that of the present criteria for entry to institutional care receive relatively low levels of provision. It is likely that the care management approach, with its more detailed assessments of need, could well lead to increased expenditure for these people beyond that currently incurred. It is this conflict between meeting broader welfare needs on the one hand and careful targeting on the other that accounts for the inability of some large-scale care management schemes elsewhere to achieve the desired downward substitution of services, despite demonstrating actual and potential welfare gains amongst those receiving the service (Kemper, 1988).

9.4.5 Multi-Disciplinary Model versus Same Discipline Model

This distinction is critical in care management for people with dementia. The care of people with dementia involves the fusion of medical, psychiatric and social care elements. For effective care management for people with dementia it is essential that arrangements are in place to facilitate the multi-disciplinary assessment of people with dementia and, particularly, to ensure specialist clinicians contribute to this process. The care process will require intervention from medical, psychiatric

and social work personnel and from primary and secondary level sources. For Sturges (1995), multi-disciplinary models have many advantages in terms of the variety of support provided for care managers and clients, but working relationships can be more difficult to develop and sustain. Challis (1999) refers to multi-disciplinary working in terms of vertical integration whereby appropriate responses for particular high need client groups are drawn from both primary and secondary level sources.

9.5 An Example of Care Management Model for People with Dementia¹⁰

The Lewisham Case Management Scheme was established to develop a model of care management in a community-based service for mental health of older people (Challis, 1999). The model integrated specialist domiciliary care, specialist mental health care and intensive case management in the care of people with dementia living in their own homes. The aim of the scheme was to provide effective community-based long-term care, which spanned the health and social service divide for older people with a diagnosis of dementia. The target population was individuals with a diagnosis of dementia, identified as having unmet needs and likely to be at risk of entry to institutional care, despite input from statutory services. Care managers with devolved budgets were responsible for providing long-term support to a protected caseload of between 20 and 25 clients. Control over a budget gave case managers the opportunity to be flexible in developing their role in response to the complex physical, psychological and emotional needs of clients and carers.

Care managers spent a considerable proportion of their budget on the purchase of home support provided through a range of helpers recruited by themselves and provided by external sources. Flexibility was a key element of the programme. Money was spent on training local helpers so that the scheme could respond with sufficient flexibility to the needs identified. Flexibility was essential, both in terms of the kind of help provided and of the times that help was available, for example, settling someone down for the night. The help given was supportive, therapeutic and practical. Under supportive goals the most frequently reported priorities were the need for interventions to relieve carer burden, provide respite and assist carers. Therapeutic interventions were most often directed at devising strategies to reduce the problem behaviours associated with the clients' deteriorating state. Practical goals were geared towards meeting the needs of the individual client in the areas of personal care, health care and domestic care. Evidence from the Lewisham case management scheme suggests that intensive case management leads to benefits

¹⁰ This section draws heavily on Challis (1999)

for patients and carers which less intensive interventions have not been able to achieve (Challis *et al.* 1997). The role played by the care manager in integrating specialist mental health support with intensive home-focused social care was critical to the success of the Lewisham scheme. There were significant reductions in the needs of older people and clear gains experienced by the carers participating in the scheme.

9.6 Implementing Care Management in Ireland

The data which were discussed in previous chapters of this report signal a problem in relation to the delivery of community care services for people with dementia and related cognitive impairment in this country. An effective integrated system of care requires that there are clear, co-ordinated and definite routes into a range of community services (Ovretveit, 1993). A mechanism through which this can be achieved is the introduction of a care manager who is given overall responsibility for developing and co-ordinating fragmented systems of community care for people with dementia. Ideally, there should be a number of care managers with small case loads operating within each community care area, or district, each reporting to the overall Co-ordinator of Services for the Elderly. Care management should be targeted on people with dementia living at home but on the margins of residential care. Case loads should be small so that sufficient time can be allocated to each case. There is likely to be a trade-off between the size of case load and the quality of care management programmes. However, optimal case load should, ultimately, be determined by local factors such as client group served, range of available services, geographical area and existing organisational structure.

Dementia is a progressive disease and care plans must, therefore, be monitored and revised over the course of the disease. The care manager would act as a single point of reference. This is very important particularly for those with dementia living alone and becomes increasingly significant as the person with dementia becomes more dependent and needs become more complex. Continuity is essential for optimal care management, not only for clients but also for service providers. The care manager should be linked to a multi-disciplinary team with regular meetings to discuss cases and review care plans.

Following the identification of the target care management population the care manager should meet with each person with dementia and their family to discuss and assess the care needs of the patient. The care plan would be devised in consultation with the family, the general practitioner and the relevant specialist services. Following the agreement of a plan, the care manager should be intensively involved in the process and delivery of care. The care manager would draw on the

full range of community-based services, and be allocated a budget which can be used to purchase appropriate community care services from outside conventional public sources. Effective care management requires the care manager to have access to the supply of available services and to facilitate the development of new services. Care managers need to have a budget to do this effectively. The evidence suggests that control over resources is an important factor in enabling care managers to respond more effectively to the varied individual needs of older people (Challis and Davies, 1986; McDowell *et al.* 1990).

Community care management packages should be designed to provide more intensive home-based care to people with dementia having similar levels of dependency and need to residents in long-stay settings. If this is to happen the budget allocated to care management schemes must be of a similar magnitude to that allocated to keep a person with dementia in long-stay care. While the devolution of budgets to individual care managers is a critical element of more successful schemes, the size of the budget also matters. For that reason the per capita allocation on care management schemes should be set at between 75 per cent and 80 per cent of the cost of alternative residential care. A budget of this size would convey significant purchasing power to care managers while still remaining below the cost of residential care. It is also close to the cost of community care estimated by Blackwell *et al.* (1992) in their study of costs in both community and institutional settings, albeit for non-specific dependent elderly populations. Devolved budgets for care management should also bring more financial and resource accountability into the system given the more open purchasing relationships in that setting.

The overall goal of care management is to deliver tailored care packages suited to the specific needs of the person with dementia and their carer (Hunter *et al.* 1997). Part of the job of the care manager would be to visit people on a regular basis to ensure that needs are being met and that services are introduced or modified as required. Ideally, any intervention should be done in such a way that it respects the competency of the carer and minimises professional involvement to the necessary provision of services. Similarly, the dignity of the person with dementia must be protected at all times, both in the assessment of need and in the provision of services. If care management undermines the 'personhood' principle of dementia care through bureaucratic interference then it will fail in its primary purpose, which is to improve the quality of life and well-being of people with dementia. Care management must supplement not supplant individual choice and preference through careful negotiation with people with dementia and their families.

The identification of care managers is inextricably linked to what we expect them to do and achieve. Care managers in dementia care would be expected to assume most or all of the roles of service co-ordinator, advocate, counsellor and gatekeeper of resources. The care manager would also be expected to develop a caring and individualised relationship with people under their care, have the interpersonal skills to intervene in crises and have some knowledge of the clinical expertise in other disciplines. Given the nature of these various tasks, the care manager should be a specialist Public Health Nurse or a social worker with training in gerontology and dementia, depending on the local circumstances prevailing within each health board. Whether specialist Public Health Nurse or medical social worker, the care manager must have sufficient expertise, time, and resources to do the important co-ordination tasks associated with the post. Conceptual clarification of the job and specialist skills training in dementia care will be needed before any new system of care management is put in place.

Professional training is a necessary but not sufficient condition for effective case management. Care management will succeed only to the extent that the following conditions are met: resources are available to support care management decision-making; expectations are realistic; and structural arrangements at the local level are satisfactory (Sturges, 1995). While the concept of care management is very important, it can only be introduced, in practice, within the framework of a more developed and comprehensive community care system. More resources are necessary if care management is to work. The co-ordination and integration of existing services are not a substitute for basic provision. Expectations should be tailored to what can be achieved, otherwise disillusion may set in before programmes can deliver on their promise. There will also have to be organisational and territorial changes at a local and regional level if new programmes are to succeed. More flexibility will be required from both the providers of services and from administrators; existing roles and territories may have to change to facilitate effective care management. In that regard, the genuine concerns of existing providers and co-ordinators of services must be handled sensitively if new forms of organisation are to succeed. Finally, care management is not about reducing costs, although this may happen, but about the more efficient and effective delivery of community care services (Kemper *et al.* 1987). This is the value added by care management practice.

9.7 Conclusion

The assignment of a care manager would go a long way towards meeting the recent call for the assessment of carer and care recipient needs in the recent *Review of the Carer's Allowance* (Department of Social, Community, and Family Affairs, 1998).

Intensive care management, linked to appropriate intervention and the provision of dementia-specific services, can have a major impact on the quality of life of people with dementia and their carers (Killeen, 1998). Care managers should have budgetary control over resources to allow them to respond quickly and flexibly to the needs of people with dementia and their carers. Given the numbers of people with dementia in the community not everyone can have this kind of service. For that reason, care management for people with dementia should, in the first instance, be concentrated on people with dementia living at home but on the boundaries of residential care. Targeting is necessary for efficiency and effectiveness reasons. Without targeting, the benefits of care management may be dissipated by having to serve too many needs in too many places. Care management will not solve all of the problems associated with home-based living, particularly if funding for community care remains low, but it should result in a closer match between the needs of people with dementia and the services available to them. All the more so if combined with the development of the local social economy as outlined in the previous chapter.



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Chapter 10

Conclusions

Chapter 10

Conclusions

10.1 Introduction

The purpose of this final chapter is to draw out the policy implications of the report and to make recommendations based on the main results of the study. The main objective of the study was to identify the costs of care for people with dementia and related cognitive impairments living in the community. A related objective was to explore the burden of dementia in Ireland and to identify the distribution of burden across all forms of care. The chapter begins by outlining the current realities with respect to policy and provision for people with dementia and their carers. This is followed by a brief discussion of data collection and costing issues. Following on from that, the key findings of the report are outlined in this order: family care provision, community care provision, financial costs and stress costs. Important issues of principle are then discussed as a backdrop to the issue of addressing need in the community. New ways of growing existing levels of provision are also highlighted. While the State will continue to be the main source of funding for dementia care, the development of the social economy, if properly designed and regulated, may be an important source of additional support for people with dementia and their carers. The chapter ends with a discussion of care management and the importance of new forms of organisation for community care to ensure that the services that are available get to the people who need them most.

10.2 Current Realities

Before proceeding to outline the main findings of this report it is useful to document the current realities with respect to the care of people with dementia and related cognitive impairments in this country. The current system of care for older people with dementia and related cognitive impairments is seriously under-funded. This is the reality facing social planners in Ireland today. Even when additional resources are sanctioned in this area the amounts are small relative to overall need, and minuscule relative to the growth in expenditure on acute hospital care services. At the moment services for people with dementia are not a priority area for government intervention. In recent years, there has been significant policy development and additional State funding in the areas of cancer and cardiovascular services. A new strategy for dementia is now required to deal, in a similarly comprehensive manner, with the problems faced by people with dementia and other cognitive impairments.

The vast majority of dependent older people live at home in the community and, as this study shows, family care is the main bulwark of support for these people. While structural changes in society may have made it more difficult for families to care, these changes have not diminished the basic willingness to care. Family care is not cheap, however, and imposes significant financial and emotional costs on carers. Generally, people do not come into contact with the health and social services until a crisis occurs, involving the older person, their carer, or both parties. Late intervention is, in turn, more likely to lead to institutional care, as the carer may no longer feel that she is able to cope. The result is a system geared to providing substitute in-patient care rather than providing anticipatory and on-going community care in partnership with older people and their family carers. Community care services remain underdeveloped in Ireland. For all the rhetoric about the important role that carers fulfil in society, they remain largely isolated, along with their elderly kin, doing an unglamorous job, for no tangible reward. The *Action Plan for Dementia* (O'Shea and O'Reilly, 1999) recommended an investment of £15 million pounds per annum over the next three years in order to meet the needs of the 31,000 people with dementia in this country. This should be the starting point for any future discussion about services for people with dementia and their carers.

10.3 Selecting Cases and Costing Care

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There will inevitably be imprecision in cost estimates for people with dementia. To some extent this can be tolerated, as long as the estimates are sufficient to enable broad conclusions to be drawn on the order of magnitude of costs for different categories of people. Selecting the right people for inclusion in the study is critical to the evaluation process. This is a difficult task in the area of dementia given the absence of a suitable population frame from which to select carer respondents. There is a high degree of sensitivity and stigma associated with dementia in this country making it difficult to identify potential carers. When this is combined with diagnostic uncertainty with respect to the illness itself, the identification problem becomes even more acute. To help overcome this problem we selected participants from two sources. The first group consisted of the carers of people known to have Alzheimer's disease or dementia. The second group consisted of carers drawn randomly from the general population through a sift process, on the basis that they were likely to be caring for people with dementia and related cognitive impairments. An analysis of the two groups allowed us to explore the additional caring costs associated with dementia. The aggregate economic and social burden of dementia was also calculated using a cost of illness framework to estimate costs for all of the main areas of provision, using national estimates of different dementia populations.

Having selected the participants for the study the next problem was to decide on the approach to costing care. There are two different concepts of costs: opportunity costs and public expenditure accounting. The latter approach deals with costs that fall on the exchequer, or costs that may fall on the exchequer in the absence of other resources. Underlying the opportunity cost approach is the following question: if this activity were not engaged in, how many resources would be saved for use in alternative activities? This is the key issue from the point of view of the allocation of scarce resources. An opportunity cost approach allows one to focus on both formal and informal resource use. This, in turn, facilitates a comprehensive approach to costing care: one that includes current and capital elements, private and public aspects, and tangible and non-tangible items. In this study we use both approaches to costing care. The analysis is, however, confined only to the measurement and valuation of costs, both formal and informal. No attempt is made to measure benefits or to compare different regimes of care for people with dementia. The resources were not available to allow us to do analysis of this kind.

10.4 Family Care Provision

Carers are mainly women, married, aged between 40 and 54, and engaged in home duties. A small but significant number of carers are older people themselves. The overall mean daily provision of care by carers looking after people known with certainty to have Alzheimer's disease is 12 hours, which is in keeping with the results from other surveys on care provision for people with dementia. This means that carers are providing, on average, around 80 hours of specified care per week. The mean daily hours of care provided by carers looking after people with dementia and related cognitive impairments from the randomly generated survey is six hours per day, or approximately 40 hours per week. Many carers refer to the constant nature of care, with very high figures recorded for surveillance and supervision of the person with dementia.

People were also asked to specify their optimal time spent caring if given the choice. For the carers of people known to have Alzheimer's disease, the optimal caring day is eight hours, equal to what most people consider a normal working day, or just under 70 per cent of what they are being asked to do at present. For carers in the randomly generated group, the optimal caring day is just under five hours, or 75 per cent of what they are doing at present. While people remain committed to the care of dependent older relatives, their preference is for more freely chosen levels of provision which would mean less care. The question of optimality is, of course, closely related to the level of support that carers receive from the State. Currently, only a small percentage of carers qualify for Carer's Allowance while community care support remains narrowly focused and fragmented,

despite recent improvements in the budget. Further improvements in either or both of these areas would affect the optimal supply of caring hours by family carers. The critical question, of course, is in which direction. While this is ultimately an empirical question, the likelihood is that increased support from the State would lead to better quality care, whatever about its impact on the amount of care supplied by families.

10.5 Community Care Provision

The data on care provision in this study confirm the paucity of community care provision for vulnerable older people living in the community. Services are largely confined to the core areas of general practitioner and Public Health Nurse provision, with lower provision in the areas of home help, home care attendant and chiropody. Day care services are more prevalent in the group of known dementia sufferers than in the general cognitive impairment group. This is not surprising given the association of the former group with The Alzheimer Society of Ireland and The Western Alzheimer Foundation, both of which provide day-care services. People with dementia who are not in contact with either of these organisations are much less likely to be receiving day-care services. Some services, such as social workers, community-based physiotherapy, meals-on-wheels and sitting services, are not provided to people in either group.

When asked to nominate services that they would like to see expanded carers were not very forthcoming, with high levels of non-response for some services. This may reflect inertia on behalf of carers who may be engaging in some form of learnt behaviour. People's expectations are, to some extent at least, determined by what they think is available, and what they think others expect of them. Society expects quite a lot from mainly female carers with inadequate levels of support. In this context it is easier to understand the reluctance of women to nominate services for development and expansion. Many carers have learned not to have too many demands and to do what is expected of them. For the people who did address the issue of additional services respite care was the most requested service.

10.6 The Cost of Care

The overall cost of community care for people in the group known to have Alzheimer's disease is £234 per week, while the cost of care for people in the group with dementia and related cognitive impairments is £120 per week. While these estimates should be seen as preliminary in nature given the difficulties with the data, differences between the two groups are consistent across all items of resource use. The main element in the overall cost of community care is family care

provision. The above estimates of community care costs are based on an opportunity cost valuation of family care provision. Replacement cost valuation would, of course, yield higher community care cost estimates, rising to £591 per week for people known to have Alzheimer's disease, if the replacement valuation is based on the hourly average industrial earnings of women.

This study also estimated the overall cost of illness for dementia incorporating all of the main areas of provision including family care, community care, residential care, psychiatric care and acute care. The results confirm the central role of the carer in the management of people with dementia. Family care accounts for 57 per cent of the overall burden of care measured on an opportunity cost basis. That proportion rises to 64 per cent if family care is valued on the basis of home help replacement cost. The contribution of family members to the caring process is a consistent finding in the literature where such costs have been measured. The major contribution of family care is in sharp contrast to the relatively low provision of community care for people with dementia. Only 6 per cent of the cost of dementia is attributable to community care services. Just under one third of the total costs of dementia are attributable to residential care.

10.7 Carer Stress

Caring for highly dependent people can also be a source of major strain and psychological distress for carers. These are real costs even if they cannot be valued in monetary terms. The results of the community survey show a very high level of psychological distress among carers, particularly those caring for people known to have Alzheimer's disease. Over half the carers of people known to have Alzheimer's disease find caring completely overwhelming, with most experiencing high levels of confinement due to caring. The vast majority of carers in the two surveys report adjustment for the family as a result of caring, much higher levels of adjustment than reported in previous surveys of carers of mainly physically dependent elderly people (Blackwell *et al.* 1992). Almost all of the carers looking after people known to have Alzheimer's disease reported upset because of changes in the person under their care. More than three quarters of this group also report emotional adjustment due to caring, while the same proportion report upset due to the behaviour of the person under their care. Almost three quarters of carers of people known to have Alzheimer's disease score above the cut-off point in the General Health Questionnaire. These findings indicate a worrying level of psychological distress among carers and confirm consistent results from the literature that GHQ morbidity in carers is closely associated with patient psychopathology.

Non-cognitive features are positively related to caregiver burden and psychological disturbance and may be associated with anxiety in caregivers and deterioration in the patient-carer relationship. For that reason interventions to deal with the plight of carers are needed urgently to counteract the potential for psychological distress inherent in the care of people with dementia. Carers need financial support and they need more services like respite care to provide them with a break from caring. At a very basic level, however, carers need training in coping with the difficulties of looking after people with dementia. Where these training programmes are in place they have been shown to be a cost-effective way of relieving stress and reducing the psychological morbidity of carers, leading to delay in the placement of the patient in an institution (Brodaty and Gresham, 1989).

10.8 Addressing Need in the Community

Before any discussion of desirable policy changes in the light of the above evidence, it is helpful to place the discussion in the context of what we hope to achieve for people with dementia and their carers under any future system. What follows is a brief outline of the principles against which any changes in resource allocation, or in the organisation of care, must be measured. These principles are taken from *An Action Plan on Dementia* (O'Shea and O' Reilly, 1999) and reflect a consensual approach to the maximisation of well-being for people with dementia and their carers:

- Respect for the preferences and rights of the person with dementia
- The comprehensive provision of care
- Bias towards home care solutions, including support for carers
- Care requirements to determine funding, not vice-versa
- Access to services on the basis of need, not income or geography
- National quality targets and outcome targets to underlie provision

The most basic principle is that the preferences of older people should be respected; that means they must be supported in their home for as long as is possible and practicable. For this to happen, services must be comprehensive, with provision structured in such a way as to respond in a flexible manner to the individual needs of older people. Care requirements should, therefore, determine the types of services and supports to be funded. This means that should people

value home-sitting services more highly than day-care services then this is what should be provided. The system of community care should enhance rather than reduce the degree of choice which people with dementia and their carers have over the conditions of their lives. For that reason, supply should not be allowed to dominate or determine demand. This means that service provision of a certain type (e.g. long-stay institutions) should not, by their current and historic dominance, be allowed to have a disproportionate influence over funding to the disadvantage of other more appropriate, but as of yet underdeveloped, services.

Old people have, by and large, expressed a preference for care in the home rather than in institutions. This should be reflected in the funding system, through an enhanced financial commitment to support home care solutions. People should not be given a subsidy for residential care unless it is clear that a similar allocation would not have succeeded in keeping them at home. This commitment is critical to the future of community care in this country. This means extra resources for supporting family carers in their work, as well as providing funds for the social infrastructure which is necessary to allow older people to continue living at home. Respite care, day hospitals and day care are important parts of the social infrastructure, as are the whole range of home care services. Services must get to the people that need them most at the most appropriate time. This is why the development of effective care management structures is critical for the development of community care services in line with the above principles. The development of the social economy is also important given the role of the voluntary sector in social care provision and the desirability of local solutions to social care problems.

10.9 Encouraging Social Entrepreneurship

The recent comprehensive review of developments in care of the older people since the publication of *The Years Ahead* (1988) report is critical of the slow rate of progress towards the development of a genuinely community-based approach to the long-term care of dependent older people (Ruddle *et al.* 1997). While there remains a general consensus that the long-term care of dependent older people should be located in the community, not enough has been done in recent years to develop community care services in a way that would significantly improve the quality of life of older people living at home. There is uniform agreement that a major gap exists between the needs of dependent older people and service provision. While the State will continue to be the most important provider, and the main source of funding, of services for people with dementia the social economy can be the catalyst for new forms of community care provision. For that reason, there is a need to explore innovative ways of developing entrepreneurial supply-side responses to the problem of social need in the area of long-term care. Where possible, the care needs of

people with dementia should be met locally through community-based support for family carers.

Finding ways to stimulate social entrepreneurship at the local level will be an important part of any new strategy for the care of dependent older people in this country. Training and education alongside the development of civic leadership will be important elements in the development of the supply-side. Equally important will be strategies to stimulate demand for any new services from older people and their families, and from the State. Innovation on the supply-side will have to be matched by expansion of the demand-side, linked to new funding arrangements, if community services for people with dementia are to be expanded. The development of the supply-side must also be associated with careful regulation to ensure that standards of care are maintained in any new provider arrangements. A legal framework will also have to be developed if organisations working in the social economy are to become fully integrated with existing statutory providers of social services. This may involve the establishment of social care contracts between the health board and local providers.

There are a number of practical steps that should be taken now to stimulate the development of the social economy. Seed funding should be made available to support new services and to encourage social entrepreneurship across a broad range of activities and people. This funding could take the form of capital grants, start-up grants, loan/credit facilities, or it might be confined to help with information gathering and training supports. Training and managerial programmes for providers will certainly be necessary, if opportunities are to be realised and exploited.

While there is agreement that genuine need does exist among older people living in the community, the critical question is how to transform that need into demands, which can be met within the social economy. To some extent, this depends on the willingness of care recipients and their families to pay for the services provided in the new social economy, since this will determine the level of State support required for any new initiatives. Willingness to pay is, of course, influenced by the amount of income available to people. For many older people, and their immediate families, the amount of money that they have available to spend on community care is small, even allowing for recent improvements in income. If consumer resistance to payment for services is high due to inadequate income, then demand may have to be stimulated by other mechanisms such as vouchers for social services, thereby offsetting some of the cost for clients. Redeemable vouchers would allow families to purchase the community care services of most value to them within the context of new care management structures.

The social economy, if properly regulated, contains the potential to address some of the social care problems facing dependent older people and their carers. The development of both sides of the social market will require careful nurturing if progress is to be made. As part of this development, the institutional rigidities associated with existing forms of social services provision will have to be tackled. Currently, social care production is, by and large, controlled by the State, and administered through the health boards. This control exerts a powerful conservatism on the organisation of social care and serves to dampen any sustained attempts at innovation and development by local and community groups. If progress is to be made in meeting the needs of vulnerable older people and their carers at a local level, the control which has been established by the State in the area of community care provision must be diluted. Partnership between the health board and local providers needs to be developed and nurtured through new care management structures. Given the enormous gap between social need and provision in this country, and the success of locally-based projects, now is the time to think about new ways of providing social care services and new ways of financing that provision.

10.10 Care Management

The development of care management structures would go a long way towards meeting the recent call for the assessment of carer and care recipient needs in the recent *Review of the Carer's Allowance* (Department of Social, Community, and Family Affairs, 1998). An effective system of care for people with dementia and their carers must be able to deliver appropriate care at the right time to people most in need of that care. Care management is the most effective mechanism for developing and co-ordinating existing fragmented systems of community care for people with dementia. Care management can also lead to the development of new services.

Care management should be targeted on people with dementia living at home but on the margins of residential care. Targeting is necessary for efficiency and effectiveness reasons. Without targeting, the benefits of care management may be dissipated by having to serve too many needs in too many places. Case loads should be small so that sufficient time can be allocated to each case. Optimal case load will depend on local factors such as client group served, range of available services, geographical area and existing organisational structure. The care manager should act as a single point of reference, providing access and continuity for both clients and providers. The care manager should have control of budgets that would allow them to purchase existing services and encourage the development of new services. The evidence suggests that control over resources is an important factor in enabling care managers to respond more effectively to the varied individual needs of older people.

Community care management packages should be designed to provide an intensive system of home-based care to people with dementia and their carers. If this is to happen then the budget allocated to care management schemes must be of sufficient scale to allow comprehensive provision of services. While the devolution of budgets to individual care managers is a critical element of more successful schemes, the size of the budget also matters. For that reason the per capita allocation on care management schemes should be set at three quarters of the per capita cost of alternative residential care. A budget of this size would convey significant purchasing power to care managers while still remaining below the cost of residential care. Devolved budgets for care management would also bring more financial and resource accountability into the system, given the more open purchasing relationships in that setting.

Care management structures should be designed in such a way that the dignity of the person with dementia is protected at all times, both in the assessment of need and in the provision of services. If care management undermines the 'personhood' principle of dementia care through bureaucratic interference then it will fail in its primary purpose, which is to improve the quality of life and well-being of people with dementia. Care management must supplement not supplant individual choice and preference through careful negotiation with people with dementia and their families. The role of carers must also be protected within any new care management structures. Carers should continue to play an important role in decision-making, working with, rather than for, the care manager. If either the person with dementia or their carer is marginalised in any new arrangements then it is difficult to see care management being a success.

10.11 Final Thoughts

The stated objective of public policy with respect to the long-term care of dependent older people is to allow people live in their own homes for as long as is possible and practicable. In recent years there has been a reduction in the number of public long-stay beds, but there has not been a compensating increase in the level of resources for community care. This trend has created enormous pressures on both the families of dependent older people and on the voluntary sector. The problems for the carers of people with dementia and related cognitive impairments have been examined in this report. The results show that the financial and psychological strains on carers are significant. Not surprisingly, there has been an expansion in private nursing home provision and in public subvention of that sector in recent years, largely as a result of the failure of public policy with respect to community care provision. New care management structures, linked to the development of the social economy, are required to provide a renewed emphasis on

community care and to support people in their own homes in the future. Future research efforts should, in particular, concentrate on the evaluation of pilot projects in care management, linked to a more extensive research programme on improving the quality of care for people with dementia and their carers. More generally, increased investment in community care services and facilities should be linked to the development of a new social care evaluation unit with responsibility for the measurement of health and social gain in community care provision.

References

Area Development Management (ADM) 1998. *Financial Supports for Social Economy Development*. Dublin: ADM Ltd.

Applebaum, R., and Austin, C.D., 1990. *Long Term Case Management: Design and Evaluation*. New York: Springer.

Blackwell J., O'Shea E., Moane G., and Murray P., 1992. *Care Provision and Cost Measurement: Dependent Elderly People at Home and in Geriatric Hospitals*. General Research Series no. 157, Dublin: ESRI.

Blessed, G., Tomlinson, B.E. and Roth, M., 1968. 'The Association Between Quantitative Measures of Dementia and of Senile Change in the Cerebral Grey Matter of Elderly Subjects' *British Journal of Psychiatry*, 114, 797-811.

Bowling A., 1997. *Measuring Health: A Review of Quality of Life Measurement Scales*. Buckingham: Open University Press.

Brodaty, H. and Gresham, M. , 1989. 'Effects of a Training Programme to Reduce Stress in Carers of Patients with Dementia'. *British Medical Journal*, 299, 2, December.

Browne M., 1996. 'Mental Disorders in Long-Stay Care Settings' in Keogh F., and Walsh A., eds, *Mental Disorders in Older Irish People: Incidence, Prevalence and Treatment*. Dublin: National Council for the Elderly.

Cahill, S.M., 1999. 'Caring in Families; What Motivates Wives, Daughters, and Daughters-in-law to Provide Dementia Care?' *Journal of Family Studies*, 5,2, 235-247.

Caveman J. and Taylor S., 1997. 'The Needs of Caregivers'. *Elderly Care*, 9, 6, Dec/Jan, 16-19.

Central Statistics Office, 1995. *Population and Labour Force Projections, 1996-2026*. Dublin: Stationery Office.

Central Statistics Office, 1997. *Census of Population, 1996*. Dublin: Stationery Office.

Central Statistics Office, 1999. *Population Projections 1996-2056*. Dublin: Stationery Office.

Challis D. and Davies B., 1986. *Case Management in Community Care*. Aldershot: Gower.

Challis D., 1993. 'Alternatives to Long-Stay Care,' in Levy, R., Burns, A., Howard, R. (eds) *Treatment and Care in Old Age Psychiatry*. Hampshire: Wrightson.

Challis D., 1994. 'Care Management: Factors Influencing its Development in the Implementation of Community Care,' in Department of Health (ed.) *Implementing Community Care*. London: Department of Health.

Challis D., Von Abendorff R., Brown P., and Chesterman P., 1997. 'Case Management and Dementia: An Evaluation of the Lewisham Intensive Case Management Scheme,' in Hunter S., (ed.) *Dementia: Challenges and New Directions*. London: Age Concern England.

Challis, D., 1999. 'Case Management and the Care of People with Dementia', in O'Shea, E. (ed.) *Planning for Dementia Care in Ireland*. Dublin: National Council for Ageing and Older People.

Chang CF. and White-Means S., 1995. 'The Labor Supply of Informal Caregivers'. *International Review of Applied Economics*, Vol. 9 (2), 1995 : 192-205

Chappell N., and Blandford A., 1991. 'Informal and Formal Care: Exploring the Complementarity'. *Ageing and Society*, 11, 299-317.

Clancy C. M. and Cooper J. K., 1997. 'Outcomes and Effectiveness Research in Alzheimer Disease'. *Alzheimer Disease and Related Disorders*, 11, 6, pp. 7-11.

Clinch D. and Hickey A., 1992. 'Cognitive Impairment in Hospitalised Elderly-Limerick', in Mid-Western Health Board, *The Elderly Mentally Infirm: Who Cares? Report of a Review Group*. Limerick: Mid-Western Health Board.

Clifford D., 1991. *The Social Costs and Rewards of Caring*. Aldershot: Avebury.

Cohen C., Teresi J. and Blum C., 1994. 'The Role of Caregiver Social Networks in Alzheimer's Disease'. *Social Science and Medicine*, 38, 11, 1483-1490.

Davey, P.J. and Leeder, S.R., 1993. 'The Cost of Illness Studies'. *Medical Journal of Australia*, 158, 583-84.

Davies, B., Bebbington, A., Charnley, H., Ferlie, E., Hughes, M. and Twigg, J., 1990. *Resources, Needs and Outcomes in Community Care*. Aldershot: Avebury

Davies, B., 1992. *Care Management, Equity and Efficiency: The International Experience*. Canterbury: PSSRU, University of Kent at Canterbury.

Dees, J.G., 1998. 'Enterprising Non-Profits'. *Harvard Business Review*, Jan-Feb, 55-67.

Department of Health, 1994. *Shaping a Healthier Future , A Strategy for Effective Healthcare in the 1990s*. Dublin: Stationery Office.

Department of Health, 1995. *Health Statistics 1993*. Dublin: Stationery Office.

Department of Social, Community and Family Affairs, 1998. *Review of the Carers Allowance*, Dublin: Stationery Office.

Denton M., 1997. 'The Linkages between Informal and Formal Care of the Elderly'. *Canadian Journal on Ageing*, 16, 1, 30-50.

Donaldson C., Tarrier N. and Burns A., 1997. 'The Impact of the Symptoms of Dementia on Caregivers'. *British Journal of Psychiatry*, 170, 62-68.

Draper, B.M., Poulos, C.J., Cole, A.M.D., Poulos, R.G. and Ehrlich, F., 1992. 'A Comparison of Caregivers for Elderly Stroke and Dementia Victims'. *Journal of the American Geriatrics Society*, 40, 896-901.

Drummond, M.F., 1980. *Principles of Economic Evaluation in Health Care*. Oxford: Oxford University Press.

Drummond, M.F., 1992. Cost of Illness Studies: A Major Headache? *Pharmacoeconomics*, 2, 1-4.

Drummond, M., Stoddart, G.L. and Torrance, G.W., 1997. *Methods for the Economic Evaluation of Health Care Programmes*. Oxford: Oxford Medical Publications.

Eagles M., Craig A., Rawlinson F., Restall B., Beattie, J., and Besson, J., 1987. 'The Psychological Well Being of Supporters of the Demented Elderly'. *British Journal of Psychiatry*, 150, 293-298.

Ernst R. L., and Hay J. W., 1994. 'The US Economic and Social Costs of Alzheimer's Disease Revisited'. *American Journal of Public Health*, 8, 1261-1263.

Ernst R. L., and Hay J. W., 1997. 'Economic Research on Alzheimer's Disease: A Review of the Literature'. *Alzheimer Disease and Associated Disorders*, 11, 6, 135-145.

Ernst R. L., and Hay J. W., Fenn, C., Tinklenberg J., and Yesavage J. A., 1997. 'Cognitive Function and the Costs of Alzheimer's Disease'. *Archives of Neurology*, 54, 687-693.

Evans, G., Hughes, B.C., and Wilkin, D., 1981. *The Management of Mental and Physical Impairment in Non-Specialist Residential Homes for the Elderly*. Research Report No. 4. Manchester: Research Section, Psychiatric Unit, University Hospital of South Manchester.

Finch, J., 1989. *Family Obligations and Social Change*. Cambridge: Polity Press.

Fitzpatrick and Associates, 1997. Potential of the Social Economy to Reintegrate Long-Term Unemployed. Dublin: Report to the Department of Enterprise and Employment and the Office of An Tanaiste.

Flaten, T.P., 1989. 'Mortality from Dementia in Norway'. *Journal of Epidemiology and Community Health*, 43, 285-289.

Folbre, N. and Weisskopf, T., 1998. 'Did Father Know Best? Families, Markets and the Supply of Caring Labour', in Ben-Ner, and Putterman, L., (eds) *Economic, Values and Organisations*. New York: Cambridge University Press.

Fortinsky R. H., Hazuda H. P., Larson E. B., Lindeman D. A., Mullican C. A., Tetzloff I. and Welte T., 1997. 'Principles Underlying Selection of Outcomes in Alzheimer Disease Research'. *Alzheimer's Disease and Associated Disorders*, 11, 6, 184-85.

George L. K., and Gwyther L P., 1986. 'Caregiver Well Being: A Multi-Dimensional Examination of Family Caregivers of Demented Adults'. *The Gerontologist*, 26, 3, 253-259.

Gerard, K., 1993. 'Setting Priorities in the New NHS: Can Purchasers Use Cost Utility Information'. *Health Policy*, 25, 109-125.

- Gibbins F J., Lee M. and Davidson P. R., 1982. 'Augmented Home Nursing as an Alternative to Hospital Care for Chronic Elderly Invalids'. *British Medical Journal*, 284, 330-333.
- Gilhooly, M., 1984. 'The Impact of Care-Giving on Carers: Factors Associated with the Psychological Well-Being of People Supporting a Dementing Relative in the Community'. *British Journal of Medical Psychology*, 56, 165-171.
- Globerman J., 1996. 'Motivations to Care: Daughters and Sons-in-Law Caring for Relatives with Alzheimer's Disease'. *Family Relations*, 45, 37-45.
- Goldberg, D. P., 1972. *The Detection of Psychiatric Illness by Questionnaire*. London: Oxford University Press.
- Goldberg, D. P. and Williams P., 1988. *A User's Guide to the General Health Questionnaire*. London: Nfer-Nelson..
- Gray, A., and Fenn P., 1993. 'Alzheimer's Disease: The Burden of Illness in England'. *Health Trends*, 25, 1, pp. 31-37.
- Grimes, A., and Maxwell, S., 1997. Redefining the Social Economy: *The Voluntary Sector in the Scottish Economy*. Brussels: Scotland Europa Centre, Paper No. 12.
- Haley, W.E., Levine, E.G., Lane Brown, S., and Bartolucci, A. A., 1987. 'Stress, Appraisal, Coping, and Social Support as Predictors of Adaptational Outcome Among dementia Caregivers'. *Psychology and Ageing*, 2, 4, 323-330.
- Harrow, B.S., Tennstedt, S.L. and McGinlay, J.B., 1995. 'How Costly is it to Care for Disabled Elders in a Community Setting?' *The Gerontologist*, 35,6, 803-813.
- Hawrylyshyn O., 1977. 'Towards a New Definition of Non-Market Activities'. *Review of Income and Wealth*, Series 23, 1, pp. 79-96.
- Hay J. W., and Ernst R L., 1987. 'The Economic Costs of Alzheimer's Disease'. *American Journal of Public Health*, 77, pp. 1169-1175.
- Hickey, A., Clinch, D., and Groarke, E.P., 1997. 'Prevalence of Cognitive Impairment in the Hospitalized Elderly'. *International Journal of Geriatric Psychiatry*, 12, 27-33.

Higginson I. J., Jefferys P. M., and Hodgson C. S., 1997. 'Outcome Measures for Routine Use in Dementia Services: Some Practical Considerations'. *Quality in Health Care*, 6, 120-124.

Himmelweit , S., 1996. 'Conceptualising Caring', Paper Presented at the International Association for Feminist Economics Conference, Washington DC, July. Quoted in Nelson, J., 1999. 'Of Markets and Martyrs: Is it OK to Pay Well for Care?' *Feminist Economics*, 5,3, 43-59.

Hofman A., Rocca W. A., Bryane C., et al., 1991. 'The Prevalence of Dementia in Europe: A Collaborative Study of 1980-1990 Findings'. *International Journal of Epidemiology*, 20, 3, 736-748.

Hu,T, Huang, L. and Cartwright, W.S., 1986. 'Evaluation of the Costs of Caring for the Senile Demented Elderly: A Pilot Study'. *The Gerontologist*, 26, 158-163.

Huang, L., Cartwright, W.S. and Hu, T., 1988. 'The Economic Costs of Senile Dementia in the United States'. *Public Health Report*, 103, 3-7.

Hunter R. L., McGill N., Bosanquet N. and Johnson N., 1997. 'Alzheimer's Disease in the United Kingdom: Developing Patient and Carer Support Strategies to Encourage Care in the Community'. *Quality in Health Care*, 6, 146-152.

Hyde J., Hillygus J., Levy B. and Levkoff S., 1998. 'Using Outcome Measures to Provide Excellence in Alzheimer Care'. *American Journal of Alzheimer's Disease*, 4, 265-272.

Irish Association of Pension Funds (IAPF), Irish Insurance Federation and the Society of Actuaries in Ireland (IAPF) et al., 1998. *Financing Long-Term Care*. Dublin: Society of Actuaries of Ireland.

Jamieson, A., 1991. 'Trends in Home Care Policies', in A. Jamieson (ed.) *Home Care for Older People in Europe*. Oxford: Oxford University Press.

Jerrom, B., Mian, I., Rukanyake, N.G. and Prothero, D., 1993. 'Stress on Relative Caregivers of Dementia Sufferers, and Predictors of the Breakdown of Community Care'. *International Journal of Geriatric Psychiatry*, 8, 331-337.

Jorm, A. F., Korten A. E. and Henderson A. S., 1987. The Prevalence of Dementia: A Quantitative Integration of the Literature'. *Acta Psychiatrica Scandinavia*, 76, 465-479.

Kavanagh, S., Schneider, J., Knapp, M., Beecham, J. and Netten, A., 1993. 'Elderly People with Cognitive Impairment: Costing possible Changes in the Balance of Care'. *Health and Social Care in the Community*, 2, 69-80.

Kavanagh S., Schneider J., Knapp M., Beecham J. and Netten A., 1995. 'Elderly People with Dementia: Costs, Effectiveness and Balance of Care', in Knapp M. (ed.), *The Economic Evaluation of Mental Health Care*. Aldershot: Arena.

Kay D. W. K. and Bergmann K., 1980. 'Epidemiology of Mental Disorders Among the Aged in the Community', in Birren J. E. and Sloane R. B. (eds), *Handbook of Mental Health and Ageing*. New Jersey: Prentice-Hall.

Keady J. and Nolan M., 1995. 'A Stitch In Time: Facilitating Proactive Interventions with Dementia Caregivers: the Role of Community Practitioners'. *Journal of Psychiatric and Mental Health Nursing*, 2, 33-40.

Kemper P., Applebaum R. and Hanson M., 1987. 'Community Care Demonstrations: What Have We Learned?' *Health Care Financing Review*, 8, 4, 87-100.

Kemper, P., 1988. 'The Evaluation of The National Long Term Care Demonstration: Overview of the Findings'. *Health Services Research*, 23, 1, 162-72.

Keogh F. and Walsh D., 1995. *Activities of Irish Psychiatric Hospitals and Units*. Dublin: Health Research Board.

Keogh F. and Rote A., 1996. *Mental Disorders in Older Irish People: Incidence, Prevalence and Treatment*. Dublin: National Council for the Elderly Report No. 45.

Killeen J., 1998. 'Home Care: Can it be a Real Choice?' *Journal of Dementia Care*, Jan/Feb.

Knapp, M. and Beech, J., 1990. 'Costing Mental Health Services'. *Psychological Medicine*, 20, 893-908.

Knight, B., Lutzky, S. and Macofsky-Urban, F., 1993. A Meta-analytic Review of Interventions for Caregiver Distress: Recommendations for Future Research'. *The Gerontologist*, 33, 240-248.

Lawlor B., Radic A., Bruce I., et al., 1994. 'Prevalence of Mental Illness in an Elderly Community Dwelling Population Using AGE-CAT'. *Irish Journal of Psychological Medicine*, 11, 157-160.

Layte, R., Fahey, T. and Whelan, C., 1999. *Income Deprivation and Well-Being Among Older Irish People*. Dublin: National Council on Ageing and Older People.

Leadbeater, C., 1997. *The Rise of the Social Entrepreneur*. London: Demos.

LoGiudiceD., Waltrowicz, W. and McKenzie, S., 1995. 'Prevalence of Dementia Among Patients Referred to an Aged Assessment Team and Associated Stress in their Carers' . *Australian Journal of Public Health*, 19, 275-279.

Lundstrom, F. and McKeown, K., 1994. *Home Help Services for Elderly People in Ireland*. Dublin: National Council for the Elderly.

Mallaghan, A., Hart, M., McFarlane, R. and Connolly, E., 1996. *A Study of Community Business Within the Social Economy in Ireland*. Dublin: ADM.

Manton K., Corder L. S. and Clark R., 1993. 'Estimates and Projections of Dementia-Related Service Expenditure', in Suzman R., Singer B. and Manton K., (eds), *Forecasting the Health of the Oldest of the Old*. New York: Springer-Verlag.

Max, W., Webber, P. and Fox, P., 1995. 'Alzheimer's Disease: The Unpaid Burden of Caring'. *Journal of Ageing and Health*, 7, 179-99.

McDowell, D., Barniskis, L. and Wright, S., 1990. The Wisconsin Community Options Programme: Planning and Packaging Long-Term Support for Individuals, in Howe, A., Ozanne, E. and Selby Smith, C. (eds), *Community Care Policy and Practice: New Directions in Australia*. Melbourne: Public Sector Management Institute, Monash University.

Mohide E. A., Torrance G. W., Streiner D. L., Pringle D. M. and Gilbert R., 1988. 'Measuring the Wellbeing of Family Caregivers Using the Time Trade-Off Technique'. *Journal of Clinical Epidemiology*, 41, 5, 475-482.

Monthly Index of Medical Supplies, MIMS Ireland, 1999. *Monthly Index of Medical Supplies*, August.

Moran R. and Walsh D., 1992. *The Irish Psychiatric Hospitals and Unit Census 1991*. Dublin: Health Research Board.

Moxley, D.P.(1989). *The practice of case management*. Newbury Park: Sage

Neilsen, J., Henderson, C., Cox, M., Williams, S. and Green, P., 1996.

'Characteristics of Caregivers and Factors Contributing to Institutionalisation'.
Geriatric Nursing, 47, 3.

Nelson, J., 1999. 'Of Markets and Martyrs: Is it OK to Pay Well for Care?' *Feminist Economics*, 5,3, 43-59.

Netten A., 1993. 'Costing Informal Care', in Knapp, M., Netten, A. and Beecham, J., (eds). *Costing Community Care*. Aldershot: Ashgate.

Neumann P.J., Kuntz K. M., Leon J., Araki S. S., Hermann R. C., Hsu M. A. and Weinstein M. C., 1999. 'Health Utilities in Alzheimer's Disease'. *Medical Care*, 37,1,.27-32.

O'Connor D. W., Pollitt P. A., Roth M., Brook C. P. B. and Reiss B. B., 1990. 'Problems Reported by Relatives in a Community Study of Dementia'. *British Journal of Psychiatry*, 156, 835-841.

Oliver J., 1983. 'The Caring Wife', in Finch J. and Groves D. (eds) *A Labour of Love: Women, Work and Caring*. London: Routledge and Kegan Paul.

O'Neill D., Begley D., McCormack N., Walsh J. B. and Coakley D., 1991. 'Dementia and Depression in a Nursing Home Population', in O'Neill D. (ed) *Carers, Professionals and Alzheimer's Disease*. London: John Libby.

Orbell S., 1996. 'Informal Care in Social Context: A Social Psychological Analysis of Participation, Impact and Intervention in the Care of the Elderly'. *Psychology and Health*, 11, pp. 155-178.

O'Shea E. and Hughes J., 1994. *The Economics and Financing of Long Term Care in Ireland*. Dublin: National Council for the Elderly.

O'Shea E. and O'Reilly S., 1999. *An Action Plan for Dementia*. Dublin: National Council on Ageing and Older People.

Ostbye,T. and Crosse, E., 1994. 'Net Economic Costs of Dementia in Canada'. *Canadian Medical Association Journal*, 15, 10, 1457-1464.

Overtveit J., 1993. *Co-ordinating Community Care: Multidisciplinary Teams and Care Management*. London: Open University Press.

Pearce, J., 1993. *At the Heart of the Community Economy*. London: Calouste

Gulbenkian Foundation.

Pearce, D. 1983. *Cost Benefit Analysis*. London: MacMillan.

Pearlin, L. I. and Schooler, C., 1978. 'The Structure of Coping'. *Journal of Health and Social Behaviour*, 19, 2-21.

Pearlin L. I., Mullan J. T., Semple S. J. and Skaff M. M., 1990. 'Caregiving and the Stress Process: An Overview of Concepts and Their Measures'. *The Gerontologist*, 30, 5, 583-594.

PLANET, 1997. *Building the Social Economy: New Areas of Work, Enterprise and Development*. Dublin: PLANET.

Putnam, D., 1993. *Making Democracy Work: Civic Traditions in Modern Italy*. Princeton: Princeton University Press.

Ramsay M., Winget C. and Higginson I., 1995. 'Measures to Determine the Outcome of Community Services for People with Dementia'. *Age and Ageing*, 24, 73-83.

Report of the Working Party on Services for the Elderly, 1988. *The Years Ahead: A Policy for the Elderly*. Dublin: Stationery Office.

Report of Partnership 2000 Social Economy Working Group, 1998. Dublin: Department of Enterprise and Employment.

Rice D. R., Fox P. J., Max P. A., Webber D. A., Lindeman D. A., Hauck W. W. and Segura E. , 1993. 'The Economic Burden of Alzheimer's Disease'. *Health Affairs*, 12, 2, pp. 164-176.

Richardson, A.W. and Gafni, A., 1983. 'Treatment of Capital Costs in Evaluating Health Care Programmes'. *Cost and Management*, Nov-Dec, 26-30.

Rimmer, L., 1983. 'The Economics of Work and Caring', in Finch, J and Groves, D. (eds), *A Labour of Love: Women, Work and Caring*. London: Routledge and Kegan Paul.

Resource Implications Study (RIS) of Medical Research Council Cognitive Function and Ageing Study, 1998. 'Mental and Physical Frailty in Older People: The Costs and Benefits of Informal Care'. *Ageing and Society*, 317-353.

- Robinson, B. and Thurnher, M., 1979. 'Taking Care of Aged Parents: A Family Cycle Transition'. *The Gerontologist*, 19, 586-593.
- Robinson, B., 1983. 'Validation of a Caregiver Strain Index. *Journal of Gerontology*, 38, 344-348.
- Rodgers S., Friedhoff L. T. and the Donepezil Study Group, 1996. 'The Efficacy and Safety of Donepezil in Patients with Alzheimer's Disease: Results of a Multi-Centre, Randomised, Double-Blind, Placebo Controlled Trial'. *Dementia*, 7, pp. 293-303.
- Rothman, J., 1992. *Guidelines for Case Management*. Itasca: Peacock.
- Rothstein Z., Prohovnik M., Davidson M., Beeri M. S. and Noy S., 1996. 'The Economic Burden of Alzheimer's Disease in Israel'. *Israeli Journal of Medical Science*, 32, 11, 1120-1123.
- Ruddle H. and O'Connor J., 1993. *Caring without Limits? Sufferers of Dementia/Alzheimer's Disease: A Study of their Carers*. Dublin: The Alzheimer Society of Ireland.
- Ruddle H., Donoghue F. and Mulvihill R., 1997. *The Years Ahead Report: A Review of the Implementation of its Recommendations*. Dublin: National Council on Ageing and Older People.
- Salek S. S., Walker M. D. and Bayer A. J., 1998. 'A Review of Quality of Life in Alzheimer's Disease'. *Pharmacoeconomics*, 14, 6, pp. 613-627.
- Schneider J., Kavanagh S., Knapp M., Beecham J. and Netten A., 1993. 'Elderly People with Advanced Cognitive Impairment in England: Resource Use and Costs'. *Ageing and Society*, 13, pp. 27-50.
- Shiell, A., Gerard, K. and Donaldson, C., 1987. 'Cost of Illness Studies: An Aid to Decision-Making'. *Health Policy*, 317-23.
- Smith K. and Wright K., 1994. 'Informal Care and Economic Appraisal: A Discussion of Possible Methodological Approaches'. *Health Economics*, 1994, 3, pp. 137-148.
- Smith K., Shan K., Wright K. and Lewis G., 1995. 'The Prevalence and Costs of Psychiatric Disorders and Learning Disabilities'. *British Journal of Psychiatry*, 166, 9-18.

Stommel M., Collins C. E. and Given B. A., 1994. 'The Costs of Family Contributions to the Care of Persons with Dementia'. *The Gerontologist*, 34, 2, pp. 199-205.

Stone R., Cafferata G. L. and Singh J. , 1987. 'Caregivers of the Frail Elderly: A National Profile'. *The Gerontologist*, 27, 5, 616-626.

Sturges P. I., 1995. 'Care Management Practice: Lessons from the USA', in Clark and Lapsley (eds) *Planning and Costing Community Care*. London: Jessica Kingsley.

Townsend, P., 1979. *Poverty in the United Kingdom*. Harmondsworth: Pelican.

Ungerson, C., 1983. 'Why do Women Care?' in J. Finch and D. Groves (eds), *Caring a Labour of Love*. London: Routledge and Kegan Paul.

Ungerson, C., 1987. *Policy is Personal: Sex, Gender and Informal Care*. London: Tavistock.

Vetter , P., Steiner, O., Kraus, S et al.,1997. 'Factors Affecting the Utilization of Homecare Supports by Caregiving Relatives of Alzheimer Patients'. *Dementia Geriatric Cognitive Disorders*, 9, 111-116.

Wager, R., 1972. *Care of the Elderly*. London: Institute of Municipal Treasurers and Accountants.

Walby, S., 1996. 'Women and Citizenship: Towards a Comparative Analysis'. *UCG Women's Centre Review*, 4.

Ward, H. and Cavanagh J., 1997. 'A Descriptive Study of the Self Perceived Needs of Carers for Dependants with a Range of Long-Term Problems'. *Journal of Public Health Medicine*, 18, 3, pp. 281-287.

Wells, Y.D., 1999. 'Intentions to Care for a Spouse: Gender Differences in Anticipated Willingness to Care and Expected Burden'. *Journal of Family Studies*, 5,2, 220-234.

Whelan, B., 1979. 'RANSAM: A Random Sample Design for Ireland'. *The Economic and Social Review*, 10, 2, 160-74.

White-Means S., 1992. 'Allocation of Labour to Informal Home Health Production: Health Care for Frail Elderly, If Time Permits'. *Journal of Consumer Affairs*, 26, 1, 69-89.

White-Means S. , 1997. 'The Demands of Persons with Disabilities for Home Health Care and Economic Consequences for Informal Caregivers'. *Social Science Quarterly*, 78, 4, 955-972.

White-Means S. and Chang C. F., 1991. 'Family Choices with Managed Care for the Home Bound Elderly'. *Southern Economic Journal*, 58,1, 203-224.

Wilkin and Jolly, 1979. *Behavioural Problems Amongst Old People in Geriatric Wards, Psychogeriatric Wards and Residential Homes, 1976-78*. Research Report No.1, Research Section, Psychiatric Unit, University Hospital of South Manchester.

Wilkin, D. and Thompson, C., 1991. *User's Guide for Dependency Measures for Elderly People. Sheffield Social Services Monograph: Research in Practice*. University of Sheffield: Joint Unit for Social Services Research.

Wimo, A., Karlsson, G., Sandman, P.O., Corder, L. and Winblad, B., 1997a. 'Cost of Illness Due to Dementia in Sweden'. *International Journal of Geriatric Psychiatry*, 12, 857-61.

Wimo A., Ljunggren G. and Winblad B., 1997b. 'Costs of Dementia and Dementia Care: A Review'. *International Journal of Geriatric Psychiatry*, 12, pp. 841-856.

Wright K., 1986. *Economic Aspects of Strategies for the Health Care of the Elderly: A Report Prepared for the European Office of the World Health Organisation*. York: University of York.

Wright K., 1987. *The Economics of Informal Care of the Elderly*. York: University of York, Centre for Health Economics, Discussion Paper 23.

Wright K., 1987a. 'Cost Effectiveness in Community Care'. York: University of York, Centre for Health Economics, Discussion Paper 33.

Terms of Reference

The National Council on Ageing and Older People was established on 19 March 1997, in succession to the National Council for the Elderly (January 1990 to March 1997) and the National Council for the Aged (June 1981 to January 1990).

The functions of the Council are as follows

1. To advise the Minister for Health on all aspects of ageing and the welfare of older people, either at its own initiative or at the request of the Minister and in particular on:

- (a) measures to promote the health of older people;
- (b) measures to promote the social inclusion of older people;
- (c) the implementation of the recommendations contained in policy reports commissioned by the Minister for Health;
- (d) methods of ensuring co-ordination between public bodies at national and local level in the planning and provision of services for older people;
- (e) methods of encouraging greater partnership between statutory and voluntary bodies in providing services for older people;
- (f) meeting the needs of the most vulnerable older people;
- (g) means of encouraging positive attitudes to life after 65 years and the process of ageing;
- (h) means of encouraging greater participation by older people;
- (i) whatever action, based on research, is required to plan and develop services for older people.

2. To assist the development of national and regional policies and strategies designed to produce health gain and social gain for older people by:

- (a) undertaking research on the lifestyle and the needs of older people in Ireland;
- (b) identifying and promoting models of good practice in the care of older people and service delivery to them;
- (c) providing information and advice based on research findings to those involved in the development and/or implementation of policies and services pertaining to the health, well-being and autonomy of older people;
- (d) liaising with statutory, voluntary and professional bodies involved in the development and/or implementation of national and regional policies, which have as their object health gain or social gain for older people.

3. To promote the health, welfare and autonomy of older people.

4. To promote a better understanding of ageing and older people in Ireland.

5. To liaise with international bodies which have functions similar to the functions of the Council.

The Council may also advise other Ministers, at their request, on aspects of ageing and the welfare of older people which are within the functions of the Council.

Membership

Chairman

Dr Michael Loftus

Mr John Brady	Ms Betty Keith
Mr John A Cooney	Ms Sheila Kennedy
Mr Jim Cousins	Ms Leonie Lunny
Ms Janet Convery	Ms Mary McDermott
Mr Joseph Dooley	Dr Diarmuid McLoughlin
Mr James Flanagan	Ms Mary Nally
Cllr Michael Finnerty	Mr Pat O’Leary
Dr John Gibbon	Ms Mary O’Sullivan
Prof Faith Gibson	Mr Peter Sands
Mr Frank Goodwim	Ms Sarah Scott
Dr Mary Hynes	Mr Bernard Thompson
Mr Eamonn Kane	Mr Liam Walsh
Mr Jack Killane	Dr Margo Wrigley

Director

Bob Carroll