



Supporting Carers

| A Social Policy Report

COMHAIRLE

Supporting Carers:
A Social Policy Report

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The conclusions and recommendations are a synthesis of the various views expressed and do not necessarily represent any one perspective.

Contents

Preface	4
Executive Summary	6
Introduction	11
Carers: Current Policy Context	12
The Tradition of Informal Care Provision in Ireland	13
Opinions on Care Alternatives	15
Profile of Carers in Ireland	17
Informal Care Provision and Social and Demographic Change	19
Improving Financial and Other Support Services for Carers	22
Expenditure on Community-based and Institutional-based Services	28
Costs of Caring	30
Policy Issues Identified	32
Recommendations	36
Conclusion	37
References	40

Preface

This is one in a new series of Comhairle social policy reports which address social policy concerns identified by the users and providers of Citizens Information Services. This report which deals with the situation and needs of family carers in Ireland summarises recent research and draws on feedback from Citizens Information Centres (CICs) on issues identified by CIC clients. It highlights the demographic pressures that, while not yet urgent, are likely to lead to both an increase in the need for care services and a decrease in the supply of those services by the traditional care providers (family carers). Until recently, the relatively low proportion of older people in the Irish population and low labour market participation rates among women have provided the underpinnings of the informal care system in Ireland. However, changes in family structures, an increase in women's labour market participation and population ageing are making this model of support less sustainable.

Analysis of policy changes and initiatives in the area of care provision shows that, while the challenges facing the system are new, most of the solutions provided continue to rely on the model of home-based care provided by family members. While home-based care is desirable for many reasons and is the preference of most people, it can not be expected to carry the future burden of supplying the majority of care services unaided. New and expanded support services are, therefore, needed in order to guarantee adequate care services and to improve the quality of life of family carers.

The provision of care services in the community will present new challenges as population ageing and longer life expectancy will inevitably result in greater demands on both the family/informal and the hospital/institutional caring systems.

It is clear from a number of studies that the situation of family carers in Ireland needs to be improved. Recent policy initiatives in this area have focused on providing greater income security for some carers. However, such developments continue to be on the basis of income maintenance supports and do not deal with the issue of payment for caring. Carer support in terms of formal service provision also continues to be inadequate to meet needs.

Plans to increase and develop supports for carers, including the Carer's Allowance and short-term respite care, outlined in Health Strategy 2001, are welcome. However, such plans need to be implemented in a consistent and effective manner if they are to make a real difference to the situation of family carers.

It is hoped that the policy recommendations contained in this report, in combination with the ongoing work of many other organisations working for the improvement of care services and carers' support, will lead to fruitful discussions, initiatives and co-operation between carers, service providers and decision makers.

Executive Summary

This Social Policy Report examines the context of family caring in Ireland and provides a synthesis of the needs of carers and policy issues arising. It is based on analysis of:

- (i) feedback from Citizens Information Centres (CICs);
- (ii) recent statistical and survey material on carers;
- (iii) questionnaires completed by regional Health Board Carer Co-ordinators;
- (iv) interviews with representatives of the Carers Association.

Demographic Trends

Current demographic trends are likely to lead to both an increase in the need for care services and a decrease in the supply of those services by the traditional care providers (mostly women). Until recently, the relatively low proportion of older people in the Irish population and low labour market participation rates among women were the underpinnings of the informal care model in Ireland. However, changes in family structures, women's labour market participation and population ageing are making this model less sustainable.

Policy Issues

There is a strong case to be made for supporting carers on the basis that care at home is the preferred option for many. There are also strong economic arguments in favour of this approach. However, there are key aspects of the carer support system that need to be enhanced and developed.

Integrating Caring, Welfare and Work Opportunities

Greater work flexibility is required for people who wish to undertake caring duties and to alternate between, or to combine, caring and working outside the home. If Ireland is to continue relying on family carers, payments to carers, and the conditions attached to these payments, need to be reformed. Two key reforms required are rights to social insurance and flexibility with regard to labour market participation.

Individual Support Systems

Support groups, training programmes and personal development courses for carers have much to contribute and should be funded on an ongoing and planned basis. There is also a strong prima facie case to be made for a specific social work support service for carers.

Home-based Support Services

Provision needs to be made for a more comprehensive range of home based support services on an ongoing basis as well as at times of crisis. Many carers need more help and support in dealing with the demands of night-time and week-end caring. Home-based respite care is particularly important since the preferred care option of most people is care in their own home.

Information

It appears that, despite various initiatives put in place in recent years to improve the provision and delivery of information, considerable information deficits still exist among carers about benefits and service entitlements. More is required in the form of information leaflets and newsletters, information days and public awareness campaigns.

Carers with Special Needs

Some categories of carers were identified as having additional specific needs:

- carers who are older themselves;
- carers in rural areas;
- carers of children with disabilities;
- carers who find themselves in the caring role 'overnight' e.g. carers looking after stroke victims, traffic accident victims;
- carers who are looking after Alzheimer's and Parkinson's disease patients;
- carers of MS (multiple sclerosis) patients;
- carers of people with acquired brain injuries.

Public Health Nursing Service

While public health nurses provide a range of services for carers and persons in need of care e.g. nursing care, advice, support, assessment of individual needs for services and special aids, there are unrealistic expectations of what public health nurses can achieve in the context of their current workloads.

Home Help Service

The Home Help service makes a vital contribution to supporting the work of carers. However, more is required in terms of :

- availability;
- consistency between and within Health Boards;
- ongoing training and skill development.

Respite Care Services

Criteria for respite care need to be more transparent and applied systematically to cater for ongoing caring situations as well as crisis interventions. Increased and more flexible opportunities for respite care are required both at home and outside the home to enable carers to take breaks on an ongoing and planned basis.

Day Care Services

Availability and opening hours of day care centres are generally too short and do not facilitate carers who wish to work outside their caring role.

Fragmented Service Provision

Difficulties arising from gaps in individual services are exacerbated by the fragmented nature of service provision. In addition to Health Boards, there are many voluntary sector service providers that work with carers. The individual carer sometimes finds it difficult to know where to go for help.

Specific Recommendations

- Comprehensive home support care packages, based on an integrated approach to care planning for individuals, as proposed in the Health Strategy 2001, are needed. These should include night-time support and week-end support.
- More personal support services for individual carers and families, including key workers, should be put in place. Specifically, a social work support service for carers should be established.
- Comprehensive, needs-based respite services are urgently required. Health Boards should enter into partnerships with private nursing homes and relevant voluntary organisations in this regard.
- More opportunities, for example, in the form of consultative forums, should be provided for carers to be involved in the process of policy making and service planning.
- Integrated information services run jointly by Health Boards, Citizens Information Centres and other relevant statutory and voluntary bodies should be developed.
- The current Health Board Carer Co-ordinator role should be extended to facilitate more co-ordination of the services provided by both voluntary and statutory organisations at district as well as Community Care area level.
- The possibility of establishing a number of dedicated carer helplines should be explored.

- Health Boards should appoint development workers to enhance the work of the voluntary organisations working with carers.
- The concept of a National Strategy for Carers should be explored. Such a strategy would contain targets for service development and a plan for co-ordinating support services.
- The provision of an additional income support for carers who are providing the highest level of care, i.e. looking after a highly dependent person (so called ‘continual care payment’) should be considered, as recommended in the 1998 Review of the Carer’s Allowance.

1. Introduction

This Comhairle Social Policy Report discusses present and future challenges for Irish policy makers in developing adequate and appropriate support structures for family carers. A number of policy recommendations are made in this regard.

Comhairle is a statutory agency responsible for the provision of information, advice and advocacy services. Comhairle carries out its functions by supporting the development of a network of Citizens Information Centres (CICs) around the country, developing and maintaining the Citizens Information and OASIS Databases and through the provision of a wide range of training and support programmes. One of Comhairle's statutory functions is to promote and develop the provision of information on the effectiveness of current social policy and services and to highlight issues which are of concern to users of those services. In carrying out this function Comhairle relies heavily on feedback from CICs based on the needs and experiences of users of the CIC service.

During 2001 the 85 CICs around the country dealt with almost 400,000 queries from members of the public on all aspects of social services. CICs identified and reported to Comhairle a significant number of cases where it was considered that the services available fell short of what was needed or appropriate in the particular situation. This feedback covers a broad range of social policy issues that arise when citizens try to access services and information about services. Part of this feedback relates to the situation of carers, and the situation of people receiving care services either at home or in other settings.

2. Carers¹: Current Policy Context

Care of older people and people with disabilities in Ireland has traditionally been carried out primarily by women who had little or no opportunity to participate in the labour market outside the home. This model is becoming increasingly unsustainable as the number of those who need care increases while the number of those who are willing and able to provide largely uncompensated informal care decreases.

Recent policy changes aimed at ensuring the supply of care services in the future have continued to rely on the model of informal (home-based) care provision. Research (for example, Garavan et al. 2001) clearly shows that older people prefer to remain in their own homes. The means-tested Carer's Allowance has been improved and a new social insurance benefit, the Carer's Benefit, has been introduced for those who want to take a break from work in order to carry out caring duties. While these policy initiatives go some way towards compensating for the loss of earnings and enabling people to combine paid employment and caring duties, the cost of providing home care is still high, particularly in terms of lost earnings and lost or diminished social opportunities. The Carer's Allowance, despite income disregards introduced in recent budgets, remains a tightly means-tested payment that is an income support rather than a payment for caring. While the improvements in carers' payments are clearly intended to secure a continued supply of informal care labour, it is not certain whether this strategy will work in the long run, especially as there are very few support structures that enable people to combine care work and increasingly attractive paid employment outside the home.

¹ This study uses the term 'carer' as a generic term referring to any person who provides unpaid home and personal care services to a relative, a friend or a neighbour.

3. The Tradition of Informal Care Provision in Ireland

The strong tradition of informal care in Ireland is evident both in policy statements and from surveys that seek to establish the popularity of different forms of care provision. Public opinion and policies are obviously inter-related – policy tends to influence opinions and attitudes, and vice versa.

One of the earliest policy documents that clearly articulated the preference for home-based as opposed to institutional care was the *Care of the Aged* report published by the Inter-Departmental Committee on the Care of the Aged in 1968. It called for greater involvement of the voluntary and community sectors, but significantly not of the State, in the provision of community care (Yeates 1997). In accordance with the principle of subsidiarity, the report recommended that the State's role (through Health Boards) be limited to providing financial assistance to voluntary bodies, and to monitoring the standards of service provision by the informal sector.

The Years Ahead report (Department of Health 1988) continued the tradition of emphasising community care, but also called for recognition of informal carers, increased financial support for people dependent on care, and more support for families providing care services. A Report on Housing of the Elderly in Ireland (National Council for the Aged 1985) called for health and housing services to support family carers. The 1985 Commission on Social Welfare Report recommended improvements in financial support, including the payment of the Prescribed Relative's Allowance to the carer rather than to the person being cared for.

The tradition of informal care in the home is also evident in recent policy statements. For instance, the 1994 Health Strategy states that health and social services for older people are intended “to encourage and support the care of older people in their own community by family, neighbours and voluntary bodies” (Department of Health 1994 p. 67). The aim of the health strategy was to ensure that at least 90 per cent of over 75-year-olds continued to live at home. A 1998 Review of the Carer's Allowance (Department of Social, Community and Family Affairs 1998) acknowledged that government policy had become focused on maintaining people in the community and referred to the valuable role of the carer in community care. The Action Programme for the Millennium (Government of Ireland 1997) recommended new

tax allowances for family carers and relaxation of the qualifying criteria for the Carer's Allowance.

While certain progress towards a more comprehensive system of state support can be detected when these reports are examined in chronological order, there is no sense of a more universalist system of provision (that would involve strong expansion of public services, funded primarily through taxes and/or compulsory insurance) emerging as a significant component of policy.

The current Health Strategy (Department of Health and Children 2001) makes some references to carers. It makes a commitment to providing 800 additional extended care/community nursing unit places per annum over the next 7 years, which is to include provision for people with dementia. The Strategy also outlines the Government's intention to reform "the operation of existing schemes, including the Carer's Allowance, in order to introduce an integrated care subvention scheme which maximises support for home care" (p. 14). Furthermore, the Strategy states that "community groups will be funded to facilitate volunteers in providing support services such as shopping, visiting and transport for older people", and that "programmes to support informal caregivers through the development of informal networks, provision of basic training and the greater availability of short-term respite care will be developed and implemented" (p. 18).

A study² (to be published shortly) to examine the future financing of long term care has been undertaken on behalf of the Department of Social, and Family Affairs in consultation with Department of Health and Children and the Department of Finance. The study examined a number of approaches to financing and funding long-term care - the potential of both the private sector and the PRSI system and whether the current system of long term care financing (through taxation) should continue. These have been assessed against the following criteria:

- meeting long term care needs in the medium and long term;
- reducing unnecessary recourse to institutional care; and
- widening consumer choice.

² Communication from the Department of Social and Family Affairs, July 2002.

4. Opinions on Care Alternatives

A number of studies (see below) show that most people in Ireland prefer informal care solutions i.e. care provided in their own home by members of their family, friends or neighbours. The role of health and social services is seen as one of supporting individuals and families to this end by the provision of support services such as respite care. While informal care remains the most popular care alternative among older people, there are some signs that attitudes may be changing.

A recent study³ (Garavan et al. 2001) on health and social services for older people (referred to as HeSSOP), published by the National Council on Ageing and Older People, asked respondents about their preferences for long-term care. Respondents were asked what type of care they would prefer in different circumstances. In the case of housekeeping care (cleaning, cooking, shopping and so on), 54 per cent of the respondents said that they preferred to receive this type of care from family, friends or neighbours, with 19 per cent preferring professionals and 28 per cent not having a preference. The percentage of respondents preferring professional care providers was slightly higher (23%) in the case of personal care services (bathing, dressing and so on), with 50 % preferring their family, friends or neighbours to provide such care.

The HeSSOP study found that the most popular living at home situation was the current home with involvement of the health board through the provision of respite care services: this alternative was acceptable to 87 per cent of the respondents. Full health board involvement in care provision (involving home help, meals-on-wheels, daily care attendants, public health nurse visits and so on) in their own home was acceptable without reservations to half the respondents. However, this type of Health Board involvement was unacceptable to 26 per cent of the respondents, and acceptable with reservations to 21 per cent. The degree to which respondents found health board intervention acceptable varied somewhat in accordance with age and degree of independence: older people and more physically dependent people found Health Board involvement less acceptable than younger and less dependent people.

When asked about options which involved moving from their current residence to another residence, almost half of the respondents would

³ This was a large, randomised survey of older people (65 years of age and older) living in the community in the Western Health Board and Eastern Regional Health Authority areas, conducted in 2000. 937 people participated in the survey (response rate 67 per cent).

not find moving into the home of a family member acceptable, regardless of whether the health board was involved in the form of respite care or not. A ‘granny flat’ or similar accommodation would be acceptable to 58 per cent (18% with reservations), and sheltered housing to 42 per cent (16% with reservations). These results show somewhat conflicting attitudes towards care and residence outside people’s own home: on the one hand, care in family members’ home is not particularly acceptable (due to the perception of being a burden), but, on the other hand, moving into sheltered housing is not particularly attractive either.

When asked about preferences in relation to different types of ‘managed residence’, the unacceptability of care outside one’s own home becomes even more obvious. Almost half (48%) would not accept accommodation in a state-run (public) nursing home and 43 per cent would not accept accommodation in a private nursing home. Private nursing homes are slightly more popular than public ones, with 34 per cent considering them an acceptable form of care and accommodation compared to 25 per cent for state-run homes. Overall, the most popular long-term care alternative was remaining in one’s own home, cared for by family members with the back-up of the Health Board in the form of respite care.

Actual use of community-based health and social services also appears to be very low. Among the older people who participated in the HeSSOP survey, only 5 per cent used the home help services, 1 per cent were receiving meals-on-wheels and less than 2 per cent of respondents had used respite services. Stigma continues to be an important reason for reluctance to use various social services. Thirty per cent of survey respondents felt that using meals-on-wheels services would be highly embarrassing, and some 20 per cent thought that having recourse to home help services, counselling, social work and personal care attendants was stigmatising.

It is clear from a comparison of the number of people reporting the need for services and the number of people actually receiving those services, that the coverage of health and social services in Ireland is inadequate. For instance, more than a third (37 per cent) of the people who are severely impaired in carrying out daily activities were not receiving any home-based services (Garavan et al. 2001). It is also evident that the needs and opinions of carers and persons receiving care differ to some extent. While carers want more respite care and other support services, some care recipients (particularly the older and more care dependent ones) dislike using these services. (This pattern is evident also in the UK - see, for example, Lewis 1999).

5. Profile of Carers in Ireland

There are no comprehensive registers of informal carers in Ireland. The HeSSOP study estimates that almost half of the older people living in the community were receiving help on a regular basis. O’Shea (2000) estimated that 97,500 households in Ireland contain a carer who is looking after an older person.

According to a census pilot survey⁴ carried out by the Central Statistics Office (September 1999), there are 35,000 people in Ireland providing more than 50 hours unpaid personal care per week; 17,000 people who provide unpaid care for 20-49 hours per week; and 79,000 people who provide unpaid personal help for 1-19 hours per week.

A study carried out in the Western Health Board (O’Neill and Evans 1999) found that 18 per cent of homes in the Health Board area contain a carer. The proportion of households where someone was a carer varied between 11 and 24 per cent between different areas within the Health Board.

The vast majority of informal carers do not receive a payment that compensates them for the caring duties performed. In the Western Health Board area, only 26 per cent of carers were receiving the Carer’s Allowance in 1999 (O’Neill and Evans 2000). Approximately 16,500 people received the Carer’s Allowance in 2000 (Department of Social, Community and Family Affairs 2001). Of these, almost 80 per cent were women. The current⁵ (July 2002) number of recipients of Carer’s Allowance is 19,405. Twelve per cent (2,364) of recipients are on reduced payments. There are currently (July 2002) 450 people in receipt of the Carer’s Benefit, a social insurance benefit that is paid (for a maximum of 15 months) to those who have a sufficient number of social insurance contributions. In 2000, 96 per cent of people in receipt of the Carer’s Benefit were women (Department of Social, Community and Family Affairs 2001).

⁴ This survey was based on a sample of 8,000 households in which persons aged 15 years or over were asked if they provide unpaid personal help for someone with a long-term illness, health problem or disability, including problems due to old age.

⁵ Communication from the Department of Social and Family Affairs.

A key question arises as to why the number of people in receipt of Carer's Allowance and Carer's Benefit is only a fraction of the total number of family carers in Ireland. There are several reasons for the low coverage and low take-up rate of the Carer's Allowance payment. Firstly, Carer's Allowance cannot be received in addition to any other social welfare payment, with the exception of child benefit. Older carers in particular are usually in receipt of pensions and, therefore, are not eligible for the allowance. Older male carers are particularly unlikely to be eligible as they are more likely to have been in employment and, therefore, to have an entitlement to a pension. While the number of people in receipt of Carer's Allowance has increased from 1,240 in 1990 (when the allowance was first introduced) to over 19,000 at present, the real net cost of the scheme is considerably lower than the gross cost as many of the people receiving Carer's Allowance were in receipt of other payments before starting to receive the allowance (Department of Social, Community and Family Affairs 1998). Secondly, approximately half of the refusals of Carer's Allowance relate to the need for care. Carer's Allowance is only granted if it is clear from a doctor's certificate that the person being cared for needs full-time care and attention for a period of at least 12 months i.e. 'requires continual supervision in order to avoid danger to him or herself. Between 1997 and 2000, approximately 10,000 applications for Carer's Allowance were refused (Dáil Debates 24.5.2001). Thirdly, while the means-test has been recently relaxed, it still excludes a large proportion of people who fulfil all other criteria (the means test takes into account the carer's and his/her spouse's income).

The 1998 Review of the Carer's Allowance stated clearly that it is an income support payment and not a payment for caring (Department of Social, Community and Family Affairs 1998). Consequently, it is only paid to carers who opt for the Carer's Allowance instead of other social welfare payments to which they may be entitled.

6. Informal Care Provision and Social and Demographic Change

6.1 Population Ageing

The existing care support system, which is already stretched, is likely to become even more so as the need for care services increases due to population ageing and increased life expectancy. While demographic change in Ireland will be less drastic than in many other Western countries (due to relatively high birth rates until recently), the number and percentage share of older people will increase as people live longer and the birth rate decreases. The number of older people (those aged 65 years and over) is projected to double between 1996 and 2031 (Central Statistics Office 1999: 33). The percentage share of over 65-year-olds in the Irish population is forecast to increase by approximately six percentage points between 1996 and the mid-2020s (see Table 1).

Table 1: Actual and Projected Population by Age, 1961–2026 (Percentage)

Age band	1961	1986	1996	2011	2026
0-14	31.1	28.9	23.7	20.1	18.0
15-39	30.4	38.1	38.8	36.1	31.9
40-64	27.3	22.1	26.0	30.7	32.3
65+	11.2	10.9	11.4	13.2	17.8
Total	100	100	100	100	100

Sources: *Joint Committee on Family, Community and Social Affairs (2001) and Central Statistics Office (1999).*

The ageing of the older population also presents a challenge for health and social services. The number of the very old (those aged 80 and over) is forecast to more than double between 1996 and 2031, and in the mid-Eastern parts of the country it will treble during this period (Central Statistics Office 1999: 33). In addition to population ageing, an increase in divorce/separation rates may result in additional pressure on public care services as people in these categories may experience greater difficulty in accessing care by a family member (O’Shea et al. 1991: 74). However, the decrease in the proportion of single older people may counteract the increasing number of divorced or separated older people (Department of Health 1995 and 1996).

6.2 Changing Fertility Rates

In addition to the ageing of the population there is the phenomenon of a decline in the total fertility rate. Between 1965 and 1994/95 the total fertility rate in Ireland declined from 4.03 to 1.85. While it has since increased to 1.93 (in 1998), long-term decline is expected to resume, albeit at a more moderate rate than between the 1970s and 1990s (Central Statistics Office 1999: 10-11). This is mainly due to increased educational attainment and labour market participation among women.

6.3 Labour Force Participation by Women

Women's labour force participation rates are also increasing rapidly (see Table 2). Between 1985 and 1999, women's employment rate in Ireland rose from a little over 30 per cent to just over 50 per cent. The percentage employed part-time increased from 15 to 30 during this period. While these rates are still below those in the Nordic countries and the UK, they are approaching the levels of participation in Germany and France, and clearly exceed the rates in most Mediterranean countries. The participation rate in younger age groups is already very high. For instance, in 1986 82.1 per cent of (non-student) females between the ages of 20 and 24 were participating in the labour market, and this share is projected to grow to 89 per cent by 2011 (Central Statistics Office 1999: 21). While the participation rate of married women has increased dramatically, it is still lower than in most other EU countries. Between 1986 and 1998, the average annual increase for married women between the ages of 25 and 49 was 3.6 per cent, and for 35-39-year-olds 6.7 per cent (op. cit. p. 22).

Table 2: Women's Labour Market Participation

	ER-85	ER-91	ER-96	ER-99	PT-85	PT-91	PT-96	PT-99
Ireland	32.1	36.1	43.3	51.4	15.5	17.9	22.2	30.6
UK	55.0	61.9	63.1	63.9	44.8	43.7	44.8	44.4
Sweden	76.4	79.1	69.0	69.0	45.6	41.0	41.8	40.0
Germany	48.5	55.0	53.8	57.1	29.6	34.3	33.6	37.2
France	50.7	52.6	52.8	53.5	21.8	23.5	29.5	31.7
Spain	25.4	31.6	32.6	37.3	13.9	11.2	17.0	17.6
Italy	33.5	36.9	36.6	38.1	10.1	10.4	12.7	15.7

ER = Employment rate, % of female population between the ages of 15 and 64.

PT = Part-time employment as % of total female employment.

Source: European Commission (1997, 1999) *Employment in Europe*.

Women's education participation rates in Ireland have been increasing dramatically, and are set to rise further. In 1986, only 14 per cent of 20-24-year-old Irish women were in education. In 1996, women's education participation rate in this age group was 26 per cent, and by 2011 this is projected to increase to 35 per cent (Central Statistics Office 1999).

The twin challenges of an ageing population and a decreased supply of informal carers pose major problems for the Irish care provision system. The problem is all the more acute because institutional care (in either public or private nursing homes) is not a viable alternative to informal care in the home. Residential care is unpopular (although attitudes may be changing), in short supply, very expensive to expand, and runs against the basic principles of the conventional model of service provision in Ireland which leans towards informal care in the community.

7. Improving Financial and Other Support Services for Carers

7.1 Income Maintenance

The Irish social welfare system contains three forms of financial support for family carers. The Carer's Allowance was introduced in 1990 to replace the Prescribed Relative's Allowance (introduced in 1968) which was paid to some pensioners who needed full-time care and attention. The Prescribed Relative's Allowance was not available to married pensioners dependent on their spouses (so that, for instance, a male pensioner being looked after by his own wife was not eligible) and was paid directly to the pensioner rather than the carer. In its present form, the Carer's Allowance is tightly means-tested and available only where constant and intensive care is needed by the care recipient. A social insurance benefit, Carer's Benefit, was introduced in October 2000, and requires a sufficient record of social insurance contributions. The Domiciliary Care Allowance (€164.30 per month) is paid to the parents of children with disabilities and is not means-tested on the parents' income.

Providing support for informal carers who look after older or sick relatives/friends or someone with a disability at home is an important priority for Government and expenditure on supporting carers has increased significantly in recent years (Department of Social, Community and Family Affairs 2001). Since 1999, credited PRSI contributions (social insurance contributions) have been awarded to some carers, and the Back to Work scheme and Back to Education Allowance have been extended to cover carers returning to work outside the home after a period of caring. The 'full-time care and attention' rule has been relaxed to allow carers to engage in employment outside the home for a maximum of 10 hours per week, and the residence criteria have been relaxed to allow non-resident carers (e.g. a daughter living in a neighbouring suburb) to qualify for the allowance. Carers are also entitled to an annual respite grant and some carers are entitled to free travel and to the Household Benefits Package which includes an electricity allowance, a telephone allowance and a free television licence.

The means-testing of the Carer's Allowance has been made less stringent: since April 2001 the weekly income disregards for means-testing have been €158.72 for a single person and €317.43 for a couple. Since April 2002 the respective figures are €191 and €382. The current rate of payment is €122.60 for a person under 66 and €137.80 for a person aged 66 and over. The respite grant has been increased

from €507.90 to €635 from June 2002 and two grants are available to carers looking after two or more persons. Budget changes in recent years have resulted in extra carers qualifying for the Carer's Allowance. However, receipt of the Carer's Allowance still leads to loss of any other social welfare benefits that the carer may be receiving and may affect a spouse/partner's benefits.

The Review of the Carer's Allowance (Department of Social, Community and Family Affairs 1998) suggested that a new non-means-tested benefit be introduced for carers who are providing the highest level of care i.e. looking after a highly dependent person (so-called 'continual care payment'). However, this suggestion has not been put into practice. Also, despite repeated calls for 'universalisation' of the payment by interest groups, such as the Carers' Association, the Carer's Allowance remains a means-tested income support mechanism rather than a payment for caring.

While the recent changes in carers' payments have improved the position of many carers, most are still not entitled to any payment that recognises their vital contribution to society. Policy initiatives and improvements in payments are clearly intended to reinforce the existing model of informal care in the home. According to the Minister for Social, Community and Family Affairs, 'Government policy is strongly in favour of supporting care in the community and enabling people to remain in their own homes for as long as possible... the State cannot, and would not wish to replace the personal support and care provided within the family and the community' (Dáil Debates 24.5.2001).

The Carer's Leave Act 2001 goes some way towards recognising the need for flexibility in employment. However, even though many people availing of Carer's Leave provisions would be entitled to Carer's Benefit, it is likely to be used only by those in secure employment. The Act, therefore, fails to address the situation of those who are in the most unfavourable position financially, e.g., those in temporary work or without sufficient PRSI contributions. Also, Carers Benefit is only payable for 15 months.

None of the policy changes in recent years have been targeted at re-balancing the gender division of care work. The (unpaid) parental leave programme (introduced in December 1998) has given fathers the

opportunity to take time off work to look after their children. However, any leave entitlement that does not include financial compensation is unlikely to go a very long way toward redressing the gender imbalance in care work.

7.2 Support Services

The social and health services in Ireland are characterised by a ‘welfare mix’: the public, voluntary (community) and private sectors are all involved in financing and producing the services. In contrast to the income transfer system that is very centralised and controlled as well as financed (for the most part) by the State, the service sector is defined more by the absence, rather than the presence, of the State (Daly 1998). Many social, education and health services have traditionally been produced by ‘public-private partnerships’, that is to say through partnership arrangements between the State and the private and voluntary sectors. The role of the State has been limited to planning, financing and quality control.

As public provision for older people requiring residential care has not been increased in step with the increased demand, the share of private sector units expanded from around 20 per cent in 1986 to more than 30 per cent in the mid-1990s (See Table 3). Due to insufficient supply of places in the public sector, the State subsidises the cost of care in private nursing homes. However, because the nursing home subvention is means-tested and normally subject to a ceiling, it frequently fails to meet the actual cost of care in a private institution.

While the main policy thrust has been towards the development of community support services, current provision is unsatisfactory for four main reasons. Firstly, intermediary arrangements between institutional care and informal care in the community are very inadequate: people are either being looked after at home with relatively little State support, or they move to an institution. It is clear that support services for informal carers are in short supply and do not meet the demand. For instance, respite care places are inadequate to cater for the range of expressed need. Home help services (help with shopping, cleaning etc.) are normally only available on a means-tested basis. Also, the role of personal assistants (helping people with physical disabilities to live as independent a life as possible) has not been developed to nearly its full potential (Joint Committee on Family, Community and Social Affairs 2001).

Secondly, communication and co-operation between statutory and voluntary services on the one hand, and between health and housing services on the other hand, are underdeveloped. The system of support service provision is characterised by the presence of myriad agencies, associations, support groups and institutions that sometimes duplicate services. In short, the system of service provision is very fragmented. This complex system of provision also makes it difficult for carers and people being cared for to find out about available services and entitlements. In a study commissioned by the South Eastern Health Board (South Eastern Health Board 2000), almost two-thirds of the people interviewed stated that they did not have enough information about the availability of support services for carers.

Thirdly, there is an element of stigma still attached to the use of many support services which reduces the take-up rate. Some carers do not make use of available services either due to feelings of guilt or because they do not think that the services available would be suitable or acceptable to the person they are caring for (South Eastern Health Board 2000). A quarter of the respondents to the South Eastern Health Board's study said that they had never had a break from their caring duties, and over a third reported that they had never been offered respite care.

Fourthly, as already stated, the public sector's capacity to meet demand for residential care is shrinking. While the absolute number of beds in public sector residential units has been increasing slowly, the share of public sector beds has decreased (Table 3). The 'traditional' provider of services, the voluntary sector has been retracting and has not been able to meet the extra demand for care. The number of beds in private long-stay units for older people has more than doubled between 1986 and 1998 while the number in public institutions increased by less than 10 per cent.

Table 3: Number of beds (percentage share) in different types of long-stay units, 1986–1998

Type of unit	1986	1995	1998	Percentage change
Public	8,811 (57.8)	9,261 (49.3)	9,572 (48.7)	+ 8.6
Private	3,272 (21.5)	6,138 (32.7)	6,965 (35.4)	+ 112.9
Voluntary	3,150 (20.7)	3,385 (18.0)	3,133 (16.0)	- 0.5
Total	15,233	18,784	19,670	+29.1

Sources: Department of Health 1986 and 1995; unofficial figures for 1998 obtained from Department of Health and Children 17.8.2001. Design of table adapted from Daly 1998.

Note: The above data is incomplete. For instance, only 460 of the 523 registered nursing homes in Ireland responded to the 1998 survey. Since most of the homes that did not respond are private ones, the actual figures for the private sector, and the private sector's share of beds, are higher than indicated here.

Increased private sector provision of beds in residential care units is of course not a problem in itself, but it has two problematic consequences. While the Irish Health Boards are under no legal obligation to provide carer support services such as home helps, they have a statutory obligation to provide nursing home subventions. Health boards are estimated to have spent nearly IEP 46 million on the nursing home subvention scheme in 2001, an increase of more than 200 per cent since 1995 (Table 4, column B). In the absence of adequate support services for family carers, it is likely that some people are unnecessarily referred to institutional care. Secondly, the reliance on the private sector is problematic because it may place a considerable financial burden on older people and/or their families. While Health Boards are increasingly resorting to subsidising places in private nursing homes, these subsidies do not cover the full cost of nursing home care.

The position with regard to Health Boards' legal obligation to provide free long-term nursing home care for people is not clear: the Office of the Ombudsman and the Department of Health and Children have conflicting interpretations of this issue⁷. The Department of Health and Children has incurred additional expenditure as a result of the Ombudsman's Report on Nursing Home Subventions. Adult children's income can no longer be included in means-testing a person for a Nursing Home Subvention and an older person must also retain at least one-fifth of the Old Age Non-Contributory pension.

⁷ See Office of the Ombudsman (2001), Nursing Home Subventions.

8. Expenditure on Community-based and Institutional-based Services

Health board expenditure on specific support services for informal carers is estimated at 10 million pounds in 2001 (see Table 4, column C). The number of persons in receipt of health board home help services increased by almost 7,000 between 1996 and 2000 (Table 4, column A). Although it still remains low in comparison with the expenditure on institutional care, Health Board expenditure on community care expanded tenfold during the latter half of the 1990s (Table 4, column E). Some Health Boards have taken steps towards increased support for carers by hiring carer co-ordinators whose task it is to facilitate a range of support networks and information provision for carers.

Table 4: Support for informal vs. institutional care provision

Year	A	B	C	D	E
1995	-	15.2	-	72.8	2.3
1996	10,386	16.9	-	113.5	8.8
1997	10,790	27.8	-	126.3	9.2
1998	13,379	23.8	0.7	140.7	17.5
1999	15,228	33.2	1.4	166.1	17.2
2000	17,994	38.5	6.0	181.1	22.5
2001	-	45.7	10.0	-	-

A = Number of recipients (over 65) of home help services by Health Board.

B = Funding provided by the Department of Health and Children to meet the costs of the Nursing Home Subvention Scheme, IEP million.

C = Health Board expenditure on support services, including personal assistance services, IEP million.

D = Health Board expenditure on institutional care, IEP million.

E = Health Board expenditure on community care, IEP million.

Source: Joint Committee on Family, Community and Social Affairs (2001).

It is reasonable to argue that the dichotomised system of care provision in Ireland is not the most cost effective available. Increased provision of respite and other support services would make financial sense from the State's point of view. For example, if carers can take regular breaks to 'recharge their batteries', fewer people will have to resort to expensive institutional care. At the moment, however, 'state intervention is... used to substitute for the carer, or used when care supports break down, [rather] than to offer practical support to ensure continuation of care in a complementary sense' (Joint Committee on Family, Community and

Social Affairs 2001: 10). Given that increased support for carers would make financial sense, the question arises as to whether the lack of greater support for informal care and intermediary forms of care is due to deep-rooted reluctance to increase the role of the State in financing and providing services.

More support services are clearly needed if the Irish welfare state is to continue relying on informal care provision. Facilitating and supporting carers to a much greater extent than has traditionally been the case is necessary. It is essential to promote the mental and physical health of carers if they are to continue providing the bulk of caring services without undue damage to their health and well-being (O'Neill and Evans 2000: 8). It is inevitable that more financial support will be necessary to convince people to continue to take on caring roles. This is particularly the case in respect of women who have entered the labour market and/or are pursuing interests outside the home.

As already stated, opportunities for combining paid employment and caring duties need to be considerably enhanced and developed. Ideally, the network of financial assistance and support services should give carers a genuine choice between caring, employment outside the home, or a combination of the two. While some carers would not wish to give up their care work almost regardless of the circumstance, it is clear that other carers would wish to be relieved of some or all of the burden of caring and would like greater choice in the matter.

In theory, there is no conflict between providing high quality institutional care and supporting family carers. In practice, however, social policies in Ireland are primarily designed to support an assumed capacity and willingness on the part of informal carers. The needs and wishes of those who need more intensive support to cope with the task of informal care are not adequately catered for under current provisions. This is also the case for those (both carers and people receiving care) who would prefer comprehensive public provision of care services. Given that the overwhelming majority (some 80 per cent) of carers are women, the current policies in respect of informal care in the home could be construed as a mechanism for 'keeping women in the home'. Social care policies promote equality only when they acknowledge and support family carers of both sexes and make care outside the home both desirable and widely available. The Nordic countries have probably come closest to this ideal scenario and this approach is also reflected in positive attitudes towards universal public care services (Svallfors 1999).

9. Costs of Caring

A key theme that recurred throughout the analysis is that caring is costly. There are many costs associated with home-based care that are not incurred by most other people. For instance, the house in which the caring takes place usually has to be very well heated, adding to heating costs. In many cases frequent laundering of clothes is necessary, leading to high electricity costs. The need for assistive technology and appliances, as well as adapted transport, sometimes increases the financial burden of caring. All of these costs would have to be carried by the State if family carers were not prepared to absorb them.

The opportunity cost of caring in the home is increasingly high. As more women work, they are likely to end up as carers after a period of paid employment. The difference between even a modest wage/salary and the Carers Allowance/Benefit is considerable. In other words, many carers experience a dramatic drop in income when they take up the role of carer.

The issue of financial support for carers is a recurrent one with carers regularly referring to the costs of both care-giving and maintaining a reasonable standard of living. The central issue, however, refers to recognition of the work and contribution of carers which, many carers feel, should be viewed in the context of the cost of the alternative forms of state-funded care.

Under current regulations, applicants for Carer's Benefit are required to apply for the benefit eight weeks before they intend to leave employment. While late claims will be accepted in emergency situations, payment cannot be made in respect of a period more than 6 months prior to the date of the claim. Also, applicants for Carer's Benefit are required to have worked 17 hours per week (or 34 hours per fortnight) in the 13 weeks prior to leaving work. Again, this does not recognise the reality that people in crisis may have to take time off to care for an ill or disabled person in the weeks preceding the application for Carer's Benefit.

While the changes introduced in Budget 2002 in respect of the Carer's Allowance (increased payment, easing of means test and increase in respite care grant) are welcome, the reality is that many carers in houses with quite modest incomes will still fail to qualify for the allowance.

Interestingly, the Budget for 2002 also contained a significant increase in tax relief for the cost of employing a person to care for a family member who is incapacitated. It is clear that this tax relief is of benefit only to high-income individuals and families as hiring a home help privately for a significant number of hours is an option only for the better-off. This measure is an indication, perhaps, of a preference for private care alternatives. For example, the resources invested in this tax relief might have been more effectively targeted at family carers who cannot afford to buy in any extra help to the home.

10. Policy Issues Identified

There is a strong case to be made for supporting carers on the basis that care at home is the preferred option for many. There are also strong economic arguments in favour of this approach. However, there are key aspects of the carer support system that need to be enhanced and developed.

10.1 Integrating Caring, Welfare and Work Opportunities

Greater work flexibility is required for people who wish to undertake caring duties and to alternate between, or to combine, caring and working outside the home. If Ireland is to continue relying on family carers, payments to carers, and the conditions attached to these payments, need to be reformed. It is likely that policies that provide insufficient financial support and services to carers or have restrictive conditions will undermine rather than reinforce informal care, particularly in the context of current labour market opportunities.

Two key reforms required in this regard are rights to social insurance and flexibility with regard to labour market participation. If the opportunity costs of informal care provision for the carer are to be reduced, social insurance credits must be awarded to all people undertaking caring duties. Both long-term carers and people who alternate between paid employment and care work should have an unbroken record of social insurance contributions that entitle them to social insurance benefits.

10.2 Individual Support Systems

A key issue that emerges from the analysis is that many carers experience isolation – geographical, social and emotional. More is required in the form of individual support systems which maximise the role and contribution of service providers (statutory and voluntary), other family members and peer group support from other carers. Carers frequently have complex needs and more help is required to assist them in acquiring the knowledge and skills needed for the caring role. Carers need assistance with planning for opportunities to maintain their own mental and physical health and well-being. This is important because many carers tend to become so involved and absorbed in their caring role that they may overlook their own needs and interests, i.e., they care for others but not for themselves. Much of care work is also heavy, manual work (lifting, washing and so on) that may result in health problems for carers.

Measures should be undertaken to redress the isolation experienced by many carers and to prevent situations where one individual has total responsibility all of the time.

Support groups, training programmes and personal development courses for carers have much to contribute in this regard. There is also a strong *prima facie* case to be made for a specific social work support service for carers. The availability of a carers' helpline would provide another avenue of support for individual carers.

10.3 Home-based Support Services

Provision needs to be made for a more comprehensive range of home based support services on an ongoing basis as well as at times of crisis. Many carers, for example, need more help and support in dealing with the demands of night-time and week-end caring. Home-based respite care is particularly important since the preferred care alternative of most people is care in their own home

10.4 Information

It appears that, despite various initiatives put in place in recent years to improve the provision and delivery of information, considerable information deficits still exist among carers about benefits and service entitlements. The challenge is to provide new and more effective means of keeping them informed of their rights and entitlements and of service availability. More is required in the form of information leaflets and newsletters; information days and public awareness campaigns.

10.5 Carers with Special Needs

Some categories of carers were identified as having additional specific needs:

- *Carers who are older themselves.* This group is increasing due to a longer life span, and many people in this group are reported as not being aware of entitlements and support services to which they may be entitled.
- *Carers in rural areas.* Service provision in rural areas is often sporadic or non-existent and carers living in these areas frequently have poor access to services.
- *Carers of children with disabilities.* Support services, especially appropriate respite care, for children with disabilities are inadequate to meet current needs.

- *Carers who find themselves in the caring role ‘overnight’* e.g. carers looking after stroke victims, traffic accident victims.
- *Carers who are looking after Alzheimer’s and Parkinson’s disease patients.* People with these conditions frequently require round-the-clock supervision and assistance in the home.
- *Carers of MS (multiple sclerosis) patients.* Services for this group are regarded as very patchy.
- *Carers of people with acquired brain injuries.*

10.6 Gaps and Inadequacies in Existing Services

Public Health Nursing Services

Public health nursing services provide a range of services for carers and persons in need of care e.g. nursing care, advice, support, assessment of individual needs for services and special aids. There is, however, a perception that there are unrealistic expectations of what public health nurses can achieve in the context of their current workloads.

Home Help Service

While the Home Help service is seen as making a vital contribution, it is restricted in its availability as a support to carers. In some instances the service is only available on a 9a.m. to 5p.m. basis and in some areas the service is not available if there is a carer ‘in place’ looking after the person in need of care. The criteria for getting home help are not consistent between Health Boards which means that people’s entitlement to services varies greatly according to the area where they live, not according to what their needs are. Some carer co-ordinators believe that training for Home Helps needs to be updated more regularly than is the case at present.

Respite Care Services

It is likely that the more accessible and effective the opportunities for respite care are, the longer people can be cared for in the community. Respite care services were generally identified as inadequate. Furthermore, entitlement to respite care was regarded as unclear despite the availability of the respite care grant and the provision of some innovative and supportive respite care packages, particularly by voluntary organisations in various parts of the country. Home-based respite care is regarded as a particularly important area where expansion of availability is required.

Criteria for respite care need to be more transparent and applied systematically to cater for ongoing caring situations as well as crisis interventions. Increased and more flexible opportunities for respite care are required both at home and outside the home to enable carers to take breaks on an ongoing and planned basis

More extensive and flexible respite care services would make the shared-care approach possible which in turn would allow some carers to work outside the home.

Day Care Services

Availability and opening hours of day care centres were regarded as inadequate and do not facilitate carers who wish to work outside their caring role.

Fragmented Service Provision

It was felt that difficulties arising from gaps in individual services were exacerbated by the fragmented nature of service provision. In addition to Health Boards, there are many voluntary sector service providers that work with carers, for example, the Carers' Association, Centres for Independent Living, the Irish Wheelchair Association and the Alzheimer's Society. The individual carer, not surprisingly, sometimes finds it difficult to know where to go for help.

11. Recommendations

- Comprehensive home support care packages, based on an integrated approach to care planning for individuals, as proposed in the Health Strategy 2001, are needed. These should include night-time support and week-end support.
- More personal support services for individual carers and families, including key workers, should be put in place. Specifically, a social work support service for carers should be established.
- Comprehensive, needs-based respite services are urgently required. Health Boards should enter into partnerships with private nursing homes and relevant voluntary organisations in this regard.
- More opportunities, for example, in the form of consultative forums, should be provided for carers to be involved in the process of policy making and service planning.
- Integrated information services run jointly by Health Boards, Citizens Information Centres and other relevant statutory and voluntary bodies should be developed.
- The current Health Board Carer Co-ordinator role should be extended to facilitate more co-ordination of services provided by both voluntary and statutory organisations at district as well as Community Care area level.
- The possibility of establishing a number of dedicated carer helplines should be explored.
- Health Boards should appoint development workers to enhance the work of the voluntary organisations working with carers.
- The concept of a National Strategy for Carers should be explored. Such a strategy would contain targets for service development and a plan for co-ordinating support services. The strategy would be based on comprehensive statistical needs assessment data.
- The provision of an additional income support for carers who are providing the highest level of care, i.e. looking after a highly dependent person (so-called 'continual care payment') should be considered, as recommended in the 1998 Review of the Carers Allowance.

12. Conclusion

While the expansion of support for carers represents some level of welfare state growth, the system continues to be rooted in a residualist model of social welfare provision. Instead of expanding the entitlement to care in institutions and the State's responsibility for support service provision (as in Scandinavia), or introducing long-term care insurance (as in Germany), the policy in Ireland has been geared towards supporting the home-based (and, in practice, predominantly female) carer. Changes in benefits over the last decade or so have given slightly more financial independence and support to carers: instead of the care payment going to the person being looked after, the carer is now the recipient. Means-testing of the Carer's Allowance is less restricted and improved respite grants are available. These improvements do not, however, represent fundamental, or systemic, change in the Irish model of supporting care provision.

In addition to providing much of the care in the community, families have also been bearing some of the increasing costs of institutional care. While nursing home subventions are available to some people on a means-tested basis, these subsidies often fail to cover the full cost of care which in some instances may be then shifted on to the care recipient's family. It would appear that little provision is being made for meeting the financial and organisational challenge of an ageing population and a decreasing supply of informal family care services. There are still no real intermediate alternatives in Ireland to home care or institutional care: when the capacity of the family carer to provide the required level of services is exhausted the person needing care has to go into an institution.

In other words, the policy strategy with regard to care services in Ireland seems to be two-pronged. First, the absence or inadequacy of good-quality institutional care and comprehensive community support services means that informal care in the home is the only available solution to many people. Second, marginally improved payments are used to enable people (mostly women) to stay at home and perform care work. This model is further reinforced by the dislike by older people of public care solutions, whether in the form of institutional care or state support services (other than occasional respite care).

While these policy choices are relatively cheap (the cost of subsidising 'informal' care work at home being considerably lower than the cost of state-provided care), they may not be viable long-term solutions. As

the number of family carers declines with increasing female labour market participation, there will probably not be a sufficient number of carers in future to look after older people and people with disabilities at home. It remains to be seen whether the call of duty and social pressure to provide care will prove stronger than the personal and financial rewards that await Irish women outside the home. So far policy reform in Ireland has done little to enable women to combine the two. The outcome of this is likely to be greater reliance on institutional care which is the less attractive option and the one which is also likely to be more expensive.

Given the preference of most people for care in their own home, and the limitations on service funding posed by the current relatively low levels of taxation in Ireland, it appears that the preferred alternative is to invest in support services for family carers. Such support services should be geared towards ensuring that carers (and potential future carers) are in a position to make choices regarding the extent to which they are involved in care work and in employment outside their care-giving role. In practice this would mean that carers could combine care work and paid work outside the home with the help of reliable support services to take over the care work when necessary. In terms of actual policies, this would mean significant expansion of flexible, mostly home-based services, such as respite, home help, meals. These different services need to be designed to facilitate both the continuation of home care in the long term and the opportunities of carers to maintain their own health and to engage in activities outside their caring role.

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