Services for Supporting
Family Carers of Elderly People in Europe:
Characteristics, Coverage and Usage

EUROFAMCARE

National Background Report
for Ireland

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August 2004

The project EUROFAMCARE is supported by the European Union - Contract: QLK6-CT-2002-02647

This report is part of the European Union funded project

“Services for Supporting Family Carers of Elderly People in Europe:
Characteristics, Coverage and Usage” - EUROFAMCARE

EUROFAMCARE is an international research project funded within the
5th Framework Programme of the European Community,
Key Action 6: The Ageing Population and Disabilities,
6.5: Health and Social Care Services to older People,
Contract N° QLK6-CT-2002-02647 "EUROFAMCARE"

http://www.uke.uni-hamburg.de/eurofamcare/

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Design: Christopher Kofahl

Final Layout: Maik Philipp, Florian Lüdeke

Hamburg, 8th September 2004

Acknowledgement

We would like to thank Mr Kevin Cullen, Director and Ms Sarah Delaney, Research Consultant, of the Work Research Centre Ltd for their assistance in preparing this report.

The compilation of this report has been greatly facilitated by access to research work funded by the Equality Authority in Ireland which was being prepared for publication at the time that this report was being prepared. We are very grateful for their generosity in this regard. Those who are interested can contact the Equality Authority for further information about their work on carers and caring.[1]

The staff of Caring for Carers Ireland especially thank Mary Kelly, whose skill and commitment has been invaluable in presenting this document.

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Summary of Main Findings

Directed to Family Carers

- There are no formal obligations on families to care nor has the state much formal responsibility in this area - this makes it very much a "grey area", with potential for ambiguity, anomaly and inequity.
- Although the Irish population is ageing this process is lagging behind by many years in comparison to the situation in other European countries. In 2002 there was a total of 436,001 people aged 65 years and over in Ireland, representing 11.1 % of the population overall. The age dependency ratio (people aged 65 years and older: people in the 15-64 years age group) in 2002 was 0.16. The current demographic "bulge" in Ireland is in the 20 to 30 yeas age group (UN, 1998), so it will be only in the 2040s that the bulge reaches the older age groups.
- Fertility rates have been falling in Ireland (from 4.03 in 1965). The total fertility rate in Ireland in 1998 was 1.94, compared to the European average of 1.45. The current relatively young age profile of the population and the somewhat above average fertility rate suggests that a “caring crisis” as a result of demographic factors alone is unlikely for the foreseeable future.
- The responsibility for caring lies with one person, the main, and often the only Carer. Over 60 % of carers are female. 30 % of all Carers are over the age of 54 years. Current trends show that adult children are more involved in parent care and grandparents in child care.
- Although women carers are in the majority, there are signs of change - more men are engaging in caring; also women carers have about the same employment rates as women in general.
- Employment rates in Ireland are at an all time high for both men and women. Employment rates for women have shown the greatest increase and now stand at 50 % (CSO 2003). The traditional higher female unemployment rates may have facilitated the caregiving role of many women. The current trend in employment for women may impact on future care giving. However, the state can no longer assume that care will be automatically provided by the family.

Implications for Family Carers and Older People

- Over 20 hours caring per week is given by 40 % of Family Carers with 27 % giving in excess of 50 hours. Studies (O'Neill, Evans) show that the overload of caring, family and work responsibilities has a negative impact on the Carer's physical and mental well-being and identifies them as an "at risk group" with regard to their own health.

- In reconciling the demands of work, family life and caring, many Family Carers experience financial difficulties and challenges due to the opportunity cost of care, reduced access to paid employment and increased costs associated with caregiving, heating, laundry and home adaptation.
- Given the social and demographic changes in Ireland it is increasingly important that family members collaborate in sharing the provision of Care.
- In the coming years, the numbers of women prepared to work as informal carers is likely to be smaller, or they will have to combine it to a greater extent with formal work. This might require a deeper reorganisation of family roles between sexes, and also greater demand of support on the government and public service. Currently care givers organisations provide support, advocacy and a platform for Family Carers which links them with policy makers and decision takers.

Service providers

- Services of relevance for Family Carers and older dependants are provided by a mix of public and voluntary sector agencies.
- Various health and social service strategy and vision documents over the last number of years have given attention to issues relevant for carers, including more support for community services to help dependant people remain in their own homes. Support for carers is also typically alluded to, although as yet no concerted action plan has been developed or implemented that addresses the needs of carers.
- There is a lack of a statutory basis for many of the community health and social services that have central relevance for carers and those that they care for, and an absence of clear links between eligibility and entitlement to these services. As a result, there is considerable scope for anomaly and inequity in access to services of importance for carers. The fact that the service delivery model is a residual one, with the "availability" of a carer or carers taken into consideration in rationing scarce services, coupled with the fact that carers are seldom direct clients of the health and social services, adds to the potential for anomaly and inequity.
- The relationship between health and social services in Ireland remains weak, the strengthening of communication will promote integration of service provision in primary health care.
- The process of Integrated care and case management needs to be mainstreamed and the partnership between the Family Carer and service providers should be developed.
- Improving health status requires the reduction of inequalities in access to health care, addressing quality of life issues and improving peoples experience of interacting with health and personal social services.

Policy Makers

- Social Cohesion**:** A significant factor in Ireland's economic development in the new Millennium is the increasing levels of employment and the labour productivity (GDP) of those employed. Ireland having the second highest rate in the EU in 2003 (source Eurostat 2003). However, questions around redistribution and greater social equality arise when considering factors in relation to social cohesion. Ireland has the highest level of at-risk-of-poverty rate after social transfers for both men and women within the EU. OECD 2001 (Source Eurostat 2003). While redistribution and greater social equality are long standing objectives, social policy models which are slower to change then the societies they seek to serve means that equity issues need to be addressed.
- The issue of how the costs of long-term care should be met is currently on the agenda of Department of Social and Family Affairs. One proposal being explored concerns the merits of introducing a universal social insurance based benefit package for households with caring responsibilities, where a package of services and / or cash could be chosen depending on the circumstances. A recent parliamentary committee has viewed this proposal quite positively[2].
- There may be a need for the establishment of a National Strategy to support Family Carers which is underpinned by legislation and with financial commitment to support caring in the home. The introduction of a comprehensive outreach system of Information, Assistive and Communications Technologies to promote independent living, security, health and social monitoring for Family Carers and vulnerable older people in the community is desirable.

  Consideration should be given to introduction of a new discipline of care in the provision of services, to enable policy makers, health service providers and educationalists embrace the reality of Homebased caring. The study indicates that Family Carers are a distinct group of people who seek parity of esteem with other service providers. Family Carers are the key providers of care in the community. They have a wealth of experience and expertise in the care of their dependant person. Family Carers should be acknowledged as partners in the provision of care and as people themselves in need of health and social care support.
- There is a case to be made for the recognition of caregiving as work and this work might have all established workforce entitlements. The occupational needs of Family Carers must be provided for in terms of appropriate training, to meet the demands of caring, giving and retraining to enter the paid workforce and to promote social inclusion.

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[2] Joint Committee on Social and Family Affairs: Report on the Position of Full-time Carers (2003)

- Finally, carers have been explicitly included within the two main pieces of Equality Legislation in Ireland - the Employment Equality Act (1998) and Equal Status Act (2002). The Equality Authority has begun to actively develop this agenda through research[3] and the establishment of an Advisory Committee of relevant stakeholders to report on the issue and make recommendations.

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[3] Cullen et al (2004, forthcoming) Equality of access to services for carers: Implications for equality of access to employment opportunities. Dublin: Equality Authority

Introduction – An Overview on Family Care

Although the Irish population is ageing this process is lagging behind by many years in comparison to the situation in other European countries. In 2002 there was a total of 436,001 people aged 65 years and over in Ireland, representing 11.1 % of the population overall. The age dependency ratio (people aged 65 years and older: people in the 15-64 years age group) in 2002 was 0.16 %. The current demographic “bulge” in Ireland is in the 20 to 30 years age group (UN, 1998), so it will be only in the 2040s that the bulge reaches the older age groups.

Fertility rates have been falling in Ireland (from 4.03 in 1965) and there has been a continuous downward trend. The total fertility rate in Ireland in 1998 was 1.94, compared to the European average of 1.45. However, although fertility rates for all ages have shown a long-term downward trend, the 1990s have seen increasing fertility rates in some age groups, particularly 30-34 and 35-39 years.

The current relatively young age profile of the population and the somewhat above average fertility rate suggests that a “caring crisis” as a result of demographic factors alone is unlikely for the foreseeable future. However, other trends are occurring that are likely to have implications for family caring.

The main factor is the high employment aspirations and increasing employment rates of Irish women. Employment rates in Ireland are at an all time high for both men and women. Employment rates for women have shown the greatest increases and now stand at close to 50 %. The highest rates of increase since 1998 have been amongst women in the 45 to 64 years age range. Of all women in employment, just under one in three (31.3 %) were working part-time (under 30 hours per week) in November 2003 (CSO, 2003).

As in most other countries, the bulk of care for dependants is provided by family members. Historically, there was a societal acceptance and expectation that this was appropriate. With rising employment levels and the necessity of dual income households this may be changing, although in the absence of representative survey data support for this hypothesis is only anecdotal.

Studies suggest that about half of family carers in Ireland are providing care for their parents or parents-in-law, about one quarter are providing care for their spouse and just under one in five are providing care for another relative (e.g. South Eastern Health Board, 2000).

No representative data could be found on the distribution of family carers in terms of whether they are caring for someone within the same household or another household. Reference: Summary, i.e. Caring in Another House. However, the indications are that carers are probably fairly equally distributed between the two situations.

There is also an ongoing debate on the responsibilities and obligations of adult children for their parents in relation to contributing to the costs of long-term care. A recent report to the government recommended that costs of care in the community should be universally provided for through social insurance whereas costs for residential might include some (equitable) element of contribution from the family.

In relation to reciprocity, there is evidence that grandparents are playing an increasingly important role in relation to provision of childcare. A significant factor associated with this is the inadequacy of the childcare infrastructure at a time when dual income households are becoming more and more the norm.

The main feature of public care service provision in Ireland is its residual nature. Care services are in short supply and are therefore rationed. One key criterion in this rationing concerns whether or not a family carer is (deemed to be) available. If they are, then services may be and often are withheld.

Another feature of the Irish situation is that the client of care services is nearly always the dependant, not the carer. This means that the needs of carers may receive a relatively low priority and that formal needs assessments of carers are not generally undertaken.

Apart from these aspects, there are some core problems with the provision of key health and social services in the community (such as home care and day centres). In general, services are in short supply and are not enough to meet needs either in a horizontal (reach all people with needs) or vertical (provide enough care for those who do get some level of service) manner. Entitlement to such services as are available is often unclear and there are many anomalies and inequities. Differential access for equal need may arise because of where one lives, whether one has a medical card (providing entitlement to public services for low income individuals / families and to all aged 70 years and older), the type of condition or disability that is involved and so on.

The main private care market is in the area of residential (nursing home) care. There is some public provision of nursing home care on a means-tested basis. Most care is in private nursing homes, with clients and / or their families paying all or a portion of the costs, depending on their means. There is tax relief available in relation to out-of-pocket costs for nursing home care and this is available either to the client or their family.

There is some private activity in the home care area but this still seems fairly limited. However, there is tax relief available for the employment of a carer and it may be expected to grow if employment rates amongst the traditional carers increase.

Representative organisations of both Family Carers and older people are quite well developed in some areas of Ireland and carer issues are strongly on the agenda.

As part of their national project "Caring for Carers" published a "Carers Charter" in 1991, in association with Professor Joyce O'Connor and Soroptimist International Republic of Ireland; it is still used as a reference point today[4]. This initiative led to the formation of Caring for Carers Ireland which represents Family Carers throughout the island of Ireland. The core objective is to promote the health, wellbeing and quality of life of Family Carers by promoting recognition, providing information, training, respite care and advocacy to promote social inclusion within the context of the "Carers Charter". Other key initiatives include the provision of Carers Clinics, development of Carers Groups Network (55), eHealth projects, Patient Discharge Summary, Security in the Home and research publications which feed into policy development at National and European levels.

Other advocacy groups include The Carers Association, representing "family carers in the home". A core aim of the Carers Association is to achieve a tangible form of recognition for the work of Family Carers. A key objective concerns the introduction of a proper cost of care payment to contribute to meeting additional costs of caring for a person at home (e.g. heating, medical care, care products, travel, dietary requirements). The Association has also articulated various other requirements in relation to improved services for carers and the removal of a variety of current anomalies in access to services and supports.

As regards older people, there is a statutory agency – National Council for Ageing and Older People (NCAOP) – with a brief to represent the interests of older people and advise the Government as regards policy and related matters. NCAOP has conducted research on caring and provides information for carers. There are also non-governmental organisations addressing the needs of older people, such as Age and Opportunity, the Irish Senior Citizens Parliament, the Alzheimers Association of Ireland.

There is some provision from other informal sources but the bulk of care is provided by family members (Ruddle and Mulvihill 1998). This research indicated that 12 $^1/_2$ % of all volunteers provide services for the sick and older people.

Recent data from the Census of 2002 indicates the following:

Total older persons (aged 65 or over) with a disability: 135,696 (31.1 %)

- One disability: 42,955 (31.7 %)
- More than one disability: 92,741 (68.3 %)

Specific disabilities:

- Blindness, deafness or a severe vision or hearing problem: 41,415 (9.5 %)

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[4] The full text of the Charter is provided in section 4.1

- A condition that substantially limits one or more basic physical activities: 90,985 (20.9 %)
- Difficulty in learning, remembering or concentrating: 41,528 (9.5 %)
- Difficulty in dressing, bathing or getting around inside the house: 52,985 (12.2 %)
- Difficulty in going outside the home alone: 73,556 (16.9 %)

This issue has recently come onto the agenda and a consultancy report was prepared for the Department of Social and Family Affairs (Mercer Ltd., 2002). The report concluded in favour of a universal social insurance-based fund to provide for the costs of care in the home and community, with a linking of public support to income and assets in the case of residential care. As regards the social insurance-based provisions for care in the home and community, a care benefit package approach was recommended, involving a choice between cash benefits (to be used to purchase care services privately) and public care services, or some mix of the two.

There are a number of key aspects of the Irish situation:

- There are no formal obligations on families to care nor has the state much formal responsibility in this area – this makes it very much a “grey area”, with potential for ambiguity, anomaly and inequity.
- There are signs of change – although women carers are in the majority more men are engaging in caring; also women carers have about the same employment rates as women in general.
- The health and social service approach is a residual one – home and community services are in short supply and are less likely to be provided if a carer is present.
- Carers are listed in the Irish Equality Legislation – the Employment Equality Act (1998) and the Equal Status Act (2000) with the current focus being on “primary carers”; this is being reviewed and an equality agenda for carers is being prepared by the Equality Authority with the help of an Advisory Committee of key stakeholders.

1 Profile of family carers of older people

1.1 Number of carers

A number of studies over the last fifteen years have provided estimates of the overall numbers of carers in Ireland as a whole (O’Connor and Ruddle, 1988; Blackwell et al., 1992; Ruddle and O’Connor, 1993; Callan and Wren, 1994; O’Shea, 2000) and in particular parts of the country (O’Neill and Evans, 1999; South Eastern Health Board, 2000). However, varying definitions of caring and different sample populations make it difficult to directly compare these studies or to use them as a definitive basis for establishing the prevalence of caring in Ireland. For the purposes of this report, the main sources providing relatively recent and somewhat comparable and representative data are the *Living in Ireland survey* in 1994, the Irish component of the *European Community Household Panel survey* in 1998, the *European Foundation survey of employment options and preferences* in 1998, and the *Census of 2002*.

Table 1: Estimates of the prevalence of caring in Ireland

Survey	**Estimated prevalence of carers (%)**
Living in Ireland Survey (1994)[1] - adult population	6
European Foundation survey (1998)[2] - adults (aged 16-64) attached to the labour market	6.3
European Community Household Panel survey (1998)[3] - adults aged 20-64	5
Census (2002)[4]	
adult population (aged 15 and over)	4.8
working age population (15-64)	5.0

Sources: [1]cited in DSCFA (1998); [2]own calculations; for reports on the survey see, for example, Bielenski et al. (2002); [3]own calculations from data provided in European Commission (2002); [4]CSO (2003) Principal socio-economic results

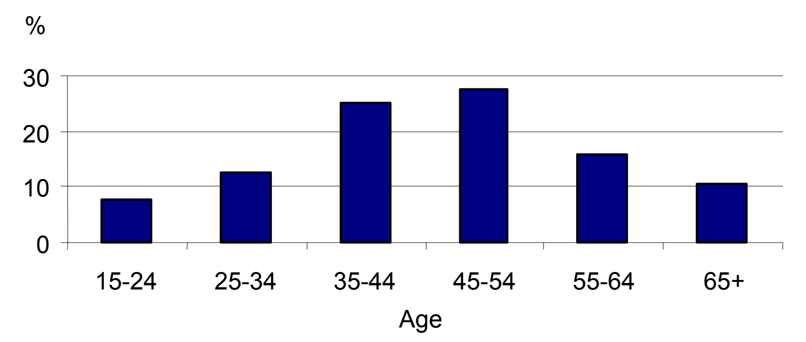
There is quite a degree of consistency in the finding of around 5-6 % of the adult population overall and a similar proportion of the adult population of working age reporting being involved in caring to some degree. This would represent between 154,000 and 185,000 adults overall and between 133,000 and 159,000 adults of working age (15 to 64 years).

The Census of 2002 has not quantified numbers of Carers providing care to a person not residing with them.

1.2 Age of carers

Figure 1 presents the age distribution of Irish carers according to the Census of 2002 (CSO, 2004). It can be seen that more than half of the carers were in the 35 to 54 years age range.

Figure 1: Age distribution of Irish carers



Source: CSO (2003) (2003)

Carers Clinic Evaluation shows that 43 % of Carers who attended the clinic were over the age of 60 years, of which 22 % were in the 70 to 80+ bracket. (B. Barron, M. McMahon Carers Clinic Evaluation 2001)

1.3 Gender of carers

Studies of carers in Ireland have found that women are more likely to be carers than men (Table 2).

Table 2: Table 1.2 Gender distribution of Irish carers

Source	Male %	Female %
Typical findings in various Irish and EU studies	25-30	70-75
Census 2002	38.6	61.4

While most earlier studies have found that women comprised approximately three quarters of carers of working age in Ireland, the recent Census found a reduced gender imbalance between men and women carers, although women were still in the majority. One reason for this may be a trend towards more male involvement in caring, perhaps reflecting some degree of role re-balancing with increasing female employment rates. However, it is possible that methodological differences between the Census and other survey-based approaches have also played a role in this finding.

1.4 Income of carers

Income support is provided to carers in low-income households (Carers Allowance) who are not in paid employment or work less than 10 hours per week in such employment. Social insurance-based income support (Carers Benefit) is also available for carers who take time out of work to care. Both payments are at relatively low levels in comparison to average earnings from employment. A statutory entitlement to leave from work for caring purposes (Carers Leave) is also available.

There are also provisions for carers within the tax system. For example, a Home Carers Tax Credit was introduced in order to give recognition to the work of carers in the home, although it is only of very limited financial value and its relevance is more symbolic than practical. There is also some tax relief for the cost of employing someone to provide care within the home. In addition, there are contributions towards the costs of care for parents of children with disabilities. Finally, financial supports are available towards the costs of care in nursing homes, either through means-tested subventions or through tax relief.

There is no representative direct data on the income distribution amongst carers in Ireland. There are two payments directly related to carer status – Carers Allowance and Carers Benefit. Carers Allowance is an income support payment paid to carers in low-income households who are not working or not doing more than 10 hours of paid work per week. There are more than 20,000 people in receipt of this allowance. Carers Benefit is a social insurance related payment that is made to carers who take time out from work for a period in order to care. So far, only about 1,000 carers have availed of this payment. Both payments are pitched at relatively low levels and are far lower than what a carer could expect from paid employment.

There is some data from the Census on socio-economic status and social class of carers. Overall, caring seems to be fairly evenly distributed across socio-economic groupings based on occupational level / type, with some tendency for higher socio-economic groupings to report a higher prevalence of caring. There is a significantly higher prevalence of caring reported amongst men and women in farming households and, to a lesser degree, in lower professional households. However, there is a strong inverse gradient in relation to likelihood of caring for longer hours per week – people in lower socio-economic grouping households and in farming households are significantly more likely to report longer hours of caring (43 or more hours of caring per week) than are those in the higher socio-economic groupings.

A similar pattern emerges in relation to social class, with a tendency for a somewhat higher prevalence of any form of caring to be reported as social class increases but a reverse pattern as regards longer hours of caring.

1.5 Hours of caring and caring tasks, caring for more than one person

One yardstick often used to indicate the extent of caring responsibilities is the number of hours spent caring per week. Some research has suggested that 20 or more hours of caring per week is the level at which negative impacts on employment begin to be seen, such as reductions in working hours and in employment rates overall (McLaughlin, 1993).

Although there is data from the Census of 2002 on hours spent caring per week, the grouping of hours of care in the published data does not allow the numbers caring more than 20 hours per week to be precisely distinguished. However, data from a pilot survey by the CSO in 1999 suggests that almost two in five (39.7 %) of Irish carers provide 20 or more hours of care per week, with more than one quarter (26.7 %) caring for 50 or more hours per week (Table 3).

Table 3: Hours spent caring by carers per week

Hours spent caring per week	%
1-19 hours per week	60.3
20-49 hours per week	13.0
50+ hours per week	26.7

Source: pilot census survey data 1999, cited by COMHAIRLE (2002)

The following are some studies that have examined the nature and amount of care provided by Irish carers under various circumstances.

Blackwell et al (1992) studied the levels of need for care amongst older people living with their carers in Ireland. They categorised the older people in terms of their degree of dependency (Table 4). Almost half of those in need of care were mostly physically independent but needed some help, for example with bathing. One in five needed help moving about indoors and / or outdoors, and a further one in eight needed help in one or more other areas. One in ten needed help with washing in addition to these other needs and one in twenty needed help in all areas.

The study also examined the number of hours that carers spent in caring of different types for the different dependency categories. Types of care were classified into three categories - physical (personal), physical (instrumental) and supervision. The main findings are summarised in Table 5 below.

Table 4: Level and type of dependency amongst older people living with their principal carer

	Category of dependency	(N=207) %
A	Mostly physically independent, may need help with bathing	45.5
B	As A, but need help with walking outdoors and / or walking indoors	19.7
C	Need help in all areas as B, but also may need help with one or more of dressing, getting in or out of bed, sitting or standing, using toilet	13.0
D	Need help in all areas as C, but also cannot wash without help	9.1
E	Cannot perform any physical activities of daily living without help	5.6
Non-scale	No clear cut pattern, but moderate to high levels of dependency	7.1

Source: Blackwell et al, 1992

Table 5: Average hours of care by level of dependency and type of care

Type of care	Level of dependency (N=207) %						
	A	B	C	D	E	Non-scale	All
Physical (personal)	1.4	6.4	11.0	16.6	29.1	7.2	7.0
Physical (instrumental)	17.1	11.2	12.9	17.7	26.2	18.4	16.0
Supervision	23.0	27.9	23.8	25.1	29.3	37.1	25.8
Total	41.5	45.5	47.7	58.3	84.5	63.8	58.7

Source: adapted from Blackwell et al, 1992

It can be seen that hours spent caring increase significantly as degree of dependency increases. However, average hours spent in supervisory care (resulting from needs such as confusion, restlessness, lack of co-operation and communication difficulties) remained more or less constant across categories, and were relatively high in all categories. It is also interesting to note that hours of help received by the principal carers in this sample were negligible, with an overall average of 2.4 hours per week.

O'Connor and Ruddle (1988) looked at the caring provided by carers living with the person cared for and by carers living in another household (Table 6). It can be seen that help with personal tasks was a lot more likely to be provided in situations where the carer and person cared for lived in the same household.

Table 6: Types of care received from carers

Type of care older people received	From carers living with them (N=325) %	From carers not living with them (N=604) %
Shopping	80.3	68.0
Doing laundry	75.8	48.5
Doing ironing	75.8	43.9
Making fire	74.6	42.3
Preparing meals	72.8	32.1
Bringing fuel	71.8	45.0
Transport	69.0	38.3
Coping with day-to-day living	67.2	38.0
Handling money / bills	56.6	25.5
Taking medication	45.5	7.2
Using telephone	41.0	15.3
Dressing	35.5	9.3
All over wash / bath	33.6	11.0
Getting about the house	31.9	9.1
Getting up and down stairs	30.4	10.7
Brushing hair / shaving	30.3	9.3
Getting to / using WC	24.4	6.3
Feeding self	17.7	6.4

Source: O'Connor et al., 1988

1.6 Level of education and / or Profession / Employment of family carer

Information on socio-economic grouping and social class was presented in section 1.4.

The Census of 2002 also provides information on educational attainment of carers. This shows no strong relationship between likelihood of caring and level of educational attainment, although people with only primary education did report a lower prevalence than other groups. However, there was a very strong trend for carers to increasingly report long hours of caring as educational attainment decreased.

1.7 Generation of carer, Relationship of carer to older person

No representative national Irish data was found on this aspect. However, data from a South Eastern Health Board Area survey (South Eastern Health Board, 2000) are broadly indicative of the findings from other studies and show that just over one half of all Irish carers care for a parent or parent-in-law and about one quarter care for a spouse, with smaller percentages caring for other relatives and even fewer caring for friends or neighbours. Caring for Carers Ireland meeting the needs of older people. The Carers Clinic Study Mid Western Health Board Area 2001 shows that 43 % of Carers were over the age of 60. 82 % Of dependants were boys aged over 10 years (See Who Will Care - v-vi Summary) among the Elderly Populations.

1.8 Residence patterns

Available data suggests that a little more than one half of Irish carers care for someone living in the carer’s household and a little under one half care for someone living elsewhere (Living in Ireland Survey 1994, cited in DSCFA 1998).

The importance of the contribution of carers who do not live in the same household as the dependant person has been recognised in the administrative provisions for carers. For example, carers caring for someone in another household are eligible for Carers Allowance or Carers Benefit if they are available full-time for caring and the households are connected by telephone and / or emergency alerting system.

The Census of 2002 provides data on the distribution of persons with disabilities and / or carers across households in Ireland. A total of 236,824 households with at least one person with a disability were identified in the Census, representing just under one in five households (18.5 %) overall. A total of 110,763 households with at least one carer were identified, representing just over one in twelve (8.7 %) of all households.

The majority of households with a carer had just one carer (76.8 %), followed by just under one in five (19.8 %) with two carers and just a small minority with three or more carers (3.4 %). This is in part a reflection of a spouse caring for their partner in two person households. It also confirms anecdotal impressions that in many households just one person takes primary or even sole responsibility for caring.

Looking at households containing at least one person with a disability, the majority (79.3 %) had no carer in the household. This in part reflects the fact that not all people with a disability require a carer. In addition, it indicates that many people with disabilities (e.g. older people living alone) are being cared for by family members living in another household.

A total of 56,304 people with a disability live alone in Ireland, representing just under one in twenty (4.4 %) of all private households. A further 34,408 households (2.6 %) comprise just a husband and wife where one or both members of the household have a disability; and 2,654 households (0.2 %) comprise just a cohabiting couple where one or both members of the household have a disability.

Table 7: Distribution of people aged 65 or more by household type, 2002

Household Type	%
Person aged 65 or more living alone	37.4
Couple, with one or both aged 65 or more	22.9
One person 65+ living with one or more people younger than 65	27.7
Two persons 65+ living with one or more people younger than 65	11.1
Three or more persons 65+ living with one or more people younger than 65	0.1

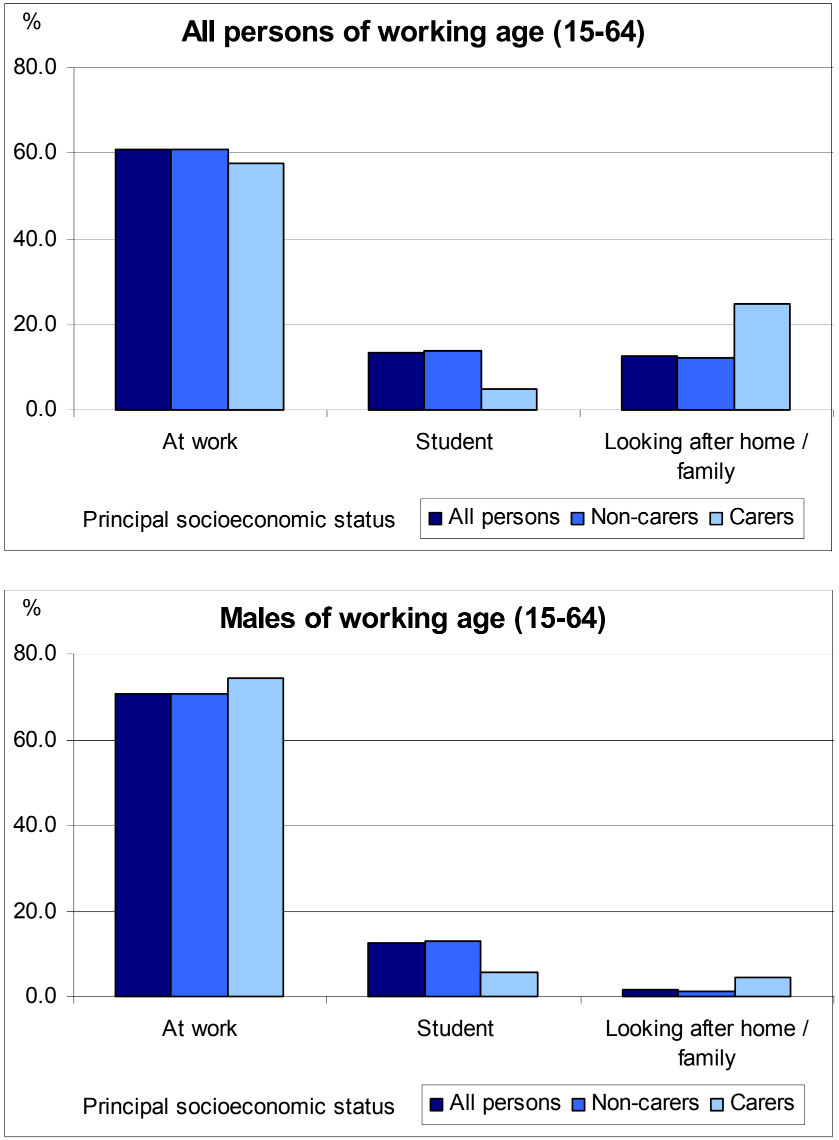
Source: CSO (2003)

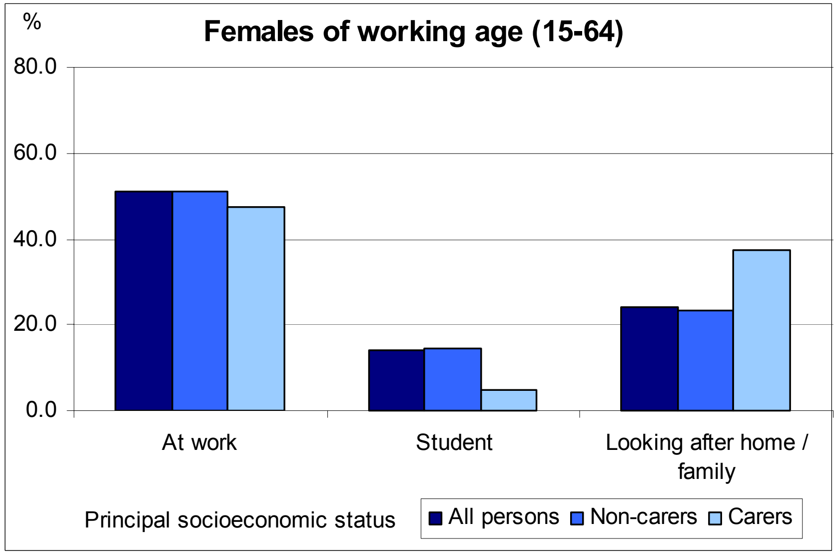
Finally, Table 7 presents data on the living situation of older people in Ireland. It can be seen that more than one third (37.4 %) of households with a person aged 65 years or older comprise an older person living alone, more than one in five (22.9 %) comprise a couple where at least one is aged 65 years or older, more than one in four (27.7 %) comprise an older person living with one or more younger people and the remainder comprise more than one older person living with at least one younger person.

1.9 Working and caring

In the 1980s and 1990s, a range of studies (O'Connor and Ruddle 1988; Blackwell et al 1992; Ruddle and O'Connor 1993; Callan and Wren 1994; Bielenski et al, 2002) found that although only a minority of carers had left the workforce specifically for caring reasons, a majority of women carers in Ireland were not in paid employment and a significant proportion did not appear to have strong employment aspirations, at least under their current circumstances.

Figure 2: Principal socioeconomic status of Irish carers





Source: Census, 2002

However, there have been significant changes in the labour market situation in Ireland in recent years, particularly in terms of increased female participation rates and in the incentives for both partners to work in married households. The recently released data on carers from the Irish census of 2002 suggests that the picture based on earlier surveys may be changing quite rapidly. In particular, the employment rate amongst female carers appears to have increased significantly to somewhere around the 50 per cent mark depending on the definition of employment that is used. For example, just under half (47.4 %) of female carers of working age reported being at work to be their principal socio-economic status (Figure 2). This is just a little lower than the employment rate for females who are not carers and for females overall.

Although the possible effects of methodological differences between the Census and other surveys cannot be discounted, the trend towards increased employment rates for carers is consistent with the especially high increases in employment rates amongst women in the 45 to 64 years age range between 1998 and 2002. For males, the employment rate for carers was actually a little higher than for non-carers and for males overall.

1.10 General employment rates by age

As indicated in Table 8, employment rates of carers in the different age groups are quite similar to those of the population overall, with rates for female carers just a little lower than those for females overall and rates for men carers a little higher than those for men overall. Although employment rates are lower amongst those aged 45 years and older there is little difference between the rates of carers and the population overall in this age group, either for men or for women.

As regards hours of work, however, carers are more likely to be in part-time employment. This greater likelihood of being in part-time employment is especially pronounced amongst women carers. This may reflect a greater tendency for women to organise their hours of work around family responsibilities, including caring.

Table 8: Employment rates by age and gender (2002)

Age and gender	All adults (aged 15-64)			Carers (aged 15-64)		
	All in employment %	Full-time employment (30 hours or more) %	Part-time employment (less than 30 hours) %	All in employment %	Full-time employment (30 hours or more) %	Part-time employment (less than 30 hours) %
All	60.8	79.0	21.0	57.7	71.9	28.1
15-24	38.5	–	–	38.3	–	–
25-44	75.3	–	–	66.7	–	–
45-64	57.5	–	–	53.4	–	–
Males	70.7	89.5	10.5	74.2	87.9	12.1
15-24	42.0	–	–	41.9	–	–
25-44	85.4	–	–	83.3	–	–
45-64	72.3	–	–	73.4	–	–
Females	50.9	65.2	34.8	47.4	57.8	42.2
15-24	34.9	–	–	35.2	–	–
25-44	65.3	–	–	56.3	–	–
45-64	42.5	–	–	41.7	–	–

Source: CSO, 2004

1.11 Positive and negative aspects of care-giving

Caring, either full-time or part-time, is recognised as having a number of impacts on carers in Ireland. These can include financial, social, emotional and health-related impacts.

Financial impacts of caring

There are two ways in which caring can have financial impacts for carers – through loss of employment income or income opportunity, including pension and through the additional costs that caring may impose.

Available evidence suggests that only a minority of carers who are in employment at the time that their caring responsibilities arise give up employment entirely. For example, only about 600 people were in receipt of Carers Benefit (the income support payment for carers taking time out from employment to care) in Ireland in 2003. Not all of those who do take time out to care are eligible for Carers Benefit (e.g. people with atypical employment situations and social insurance contributions) and those that are receive a payment that is a lot lower than what could be achieved in paid employment. On the other hand, carers may remain in employment but reduce their hours of work (and working women carers in Ireland are more likely to be in part-time work than are non-carers) or they may give up promotion opportunities (e.g. O'Connor and Ruddle, 1988; Ruddle and O'Connor, 1993; O'Shea, 2004).

In addition, many carers are not in the workforce (e.g. because of current or past childrearing responsibilities) when they take on caring responsibilities. In such cases, caring can impose opportunity costs because of postponed return to work.

Financial impacts in relation to costs of care are an important issue on the agenda of carer organisations in Ireland. Ruddle and O'Connor (1993), for example, found that 71 per cent of carers of older people with dementia reported that there were additional expenses involved, including heating, clothing, incontinence supplies and laundry costs among others. In addition, twenty per cent reported that they had to have adaptations to their homes to cater for the dementia sufferer. Caring for Carers Ireland in their study Carers Clinic Evaluation 2002 indicated that family carers experienced widespread poverty due to, limited means, high costs of caring, inability to access benefits and entitlements and that over 50 % of carers were themselves in old age. O'Shea (2004) found that some carers may need to buy more expensive convenience foods, take taxis shopping and so on since they no longer have time to do their own due to the restrictions of the caring role. Finally, Blackwell et al (2001) found that 38.5 per cent of carers experienced financial worries that resulting from providing home care.

Caring for Carers Ireland European Conference The Carers Charter: A European Challenge 2004 Working group report on Working and Caring, indicated that Carers called for caring to be defined as work (it was accepted that careful definition would be required, perhaps with a formal registration system). Carers should have the right to choose to do this work rather than having it taken for granted, and as workers should have all established workforce entitlements.

This work takes substantial health-care and financial burdens off the state; this work should be recognised in a just manner, by means of fair compensation through reasonable carers allowances, removal of means-testing, social welfare cover, access to retraining schemes and assistance in re-entry to the labour market (when care is no longer needed), etc.

Some carers may find themselves housebound much of the time, especially when the person is immobile or confused (O'Connor and Ruddle, 1988). Both O'Connor and Ruddle (1988) and Ruddle and O'Connor (1993) found that carers reported that caring had affected their social life to some degree, with carers feeling less able to leave the house, going out in the evening less frequently and finding themselves too tired to engage in social activity.

Social impacts of caring

Some carers may find themselves housebound much of the time, especially when the person is immobile or confused (O'Connor and Ruddle, 1988). Both O'Connor and Ruddle (1988) and Ruddle and O'Connor (1993) found that carers reported that caring had affected their social life to some degree, with carers feeling less able to leave the house, going out in the evening less frequently and finding themselves too tired to engage in social activity.

Emotional impacts of caring

In O'Connor and Ruddle's 1988 study, it was found that emotional strain was the most evident impact among carers. Sixty-six per cent of respondents found the changes in the older person upsetting and 30 per cent found problems such as incontinence or memory loss difficult to cope with. Over one third of carers reported having felt completely overwhelmed with worry over the person being cared for. In 1993, Ruddle and O'Connor (1993) found that 38 per cent of carers experienced 'a great deal' of stress in caring with a further nineteen per cent describing themselves as experiencing 'quite a lot' of stress.

The study conducted by the South-Eastern Health Board (2000) found that whereas 89.3 per cent of carers expressed their emotional health as very good (40.7 %) or good (48.6 %) before becoming a carer, these figures fell to 19.2 per cent and 40.7 per cent respectively following engagement in the care giving role.

Health-related impacts

O'Connor and Ruddle (1988) found that 24 per cent of carers in their study were in poor health themselves. Almost one third of carers (30 %) believed that their health had suffered due to the demands of caring. Half of this group rated themselves as having fair or poor health. In addition, among this group of carers 68 per cent suffered from some chronic health problems. Ruddle and O'Connor (1993) found a slightly more optimistic picture, with eleven per cent of respondents rating themselves as having poor or very poor health. However, to complicate the picture, 38 per cent of the carers said they experienced health problems. Almost three-quarters of the carers had been to their GP in the year prior to interview. Twenty-five per cent of these had had an illness requiring prescribed medication and ten per cent had been so ill as to require hospitalisation.

The South-Eastern Health Board study (2000) found a more serious situation, with a significant proportion of carers reporting deterioration in their physical health since becoming a carer. Although no objective measure of health status was applied, 83.2 per cent described their physical health as very good (45.3 %) or good (37.9 %) prior to becoming a carer but only 56.8 per cent reported the same positive expressions of physical health since becoming a carer. Results from research conducted in the Western Health Board Area (O-Neill & Evans 1999).

Results indicated that carers represent a substantial proportion of the Board's population and make a huge contribution to the care of the physically and mentally ill and disabled. The majority of the people receiving care were elderly. Many carers devoted all their time to their caring role and were on-call 24 hours a day to help the person they look after. The carers were generally found to provide high quality long-term care. They experienced a range of negative physical, psychological, social and financial effects and received little practical, emotional and financial support. Financial support was the most important issue for the carers, followed by support groups and the provision of respite services.

The people receiving informal care were extremely satisfied with the quality of care they received. However, many of them worried about the carer's health and the cost of care. Members of the public who were not carers were found to have a positive attitude to informal care and believed that the home is the best place for an ill or disabled person. Most non-carers would choose informal care for themselves or a family member and many would be willing to provide care themselves.

1.12 Profile of migrant care and domestic workers (legal and illegal)

There is no data available on the provision of care by migrant workers. However, Ireland has experienced relatively high levels of migrant workers over the past decade and there is anecdotal evidence of some migrant women working in the domestic and care sectors.

1.13 Other relevant data or information

- The ageing profile of Carers of older people (Carers Clinic Evaluation Report)
- The increasing number of people with high dependency needs being cared for in the community (Carers Clinic Evaluation Report)
- Families wish to continue to care: *Contemporary Family Policy - Daly. M and Clavero. S., (2002)*

2 Care policies for family carers and the older person needing care

2.1 Introduction: Family ethics and expectations

2.1.1 Expectations and ideology about family care

Historically, Ireland had a strong ethos of intergenerational family support and reciprocity (Arensberg and Kimball, 1968). This is reflected in the fact that family carers provide the bulk of care for older and disabled people in Ireland, partly as a result of normative cultural expectations and partly a result of necessity due to the lack of any clear state responsibility in the area. However, family expectations may be changing (Delaney et al 2002) due to a number of factors, including increasing numbers of women entering the workplace, dispersal of extended families over increasingly wide geographical spaces and less focus on women as obligatory caregivers. There is increasing pressure on the state to provide basic care for dependent adults.

The Census of 2002 provides information on the prevalence of caring amongst some minorities, including indigenous Irish “Travellers” and immigrants from other countries. The following are the numbers of carers from various minority communities:

- Travelling community that lives in temporary housing: 510
- Non-Irish people: 6,198
    - UK: 3,533
    - Rest of EU: 585
    - Rest of Europe: 475
    - Africa: 349
    - Asia: 661
    - America: 402
    - Other nationalities: 193
    - Nationality not stated / no nationality: 892

No information is available on cultural differences in relation to caring.

2.1.2 Legal or public institutional definitions of dependency

There is no overall legal or public institutional definition of dependency in Ireland. Definitions differ according to care group and / or administrative context. Dependency is assessed differently in different areas, using different scales and different weightings for the social circumstances of the dependent person. The introduction of standardised, consistent and appropriate needs assessment is an important issue on the agenda at present.

Dependency is typically assessed by reference to need for help with activities of daily living, available social support, medical condition, housing conditions, number of people in the household, ability of the household members (if any) to provide care, extent of support from the community and the services already being received. Three main categories of dependency are often distinguished - high, moderate and low dependency.

An operational definition of dependency can also be extrapolated from the eligibility requirements for Carer's Benefit set by the Department of Social and Family Affairs, where the person being cared for "*must be aged 16 years or over and be so incapacitated as to require full-time care and attention or aged under 16 and in receipt of a Domiciliary Care Allowance, and must not be resident in an institution; for those not in receipt of the Domiciliary Care Allowance the degree of medical incapacity and the expected duration of incapacity must be certified by a medical doctor*." Full time care is here defined as where the person being cared for is "*so disabled or invalided as to require continuous supervision in order to avoid danger to him or herself, or continual supervision and frequent assistance throughout the day in connection with normal bodily functions, and he or she is so disabled or invalided as to be likely to require full-time care and attention for a period of at least twelve months*".

Legal entitlements to benefits for caring

There are two main types of financial support for carers – income support provisions and support for the costs of care.

- **Income support provisions**

There are two main types of income support provisions – Carer's Benefit and Carer's Allowance. To be eligible for these payments carers must be caring for someone who needs full-time care and must not engage in more than ten hours of employment or training per week.

Carer's Benefit

Carer's Benefit is a social insurance payment payable for up to 65 weeks for each care recipient (it may be claimed more than once, if care needs to be provided to a second person at a different time) to people who give up work to care for an incapacitated person. The maximum weekly rate is €139.70 if caring for one person and €209.60 if caring for more than one person.

Carer's Allowance

The Carer's Allowance is a means-tested payment to carers that is not related to labour market history prior to claiming. There is no maximum duration for receipt of the allowance. The current maximum weekly rate is €129.50 for carers under the age of 66 and €147.80 for those aged 66 and older where care is provided for one person up to a maximum of €194.40 and €221.70, respectively, where care is provided for more than one person.

Tax credits for carers and / or their spouses

The Home Carer's Credit was introduced as an additional compensation for stay-at-home spouses who were caring for children or for other dependants when individualisation of the standard tax band was begun. However, this tax credit is so low as to be essentially a symbolic gesture. Also, it is only available to married couples and not to cohabiting arrangements. There is also the fact that most of the tax measures in this area are more relevant to the carer's spouse than to the carer as it is the former that actually receives the direct financial benefit.

- **Support for the costs of care**

This section focuses on direct financial supports to help meet the costs of privately purchased care.

Tax-based supports

There are two main tax-based provisions – the employment of a carer allowance and the tax relief allowable on health / medical expenses incurred on behalf of a dependant. Both are potentially substantial supports for the cost of care for a dependent, in one case for the purchase of paid care in the home and in the other for the purchase of private residential care.

Nursing home subventions

Nursing home subventions are paid by the health boards to help clients meet the costs of private nursing home care. They are contingent on an assessment of the level of dependency and the means of the applicant and his / her spouse.

Domiciliary Care Allowance

The Domiciliary Care Allowance is a monthly means-tested payment payable by the health boards to carers of a severely disabled child aged under 16 that is living at home. The current rate is €179.80 per month.

2.1.3 Legal responsibility for providing, financing and managing care

With the exception of obligations on parents in relation to their children, there are no formal legal responsibilities on families to provide care for dependants in Ireland. In addition there is no clear state responsibility to provide care for dependants.

2.1.4 Relevant case law on the rights and obligations of family carers

During the early 1990s Irish Health Boards regularly included the means of adult children in assessing eligibility of older people for financial support for the costs of nursing home care. This has since been judged to be contrary to the relevant statutory regulations.

Another relevant judgement was that of the Supreme Court which ruled that the State did not have an indefinite (e.g. lifetime) obligation to provide educational services for those in need. This was in the context of the current conflation of educational and care services for children with severe physical and / or intellectual disabilities in Ireland. Such children generally are eligible for education / care until they are 18 years old and but must often then rely on the family for most or all of their care. This is often a source of great stress for families.

2.1.5 National legal definition of old age

The legal definition of old age in Ireland is 65 years and over. However, automatic entitlement to a medical card is only given to those who have reached the age of 70.

2.2 National policies (general principles, orientation, action plans)

2.2.1 Family carers

Constitutional recognition / rights

A recent Constitutional Review Group was of the view that constitutional recognition should be given to the contribution of carers (and of parents) in the home and recommended a specific wording for this. The practical implications of such a constitutional change are not very clear, however, and there is a need for further reflection on the relative merits of a constitutional provision and how it might help to advance equality of opportunity for carers, as well as the form that such a provision might take.

Equality legislation and policy

Carers are one of the groups included (under the Family Status ground) within the scope of the two main pieces of equality legislation in Ireland – the Employment Equality Act (1998) and the Equal Status Act (2000). The statutory equality agency – the Equality Authority – is currently working on an equality agenda for carers and has convened an Advisory Committee of relevant stakeholders to report on the matter.

Health and social services to support carers

Various health and social service strategy and vision documents over the last number of years have all given attention to issues relevant for carers, including more support for community services to help dependant people remain in their own homes. Support for carers is also typically alluded to, although as yet no concerted action plan has been developed or implemented that addresses the needs of carers.

There is a lack of a statutory basis for many of the services outlined in Chapters 3 and 4 that have central relevance for carers, and also an absence of clear links between eligibility and entitlement to these services. This leaves considerable scope for anomaly and inequity in access to services. The fact that the service delivery model is a residual one, with the "availability" of a carer or carers taken into consideration in rationing scarce services, coupled with the fact that carers are seldom direct clients of the health and social services, adds to the potential for anomaly and inequity.

It is interesting to note also that the Review Group on the Carer's Allowance (DSCFA, 1998) concluded that the provision of reduced services, particularly in the respite care area, to those who have informal carers is akin to an 'inverse care law' that should not be practised if the objective of supporting carers is to be met.

Taxation

Although there are a variety of tax-based provisions for carers, there appears to be no coherent overall rationale underlying these (Comhairle, 2002).

The introduction of the Home Carer's Tax Credit in 2000 was a tax-based recognition of the role of carer. However, the recognition is more symbolic than practical as the level of financial benefit is very small. More important from a practical point of view are the potentially very significant tax reliefs that are now provided in respect of costs of care, whether nursing home costs or costs of employing a carer in the home.

Labour market policy and regulation

Labour market policy in Ireland has undergone profound change in the last 10-15 years. It has moved from policies aiming in effect to reduce participation rates of some groups (to reduce registered unemployment levels) to shared policies with our European partners that aim to significantly increase both participation and employment rates for men and women.

The old model discouraged or at least did not encourage labour force participation by women with children or otherwise engaged in "home duties", and those at the older end of the working age range. The new model encourages high participation rates for all, including these groups. Incentives have been provided through a certain amount of individualisation of the tax system since the 1999 budget and through the provision of financial incentives to encourage private provision of childcare services.

Since the dramatic turn around in the Irish economy and labour market, there has been a growing recognition of "carers" as an under-utilised potential labour supply. This has been reflected both in policy documents and in explicit targeting of carers in "return to work" and related initiatives, as well as in a recognition of carers within the work-life balance arena.

One issue not currently on the agenda in any practical manner, however, is the need for co-ordination of labour market and health and social service policy. At present, these policies can be said to be pulling in opposite directions, with health and social service policy predicated on the continuing availability of family carers and labour market (and taxation) policy encouraging potential or actual carers into the workforce.

Issues for carers are now increasingly on the agenda in the work-life balance context, although lagging behind the attention being given to working parents.

Social insurance / social welfare provisions

As already discussed earlier, income support is provided to carers in low-income households (Carers Allowance) who are not in paid employment or work less than 10 hours per week in such employment. Social insurance-based income support (Carers Benefit) is also available for carers who take time out of work to care. Both payments are at relatively low levels in comparison to average earnings from employment. Carer groups and others have also pointed to various anomalies and inequities in relation to who receives such payments. A statutory entitlement to leave from work for caring purposes (Carers Leave) is also available.

2.2.2 Disabled and / or dependent older people in need of care / support

Policy specific to the needs of older people began with the publication of *The Years Ahead – A Policy for the Elderly* in 1988 (Department of Health, 1988). This was the first major national policy to focus on the need to develop services for older people. The National Council on Ageing and Older People's *A Review of the Implementation of The Years Ahead Repo*rt (1997) recommended that the Department of Health should develop a new health strategy for health and social care services for older people which would include a clear philosophical framework to inform service delivery.

In response to these developments in health and social care for older people, many health boards have developed new strategies aimed specifically at improving service provision for older people (Midland Health Board, 1997; Southern Health Board, 1999; South-Eastern Health Board, 1996; Western Health Board, 2001; Mid-Western Health Board, 1999; North-Eastern Health Board, 2001; Eastern Health Board, 1995; Eastern Health Board, 1998; North Western Health Board 1999).

The health boards have recognised that there is an urgent need to co-ordinate and integrate services, to make them more accessible and equitable, and to have a person-centred focus. In terms of care for older people, with the aim of maintaining them with dignity in their homes, these needs become even more important. The introduction by health boards of Care Groups or Service Planning Groups with a multi-disciplinary focus was an attempt to increase co-operation and integration in planning and strategising.

2.2.3 Supports for working carers

The prevalence of caring amongst the Irish workforce is a little under five per cent (CSO, 2004) and this is about half of the estimated prevalence within the EU workforce overall. One part of the explanation for this may derive from the younger age structure of the Irish population (and hence a lower need for care) and of the workforce (and hence a lower likelihood of being a carer).

The percentage of the female workforce that are carers (5.7 %) is about 43 percent higher than that of the male workforce (4.0 %). However, because there are more men in the workforce than women, the absolute numbers of male and female working carers are very similar.

The prevalence of caring amongst the workforce increases with age, with the highest percentage (7.2 %) in the 45 to 64 years age range, representing about one in fourteen of the workforce overall and almost one in ten of the female workforce in the age range.

Carer-friendly work arrangements

The Employment Equality Act (1998) outlaws discrimination in relation to employment on any of the nine grounds covered under the legislation. „Primary" carers are included under the „family status" ground. As of yet, there seems to have been little actual attention to carers issues in the practical application of the legislation, although the Equality Authority are now giving attention to developing the equality agenda in this area.

More generally, carers are being given some attention within the work-life balance arena, with carers being identified as a group under the social partnership procedures (involving employers, trades unions and government). So far, however, the needs of carers do not seem to have been given as much attention as those of parents and there has been no direct research on the availability or take-up of carer-friendly working arrangements in Ireland.

Carer's Leave

The Carer's Leave Act (2001) provided a new entitlement for an employee to avail of up to 65 weeks unpaid leave from his / her employment to enable him / her to personally provide full-time care and attention for a person who is in need of such care.

The Act applies both to direct employees and to those employed through an employment agency. The period of leave entitlement is subject to a maximum of 65 weeks in respect of any one person cared for and the minimum statutory entitlement is 13 weeks. Leave may be taken in one continuous period or more than one period, with the minimum statutory entitlement being 13 weeks for any given episode.

Social insurance credits

Carers in receipt of Carer's Allowance or Carer's Benefit may be able to get credits for the period spent caring. These are awarded after ceasing to receive the allowance / benefit. To qualify, the carer must have a paid contribution in the two years before they started receive the payment. Carers on Carer's Benefit are generally likely to qualify but many other carers may not.

Return to work

Carers who are seeking to return to work have been identified as a group that need particular support. They are generally treated in the same manner as other groups by employment and employment related services, for example in back-to-work or back-to-education allowances. However, as many carers are not on the Live Register because of the requirement to be available, at least in principle, for full-time work, they may be at a disadvantage in relation to access to training or other services that give priority to those on the Live Register.

2.3 Local or regional policies, regulations and service provision

Most overarching policies and regulations in Ireland apply at the national level and there are few regional or local differences in this regard. However, the regional health boards have significant autonomy and discretion as regards the services that they provide and how they allocate their budgets. This has resulted in considerable variation across and within health boards as regards the range of services that are available and the conditions under which they are provided.

3 Services for family carers

Services for family carers	Availability			Statutory	Public, Non statutory	Voluntary		Private
	Not	Partially	Totally			Public funding	No public funding	
Needs assessment (formal – standardised assessment of the caring situation)		X[2]			X	X		
Counselling and Advice (e.g. in filling in forms for help		X[3]			X[4]	X[5]	X	
Self-help support groups		X				X	X	
"Granny-sitting"		X				X	X	
Practical training in caring, protecting their own physical and mental health, relaxation etc.		X[6]				X		
Weekend breaks		X				X		
Respite care services		X				X[7]	X	
Monetary transfers		X		X[8]		X		

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[2] Formal assessment concentrates on the needs of the dependent person, not the carer, and there are no formal provisions for carer needs, per se. More generally, uniform assessment standards are not defined or applied, rationing criteria are not transparent or consistently applied and much discretion is left to the health boards and to individual professionals. Caring for Carers Ireland conduct needs assessment of Family Carers through the Carers Clinics.

[3] Counselling is not provided universally to all carers or dependants. A relatively ad hoc approach to information and counselling provision is split between statutory and voluntary providers. More carer-focused approaches are mostly offered by voluntary organisations established to support carers.

[4] The main contributions of public bodies relate to information provision. Various agencies such as COMHAIRLE and the National Council on Ageing and Older People identify carers as client groups and target them in their information services.

[5] Voluntary organisations such as Caring for Carers Ireland and The Carers Association provide a lot of support. Some receive some public funding but also must raise a lot of funds themselves. They provide information on entitlements, legal and financial advice, liaison with statutory organisations, counselling and emotional support etc.

[6] Caring for Carers Ireland has developed a network of Carers Groups, Carers Clinics, Training Programmes for Family Carers, Respite Care and Information, National Respite Weekend and Conferences, Health Promotion and eHealth programme. The Carers Association provides home respite services, training, information, support and counselling, advocacy, information packs and lobby the government. It operates from carers' resource centres nationally.

[7] Respite Care is provided by Health Boards. Voluntary organisations provide the bulk of Respite care. Some voluntary organisations administer a Limited Respite Care Fund.

[8] The only "cost of care" type monetary transfer is Domiciliary Care Allowance paid to parents of children with disabilities. This is discussed further in Chapter 3. There is also an annual grant to carers towards the costs of purchasing respite care. Home subvention is now being paid to Family Carers by Health Boards.

Services for family carers	Availability			Statutory	Public, Non statutory	Voluntary		Private
	Not	Partially	Totally			Public funding	No public funding	
Management of crises		X[9]			X	X		
Integrated planning of care for elderly and families (in hospital or at home)	There have been some developments but no real, comprehensive integrated approach yet[10]				X	X		
Special services for family carers of different ethnic groups	X[11]							
Other								

3.1 Examples of good practice

3.1.1 The Carers' Charter

The Carers' Charter was compiled by Professor Joyce O'Connor, Director National College of Industrial Relations, in association with Soroptimist International, Republic of Ireland National Project "Caring for the Carers" and with the help and support of carers and groups working with carers. It is often used as a reference point today. The work of Caring for Carers Ireland has been governed by the principles of the Carers' Charter.

The Carers' Charter is as follows:

1. Carers have the right to be recognised for the central role which they play in community care and in creating a community of caring
2. Carers have the right to acknowledgement and address their own needs for personal fulfilment
3. Carers have the right to acknowledge and address their own needs for personal fulfilment

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[9] Crisis management is almost always routed via some General Practitioners into the tertiary health services. Often this is done via referral to accident and emergency services. This applies to social as well as health-related crises.

[10] Following the recent publication of a national report recommending the introduction of care and case management (Delaney et al, 2002), care and case management pilot projects were instigated both in the statutory health sector and in the voluntary sector. However, these projects have, to-date, not been mainstreamed.

[11] As Ireland has only recently become a recipient of significant numbers of people from different ethnic groups, limited provision has been made for ethnic minority carers, ie Caring for Carers Training Programme.

4. Carers have the right to practical help in carrying out the tasks of care-giving, including domestic help, home adaptations, appliances, incontinence services and help with transport
5. Carers have the right to support services, e.g. public health nurses, day centres and home helps in providing medical, personal and domestic care
6. Carers have the right to respite care both for short spells as in day hospitals and for longer periods to enable them to have time for themselves
7. Carers have the right to emotional and moral support
8. Carers have the right to financial support and recompense which does not preclude carers taking employment or in sharing care with other people
9. Carers have the right to regular assessment and review of their needs and those of people for whom they care
10. Carers have the right to easy access to information and advice
11. Carers have the right to expect involvement of all family members
12. Carers have the right to have counselling made available to them at different stages of the caring process including bereavement counselling
13. Carers have the right to skill's training and development of their potential
14. Carers have the right to expect their families, public authorities and community members to provide a plan for services and support for carers, taking into account the unique demographic developments up to and beyond the year 2000
15. Carers have the right to involvement at all levels of policy planning, to participate and contribute to the planning of an integrated and co-ordinated service for carers
16. Carers have the right to an infrastructure of care, a supportive network to which they can relate when the need arises

Carers Clinic

Caring for Carers in partnership with the Mid Western Health Board established a Carers Clinic to meet the needs of Family Carers of Older People who are themselves Carers, to address isolation and to promote social inclusion. Following a **Needs Assessment** the Clinic develops **integrated packages** of care for Family Carers.

Respite Care Programme

Family Carers who would otherwise not have a break from their 24 hour day caring roll have benefited from the Caring for Carers Ireland Programme which includes an annual National Respite Break and Conference. This provides a forum and platform for Family Carers. To date 8,000 have been facilitated with in-home respite and week-end breaks.

Patient Discharge Summary

Through partnership with Hospital and Community Service Providers Caring for Carers have compiled a Patient Discharge Summary to provide information to patients and their Carers to promote the safe transfer of Care from Hospital to home.

eHealth Project

One of the biggest challenges facing older people and those they care for is a sense of isolation and social exclusion. To help overcome this Caring for Carers in partnership with Comhairle, Mid Western Health Board, Ennis Citizens Information Centre and Ennis Information Age Town established a Programme using Information Technology to improve access to information, advise and advocacy on a broad range of health and social services for a target group of over 1,500. The Carer's Centre acts as a hub linking together 5 Day Centres through use of web cam. Carers now can access a wise range of services without having to leave their local area. On-going training ensures Carers take advantage of new technology. Caring for Carers were finalists in the eHealth Europe Awards 2004.

Personal Security Systems

Security devices are provided by Caring for Carers to vulnerable older people in the community to promote safety and security in the home.

3.1.2 Carers Benefit and Carers Leave

Although there are many problems with the Irish approach to supporting carers and those that they care for, there has been increasing recognition of the need to support carers to take time out from working to care for a dependant person. A right to do this was introduced with the Carers Leave legislation and a certain level of social insurance based income support is provided through Carers Benefit.

3.1.3 Equality legislation

Ireland may be unique in the referencing of carers in its equality legislation – the Employment Equality Act (1998) and Equal Status Act (2000). The equality agenda for carers is currently being elaborated by the statutory equality agency – the Equality Authority.

3.1.4 Services provided by carer organisations

- **Caring for Carers Ireland:**

A national non-governmental organisation with a growing network of 55 Carers Groups North and South. Caring for Carers aims to promote the health, well-being and quality of life of Family Carers and those for whom they care. They also promote recognition, providing information, training, respite care and advocacy to promote social inclusion within the context of the carers' charter.

Services Provided: Caring for Carers Ireland has developed a network of Carers Groups, Carers Clinics, Training Programmes for Family Carers, Respite Care and Information, National Respite Weekend and Conferences, Health Promotion and eHealth Programme. The Carers Association provides home respite services, training, information, support and counselling, advocacy, information packs and lobby the government. It operates from carers' resource centres nationally. Establishment of Carers Groups; Carers Clinic; Training Programmes for Family Carers; Respite Care and Information; National Respite Weekend and Conference and Information days; eHealth Programme.

Publications: Carers Clinic Evaluation, 2003; The Balance of Care - A Study of Carers Needs, 1997; Information and Contacts for Family Carers, 1993; Carers Charter in Action, 1992; Carers Charter, 1991.

Affiliated to: Irish Health promoting Hospitals Network, Irish Red Cross Society; Age European Platform for Older People; Soroptimist International; Active contributors to a number of European Projects and networks.

Geographical Area Serviced: Nationwide and the North.

Branches: 55 Groups nationwide.

- **The Carers Association:**

The Carers Association is a national voluntary organisation representing family carers in the home who provide fulltime care for a family member who may have a disability. It provides home respite services, training, information, support and counselling, advocacy, information packs and lobby the government. It operates from 16 carers' resource centres nationally and employs over 180 people.

Services Provided: Home respite; training; information; advice; support; counselling; support groups; carers resource centres and outreach centres.

Publications: Annual Report, Take Care Magazine.

Affiliated to: Disability Federation of Ireland.

Geographical Area Serviced: Nationwide.

Branches: 16 resource centres nationally.

- **The Alzheimer Society of Ireland:**

It is the mission of the society to work for and on behalf of people with dementia and their carers and ensure they have the necessary supports and services to enable them to maximise quality of life, respecting the needs, rights and dignity of the individual.

Services Provided: Practical information and emotional support through our help lines; provision of literature; day care and respite; home support and support groups.

Publications: Annual Report; quarterly newsletters; information leaflets and information for carers.

Affiliated to: Disability Federation of Ireland; Alzheimer Europe; Alzheimer's Disease International; Neurological Alliance of Ireland; Age Action; The Alliance for Mental Health.

Geographical Area Serviced: Nationwide.

- **Carers Support Programme - CROSSCARE:**

The aim of the programme is to improve the quality of life of family carers who are often vulnerable and under considerable stress The aim is achieved by offering support in the form of information, knowledge, practical skills, counselling, personal development and group support to the carer. CROSSCARE believes that if the carer is appropriately supported, not only will the well being of the carer improve but it may also enable the carer to remain in the family home and in the local community, thereby avoiding the prospect of long term institutional care. Support group meetings are held monthly.

Services Provided: Information, advice, support: one-to-one, phone support, group support, respite breaks for carers, bereavement support for carers.

Publications: Internal newsletter, Annual Report.

Geographical Area Serviced: Community Care Areas 6,7,8 (National Area Health Board), Dublin Area.

- **Caring and Sharing Association:**

Caring and Sharing Association is a voluntary group which develops friendships through a variety of activities such as Lourdes Pilgrimages, respite breaks and local social groups.

Services Provided: Respite breaks and social services; pilgrimages to Lourdes with full palliative care (medical, spiritual and companionship); training and support for carers.

Publications: Annual Report.

Affiliated to: Disability Federation of Ireland.

Geographical Area Serviced: Greater Dublin, Cork City and County Longford.

4 Supporting family carers through health and social services for older people

4.1 Health and Social Care Services

The Department of Health and Children has overall responsibility for the development of health policy and planning of services in Ireland.

The Health Boards were set up under the Health Act, 1970 (Department of Health 1970) and came into being in April 1971. They have a statutory responsibility for administering the health and personal social services provided for in health legislation and by ministerial initiatives. There are seven Health Boards and an additional three Area Health Boards set up under the Eastern Regional Health Authority (covering the Greater Dublin Area and hinterland). Each one is regionally based and varies in size depending on the population it serves. The Health Act of 1970 specifies in broad terms the constitution of each Health Board and how it is to be managed. Each Board has twenty-one members, twelve of whom are elected representatives from County Councils and Borough Councils, six professional representatives and three ministerial appointees. Each Health Board is quite unique and may vary in structure and in how it defines its services.

In November 2001, the Department of Health and Children launched *The Health Strategy – Quality and Fairness – A Health System For You*. This contained proposals for significant reform of the health service towards a more integrated and person-centred approach. Key points for the care of older people include:

- 7,000 day centre places to be provided. Recruitment of staff to improve community care.
- 600 additional day hospital beds with specialist treatment. Development of geriatric services – appointment of additional geriatricians.
- 800 additional extended care / community nursing per annum over the next 7 years including provision for people with dementia. Improved staffing levels in extended care units.
- National treatment protocols will be put in place to make sure that all patients receive a uniformly high quality of care.
- National standards for community and long-term residential care of older people to be prepared.
- Remit of the Social Services Inspectorate to be extended to include residential care for older people.

However, full implementation of this strategy has yet to take place.

4.1.1 Health services

4.1.1.1 Primary health care

Primary care is an approach to care that includes a range of services designed to keep people well, from promotion of health and screening of disease to assessment, diagnosis, treatment and rehabilitation as well as personal social services. The services provide first level contact that is accessible by self-referral and have a strong emphasis on working with communities and individuals to improve their health and social well being.

Primary care includes the range of services that are currently provided by general practitioners (GPs)[16], public health nurses (PHNs), general nurses, social workers, practice nurses, midwives, community mental health nurses, dieticians, dentists, community welfare officers, physiotherapists, occupational therapists, chiropodists, community pharmacists, psychologists and others. The current primary care system is delivered by a combination of these disciplines, very often working in isolation, either as private practitioners or as direct employees of the public health system. GPs are independent contractors while most other services are provided by employees of health boards and voluntary organisations.

Community and home care teams (doctor, nurse, health visitor, physiotherapist etc)

Although the health boards are obliged to provide some services, for the most part they have discretion in whether or not to make a particular service available. Because most community health and social services are not underpinned by any statutory requirements on the health boards to deliver them, there is no absolute entitlement, as such, for most services even though a person may be legally eligible (Consultative Forum Sub Group on Eligibility, 2001).

Rules of entitlement to community health and social services are often quite vague and are generally not as clear-cut as entitlement to hospital services. In general, medical cardholders are entitled to available community care services free of charge although health boards may, at their discretion, impose some charge. They may also make services available to people without medical cards, with the discretion to charge in part or in full for the services provided. However, in either case it is not always possible to actually obtain a given service, as there is wide variation in the level of services available in different parts of the country.

There is little official information available on the extent of availability of services across the various health boards or across community care or other geographical units within the health boards. Services are generally under-funded and over-stretched and there is not much official information available either on the real levels of potential demand (the numbers in need of or who could benefit from each service and / or who would be likely to avail of the service if it were available and accessible) or on the extent to which demand is being met across different client groups.

Where the carer is taken into account it is often only to reduce or withdraw the service if the carer is present. There is little provision of direct services for carers and the needs of carers are not typically taken into account in the provision of services for those for whom they care.

Use of Community Health and Social Services

A recent study of health and social services for older people – the HeSSOP study - investigated the utilisation of a range of services (Garavan et al, 2001).

- General Practitioner Services

The general practitioner is a pivotal health professional contact for older people and their carers. 93 % of older people in the HeSSOP study had consulted their GP in the previous 12 months (an average of 5.3 visits). There was evidence of regular contact with the GP and preventative care in the high number of older people who had had a general health check (almost 75 per cent in the past three months) and their blood pressure checked (98 % in the past year).

- Nursing Services

The Public Health Nurse (PHN) was the main home-based service used by older people in the community, 15 % having been visited by the PHN in the year before the study. Fourteen per cent of people visited would have liked to have used the service more and three per cent of those not visited said they would have liked to have received the service.

- Therapy Services

Three per cent of older people had received community-based physiotherapy in the past year with less than one per cent receiving occupational therapy or speech therapy. In each case, there were more older people who wanted to use the services but had not done so in comparison to the numbers of older people who had actually used them.

Availability and Access to Community Health and Social Services

- General Practitioner Services

General Practitioner Services are accessible to all those over the age of 70 free of charge. Under 70 years, those eligible for the general medical scheme can avail of GP services free of charge. All others must pay (approximately €40) per visit.

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[16] Persons who are unable without undue hardship to arrange general practitioner services for themselves and their dependants receive a free general medical service known as the Genera Medical Scheme (GMS)

GPs are the most widely distributed and accessible points of entry to primary, secondary and tertiary care. However, many lists are over-subscribed resulting in reduced consultation times and fewer home visits.

- Public Health Nursing

Health boards are obliged to provide a free nursing service to medical cardholders although the actual services that must be delivered are not clearly specified. The service is not necessarily confined to medical cardholders, although they get priority as they have a legal eligibility. However, the service is generally felt to be under-resourced and there are variations in the numbers of nurses per capita and in the services provided across health boards.

The access issues for carers in relation to the more practical day-to-day services of public health nurse services centre on the fact that the client of the PHN service is the older or disabled person, not the carer. There is an absence of common definitions of service purpose and of common standards of service quantity and quality across health boards and community care areas. This means that where one happens to live can be an important factor in determining access to nursing services and, if the service is provided, how much service one gets.

There is anecdotal evidence (Finucane et al, 1994) that gender biases may sometimes operate in relation to carers, with men being viewed as less able to provide care and / or that they should be in employment and are therefore less available to provide care.

- Therapy Services

Therapy services are severely understaffed and under-resourced, especially with respect to domiciliary care. This therefore restricts their accessibility, with strict rationing in force. Rationing criteria are not clear and vary from health board to health board. Eligibility is based on possession of the medical card and level of assessed need.

- Chiropody

Chiropody was the home-based service most used by older people in the HeSSOP study (Garavan et al, 2001) with 16 per cent having availed of it during the previous year. In addition to being one of the two most used services, chiropody also had the highest additional demand – 12 % of those older people who had not used it would have liked to have done so.

It should be noted that with the exception of the public health nurse and some GPs (GP home visits are declining) most of these services are available in the community, with a markedly restricted domiciliary service.

- Social Work and Counselling Services

One per cent of older people in the HeSSOP study living in the community had seen a social worker in the 12 months prior to interview, with fewer using counselling or psychological services. In both cases, twice as many people would have liked to have used the service than actually received it.

Barriers to Service Use

Key barriers to service utilisation were grouped into two main categories in the HeSSOP study (Garavan et al, 2001),one set of factors related to reluctance to avail of certain services at the interface between professionals and the public, such as lack of information about the availability of a service or the suitability of a service for particular health conditions. One aspect of this was lack of knowledge of services. Not knowing about a service was a barrier to almost one in ten people. When asked specifically about accessing information on services, 14 % said this was difficult or very difficult. Stigma was also reported as a barrier to using services. Thirty per cent reported they would find using the meals-on-wheels services to be 'highly embarrassing'. Almost twenty per cent gave the same rating to the home help service. Counselling, social work and personal care attendants were also described as highly embarrassing or stigmatising services by between 18 and 21 per cent of the overall population.

The other set of factors related to access to services included transport, cost and presence of a carer.

Cost was given as the reason for not using some services. Two thirds of these older people had medical cards and thirty-eight per cent had private health insurance. Almost one in ten reported having neither a medical card nor private insurance. Many medical card holders reported making payments for health and social services in the past year.

Transport was reported as a barrier to service use by less than one per cent of the population studies. Those in rural areas were twice as likely to report such problems.

Finally, here is anecdotal evidence to indicate that where there is a carer in the home services may be withheld when resources are scarce.

4.1.1.2 Acute hospital and tertiary care

General provision for older people

Broadly speaking, there are three different types of hospital in Ireland, but there is very little difference in practice between the first two types:

- Health board hospitals, owned and funded by the health boards
- Voluntary public hospitals, most of whose income comes directly from the government. Voluntary public hospitals are sometimes owned by private bodies, i.e., religious orders. Other voluntary public hospitals are incorporated by charter or statute and are run by boards often appointed by the Minister for Health and Children.
- Private hospitals, which receive no funding.

Public health services are provided in what can be broadly termed the public hospitals – health board hospitals and voluntary public hospitals. Most of these hospitals also provide private health care but they must clearly distinguish public and private beds. The acute hospital and general hospital sector caters for all age ranges including older people.

Special geriatric facilities (geriatricians, geriatric beds, assessment units, rehabilitation units etc)

Health boards provide specialist services through geriatric departments to patients in hospitals or referred by their GP. Geriatricians and Psychiatry of Old Age physicians provide care assessments for older people. They work with a team of specialists such as physiotherapists, occupational therapists, speech therapists and so on, to provide appropriate care in hospital as well as suitable supports through the Community Care services. Such services may deal with the medical and other problems of ageing to promote rehabilitation.

4.1.1.3 Long-term health care facilities (includes public and private clinics)

Welfare homes, Community hospitals or Community Nursing Units are institutions run by Health Boards, which provide accommodation and nursing care for older people in need of care. The Health Board carries out an assessment of the needs of the person involved. In some cases long stay charges or charges for institutional assistance may be levied. All residents are entitled to retain some personal money.

- Boarding out

Health Boards may make arrangements for the boarding out of dependent persons in a private house and for the payment of all or part of the costs. Boarding out has not developed in a significant way.

- Nursing homes

A combination of publicly financed and private nursing homes is used to supply nursing home services in Ireland. In general, there are not enough places in the public system and in some cases health boards have contracted beds in private nursing homes and pay almost all the costs involved. The more usual situation is that clients may get a subvention from the health board towards the costs of private nursing home services.

Those wishing to avail of such care have their needs assessed by the health board. The assessment criteria include standard of housing, social situation, family support and health. In general those in long-term care in public institutions are expected to pay almost all their income towards the costs although they are entitled to retain some “pocket money”. For those with savings, this pocket money may be reduced. Those entering a private or voluntary nursing home must pay the costs involved. In certain circumstances, they may qualify for a health board subvention.

Eligibility for publicly provided care or for subvention for private care is based on an assessment of dependency and on means. The fundamental requirement for an assessment of dependency is that independence is impaired to the extent that nursing home care is needed because the appropriate support and nursing care required cannot be provided in the community. The means test for private subvention for private nursing home care takes into account the income and assets of both the applicant and his / her spouse, where relevant.

Presence of a carer in the home appears to be a factor that is taken into account in rationing access to public nursing home services or to finance from the health boards for private nursing homes. However, although there has been no direct research on the topic, it is possible that this aspect may be less influential in comparison to how it affects access to community care services. For instance, carers are clearly “present” in many cases where older dependants move into nursing home care, but may be unable and / or unwilling to provide the necessary level of care.

4.1.1.4 Hospice / palliative / terminal care facilities

There are currently five specialist palliative care in-patient units in Ireland:

- Marymount Hospice in Cork
- Milford Care Centre in Limerick
- Our Lady’s Hospice, Harold’s Cross, Dublin
- St Francis Hospice, Raheny, Dublin
- Galway Hospice

There is also a palliative care in-patient unit in Sligo (the North-West Hospice) which is currently developing its services. The North-West Hospice provides home care services – The Foyle Hospice in County Derry (Northern Ireland), provides home care services in parts of County Donegal (Republic of Ireland). There are seven consultant physicians in palliative medicine in Ireland.

Each of the specialist palliative care in-patient units has specialist palliative care teams working in the community. The specialist units also provide a day care service for patients and some also provide a specialist palliative care service to acute general hospitals in their areas.

A home service usually involves home care nurses providing a service to terminally ill people and their families. The Irish Hospice Foundation was established in 1986 as a voluntary support organisation for the development and improvement of hospice services. It supports hospital-based palliative care services and acts as a support for the Voluntary Hospice Movement, which is an affiliation of voluntary hospice support groups in Ireland. The Irish Hospice Foundation is partly funded by the Department of Health and Children through the Eastern Regional Health Authority. The Irish Cancer Society is also involved in the development of palliative care services in Ireland. It organises home care nursing, sometimes called twilight nursing.

Hospice patients are referred through their GP or on admission to hospital for palliative care services.

4.1.1.5 Role that family carers are expected to play

Family carers are not generally expected to undertake health care tasks for in-patients. However, family members would normally be expected to regularly visit in-patients and to collaborate to some extent in discharge planning (i.e. to provide information on the patient's home circumstances and discuss their own willingness to provide care).

4.1.2 Social services

The Department of Social and Family Affairs oversees some aspects of social care but its main function is the administration of social welfare payments. The Department is divided into two main sections, Aireacht and Social Welfare Services.

The Aireacht is responsible for the overall management of the Department and for the formulation of the social protection and related policies, which are kept under constant review.

Social Welfare Services is the executive arm of the Department and is responsible for the day-to-day administration and management of social welfare schemes and services (such as Carers Allowance and Carers Benefit). The services are delivered through a network of local, regional and headquarters offices. The regional structure is based on ten regions.

In addition, a number of State Agencies come under the aegis of the Department including the Social Welfare Appeals Office; Comhairle, the social services information centre; The Pensions Board; The Offices of the Pensions Ombudsman; The Combat Poverty Agency and the Family Support Agency.

Most of the practical day-to-day community social services are administered and delivered via the health services and it has been argued that they are often subordinate to health services. As a result, social services are rather fragmented and under-developed in Ireland.

4.1.2.1 Residential care (long-term, respite)

Services providing residential care include:

- Sheltered housing / supported living arrangements
- Respite care
- Nursing home care

Sheltered housing / supported living arrangements

Sheltered housing / supported living facilities are not very developed or widely available in Ireland, although some local authorities provide special accommodation for older people. This is usually communal accommodation with security features, for example wardens and security cameras. Voluntary housing organisations also provide sheltered accommodation either in group schemes or sheltered housing. Couples where one partner is aged 60 or over and the other is aged 55 or over, or single persons aged 55 or over, are eligible for special housing if they are otherwise entitled to local authority housing and have priority on medical or compassionate grounds. Voluntary housing organisations have some discretion in the selection of those that they house in accordance with their own policy but the majority of their houses are let in consultation with the local authority. Tenants in sheltered houses pay rent and they may qualify for rent supplements. Voluntary organisations do not usually apply a means test to those to whom they let houses in accordance with their own policy.

Respite care

Respite services provide alternative family or residential care for a dependent person in order to enable the carer to take a short break, holiday or rest. It can cover very short-term respite, for example, a 'sitter' for an evening, or a much longer arrangement for a holiday. Respite care is typically organised through a public health nurse or GP and is provided to varying degrees around the country, in some cases by the health board and in others by voluntary organisations. Alternative care with a family is sometimes available for children with disabilities, whereas residential care is usually provided for older people.

There is also the Respite Care Grant Payment available to recipients of the various carer-related social welfare and community welfare payments (Carer's Allowance, Carer's Benefit, Domiciliary Care Allowance and so on) that carers can use in whatever way they wish. Demand for respite care exceeds supply and there are also significant variations in the availability of respite services across the country. Respite services are directly targeted towards the needs of carers. However, there is little information available on the actual criteria used across the health boards in assessing needs and prioritising provision of respite services.

Voluntary organisations provide respite care services availability is dependent on resources. Caring for Carers Ireland hold an Annual Respite Break and Conference for Family Carers - 8,000 have been facilitated to date at National and Local levels.

Nursing homes

Nursing home care has been discussed in the previous section and so will not be gone into in much detail here. Statistical information on nursing home care is provided below, including breakdown by public / private / voluntary care

4.1.2.1.1 Basic data on % of > 65s in residential care by age group and type of care

There are 6,196 beds in private and voluntary homes that are occupied by older people in receipt of public subvention from the health boards. In addition, there are 1,281 contract beds in the system whereby the health board enters agreement with the private sector to provide extended care in private nursing homes for eligible older people. As part of the 2000 / 2001 Winter Initiative a further 385 beds have recently been made available for older people in the private sector, primarily for older people leaving acute care facilities. Adding these beds to the publicly provided beds means that 80 per cent of all beds in the long-stay sector (19,277) receive public funding of some sort from the exchequer. There are an estimated 4,775 beds in private and voluntary homes that are purely private and the people occupying these beds do not receive any financial support from the health board (O'Shea, 2002).

Estimates of the number and percentage of long-stay residents by age category across health boards is shown in Table 4.2 for the year 2000. The estimated number of long-stay residents aged 65 years and over currently in long-stay care beds in Ireland is 19,548.

Table 9: Non-Acute Beds for Older People by Type of Facility in the Long-Stay Sector, 2000 (O'Shea, 2002)

Type of Facility	Beds (N)	Beds (%)	Beds / 1,000 Elderly Population (CSO)	Beds / 1,000 Elderly Population (NCE)
Health Board (HB) Extended Care	9,045	37.7	21.1	20.9
HB Elderly Mentally Infirm	551	2.3	1.3	1.3
HB Assessment and Rehabilitation	974	4.0	2.3	2.2
HB Respite	497	2.1	1.2	1.1
HB Convalescent	245	1.0	0.6	0.6
HB Other[12]	103	0.4	0.2	0.2
Sub-Total: HB Provided	11,415	47.5	26.7	26.3
HB Subvented Beds	6,196	25.8	14.5	14.3
HB Contract Beds	1,281	5.3	3.0	3.0
Winter Initiative Beds[13]	385	1.6	0.9	0.9
Sub-Total: HB Funded in Private Facilities	7,862	32.7	18.4	18.2
Total HB Funded Beds	**19,277**	**80.1**	**45.1**	**44.5**
Private and Voluntary Beds (Non-Subvented)	**4,775**	**19.9**	**11.1**	**11.0**
Total Beds	**24,052**	**100.0**	**56.2**	**55.5**

This is 4,510 less than the number of beds in the system reflecting occupancy rates of between 90 and 95 per cent across the regions, the omission of people under 65 years of age in long-stay beds and the omission of people in respite, assessment / rehabilitation and convalescent beds. The vast majority of long-stay residents are aged 75 years and over, with only 16 per cent of residents aged between 65 and 75 years. The proportion of residents aged 75 years or over is greater than or equal to 80 per cent in each health board with

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[12] Includes psycho-geriatric beds

[13] At the time of going to press this had risen to 592 beds

the Eastern Regional Health Authority (ERHA) recording the highest rate at 86 per cent. The Midland Health Board (MHB) has the lowest percentage of residents aged 75+ years at 80 per cent. Two in every three residents in long-stay care are over 80 years of age with the Eastern Regional Health Authority having the highest percentage at 71 per cent. Age is clearly an important factor in determining admission and residency in long-stay care (O'Shea, 2002).

Table 10: Estimated Number and Percentage of Long-Stay Residents in all Types of Long-Stay Facilities by Age Category by Health Board Region, 2000 (O'Shea, 2002)

Health Board Region									
Residents (N)	**ERHA**[14]	**M**[15]	**MW**[16]	**NE**[17]	**NW**[18]	**SE**[19]	**S**[20]	**W**[21]	**Total**
65-69	271	63	107	91	75	147	133	118	1,005
70-74	549	174	235	141	136	265	328	247	2,075
75-79	914	199	436	253	233	427	612	421	3,495
80+	4,168	772	1,310	782	812	1,472	1,928	1,729	12,973
65+	5,902	1,208	2,088	1,267	1,256	2,311	3,001	2,515	19,548
Residents (%)									
65-69	5	5	5	7	6	6	4	5	5
70-74	9	14	11	11	11	11	11	10	11
75-79	15	16	21	20	19	18	20	17	18
80+	71	64	63	62	65	64	64	69	66
65+	100	100	100	100	100	100	100	100	100

4.1.2.1.2 Criteria for admission (degree of dependency, income etc.)

no information provided

4.1.2.1.3 Public / private / NGO status

no information provided

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[14] Eastern Regional Health Authority

[15] Midland Health Board

[16] Mid-Western Health Board

[17] North-Eastern Health Board

[18] North-Western Health Board

[19] South-Eastern Health Board

[20] Southern Health Board

[21] Western Health Board

4.1.2.1.4 Does residential care involve the participation of carers or work with carers?

Not as such, although entry into and / or exit out of residential care is often decided-upon in consultation with family members. Carers often have to independently monitor the care of dependants in residential care, and liase with care staff and advocate on behalf of the client when necessary.

4.1.2.2 Community Care Services (statutory coverage and whether aimed primarily at older people living alone or including support to family carers)

As with the health services, entitlement to community services is vague and there is wide variation in the level of services available in different parts of the country. Care services are aimed primarily at older people living alone. The needs of family carers are not directly assessed and the assessment is focused on the dependent older person.

4.1.2.2.1 Home help

Home help in Ireland is considered to comprise services that provide practical help and support in the home to people with difficulties in performing everyday self-maintenance activities themselves. All health boards either provide a home help service directly or make arrangements with voluntary organisations to provide such services. Some health boards also provide care assistants whose role focuses on personal care. There is some debate on the relative merits of expanding the provision of this more specific service or of expanding the repertoire of skills and duties of home helps. This issue has not been resolved and for the purposes of this report, 'home help' is also intended to also cover care assistants where relevant.

The home help worker usually helps with normal household tasks although they may also help with personal care. They are expected to provide a set number of hours assistance each day or each week, with the precise arrangements usually being agreed between the client and the health board. The sort of work that a home help is normally required to do includes light cleaning and possibly some shopping and cooking and laundry but it depends on the client's individual needs. More than 80 per cent of recipients of home help services are elderly people but less than one in thirty older people actually receive the service.

The service is generally free to medical card-holders and is always free to people who have contracted Hepatitis C directly or indirectly from the use of Human Immunoglobulin-Anti D. For other clients, charging practices vary greatly from area to area and some people may have to make a contribution towards the cost even if they hold a medical card. In some cases, they may have to pay all the costs involved although the health board may make an arrangement whereby it takes on all the responsibilities of the employer while the client pays the costs.

Each application for home help services is considered on its own merits. However, as demand exceeds supply, a health board may take a number of factors into account, including income, other family support available, remoteness from services and availability of suitable people to provide the service.

Studies of the home help services in Ireland have found significant variations across health boards in the objectives, organisation, scope and levels of provision of the service, as well as anomalies in the assessment of need and eligibility (Lundstrom and McKeown, 1994; Ruddle et al, 1997). Key concerns have been expressed about the home help service in Ireland (Haslett et al, 1998) including:

- Lack of recognition of the service
- Under-prioritisation and under-funding of the service
- Slow development of the service
- Lack of standardisation at many levels which resulted in unevenness and inequity
- No right of redress
- Lack of parity between voluntary and statutory service providers

4.1.2.2.2 Personal care

no information provided

4.1.2.2.3 Meals service

Meals services are provided by a mix of statutory and voluntary bodies. The ways in which these are provided vary from area to area, and can include direct delivery to the home or provision at community centres. Access to meals services is generally by referral and clients may be asked to contribute towards the costs. Over 80 per cent of recipients of meals services are elderly people but only a small minority of older people actually receive the service.

4.1.2.2.4 Other home care services (transport, laundry, shopping etc)

Most home care services such as laundry or shopping are covered by the home help service. However, health boards and / or voluntary organisations sometimes provide transport services to day hospitals, day centres, outpatient departments and other hospital services. There is not much information available on the current status of transport services across the country, although there appears to be a lot of geographical variation.

4.1.2.2.5 Day care / Community care centres

Day centres or day care centres in Ireland are provided by the health boards and a variety of voluntary agencies and offer a range of social and rehabilitative services for older people and people with disabilities. They include centres that provide day activation, such as recreational, sport and leisure facilities, and specialised clinic facilities that provide a combination of medical and rehabilitation services. It is interesting that even as far back as 1988 (Working Party on Services for the Elderly, 1988) it was proposed that one of the main purposes of day care centres, inter alia, should be to relieve caring relatives, particularly those who have to go to work.

There is no statutory obligation on health boards to provide day care services. Although day centre services in Ireland are not well documented, it appears that the availability of day care places and the range of facilities provided varies widely, as does the provision of transport to and from the day centres. Some areas have no day care facilities at all. The health boards themselves have estimated that many more places are needed than are actually available (Ruddle et al, 1997). Transport is often a limiting factor in respect of attendance, particularly for people in rural areas. Services are only available on weekdays. Day centres providing medical care are less widely available than those with a more social function. Access to day centres is by referral and the eligibility conditions vary from area to area with means tests applying in some cases.

Apart from facilities for older people there are also issues for adults with disabilities, particularly those with heavy care needs due to physical or intellectual disability. For those who have outgrown the educational facilities for children with severe physical and intellectual disabilities there is a significant shortage of suitable day care facilities. This is an important impediment to employment for many carers.

4.1.2.3 Other social care services

Training of Family Carers

Caring for Carers Ireland provide a 13 week modular skills training programme "Caring in the Home" for Family Carers at 17 locations throughout the country. The course aims to promote the health and wellbeing of the Family Carer and to improve access to services and supports. Speakers are drawn from locally based multidisciplinary health and social service personnel in order to facilitate greater integration in care provision and to raise awareness of the carers own needs amongst service personnel. On completion of training a Carers Group is established to provide on-going support.

Other training programmes include:

- Safe Lifting of Patients

- Cardio Pulmonary Resuscitation
- Computer Skills Training
- First Aid
- Therapeutic Hand Care
- Personal Development
- Volunteer Carers Course
- Lifewise Course

The Carers' Association provides training for family carers and Home Support Personnel. These modular training programmes are provided from 16 Carers' Resource Centres. The Courses last 26 weeks and combine 13 classroom training modules with ongoing work in the home. Participants attend a training session for one morning every two weeks. The courses comprise three streams, each of which consist of four modules:

- Stream 1: Caring for Yourself
- Stream 2: Caring in the Home
- Stream 3: The Carer as a Person

Home Adaptation

Home adaptation services focus on ensuring that the living environment supports independent living for older people or disabled people. The Disabled Persons Grant scheme is the main service of relevance. This scheme is available to disabled persons from their local authority where changes need to be made to a home to make it suitable for a person with a physical or intellectual disability or a mentally ill person. Grant aid for changes may include making the home wheelchair-accessible, moving light switches, door handles, installation of a ground floor bathroom and toilet, and other relevant modifications.

The Special Housing Aid for the Elderly scheme also has some relevance in this area. This scheme of home improvements is operated by the health boards and is concerned with improving living conditions of older people by carrying out minor repairs to the main areas of the older person's home. Works undertaken under the scheme are carpentry, plumbing, painting and decorating as well as general cleaning.

Both local authority tenants and owner-occupiers may be eligible for the disabled persons grant scheme, as long as their home is at least one year old. Housing association tenants may be eligible in exceptional circumstances. Tenants in private rented accommodation are not eligible. For local authority tenants, the local authority will meet the entire cost of the adaptation. For owner-occupiers, up to 90 % of the cost may be granted, generally up to a maximum of €20,320. Those unable to get a loan from a bank or building society to pay for the other 10 % may be able to get a local authority home improvement loan.

There is no income limit for eligibility and the grant is usually awarded on the basis of need rather than income. When the local authority receives an application the health board is asked to assess the applicant's circumstances. This is done through a visit to the home by a health board occupational therapist.

In recent months, the Department of Environment and Local Government has commenced a review of the scheme. Given the large number of applications, some local authorities have suspended the scheme pending this review.

The special housing aid for the elderly scheme only applies to those who own their own homes or are buying them. Those living in local authority housing are not eligible. Applicants may get help under the scheme if they cannot afford to pay for the improvements or if there is no one in their household who could do the work. The availability of this service varies from area to area.

Assistive Technology

Assistive technology, sometimes also referred to as 'rehabilitation technology' or 'technical aids', is the term used to describe technological products and systems that are of particular benefit to people with disabilities and / or older people. They include the various more traditional technical aids and appliances (such as wheelchairs, walking aids, low vision aids and so on) and newer technologies like those based on smart home principles (such as automatic door and curtain openers / closers, automatic switching on / off of appliances, and so on).

The legislative basis for publicly funded provision of assistive technology services for people with disabilities in Ireland is limited and poorly developed (Commission on the Status of people with Disabilities, Working Group on Technology and Telecommunications, 1996). In practice, such assistive technology services as exist are supplied by a combination of the health boards and voluntary organisations (such as the Central Remedial Clinic, National Council for the Blind and National Association for Deaf People) with public funding to supply services.

The main piece of legislation of relevance is the Health Act (1970) although the Act does not explicitly refer to assistive technology as such. The Act makes provisions for the Health Boards to supply "medical or surgical appliances", ophthalmic and aural appliances and "equipment, materials or similar articles for a disabled adult person where neither the person nor the person's spouse (if any) is able to provide for his maintenance". However, there are no specific obligations in relation to what equipment or appliances must be provided or on the circumstances under which they should be provided. As a result, there are no clear obligations placed on the Health Boards, there are differences of interpretation between Health Boards and there is no clear statement of entitlements for people with disabilities.

Within the health boards, the community Occupational Therapy service is mainly responsible for assessing needs and recommending assistive technology. A wide spectrum of needs and technologies are covered, for example electric beds, hoists, specialised seating, wheelchairs, aids for bathing, showering, toileting and lifting, and structural adaptations to the home such as ramps and extensions.

Health boards provide certain medical and surgical aids and appliances free of charge to medical cardholders. Lists of what are available are generally not provided to clients or to the general public. People without a medical card may also have such aids and appliances supplied free of charge if they are part of hospital treatment. In practice, the health boards may also provide some help with the costs under other circumstances.

According to the Working Group on Technology and Telecommunications of the Commission on the Status of People with Disabilities (1996), the present service delivery system for assistive technology in Ireland is totally inadequate and operates very unjustly. The legislative basis is vague and open to interpretation, leading to many anomalies and to uneven access to services for different groups and in different regions of the country. The services provided by the Health Boards are fragmented, discretionary, different in different regions and usually very poor. There is no accountability and no means of appealing decisions, and the service is often very slow. Apart from the lack of a proper statutory basis for assistive technology services, a shortage of occupational therapists has also been identified as an important impediment.

Information and Communications Technology

Between June 2001 and December 2002 with a budget in the region of €8, CAIT (Community Application of Information Technology) supported over 70 community-based projects throughout the country and was designed to address the digital divide by encouraging late adopters to engage with ICT in beneficial ways, and empowering communities to harness the benefits of new technologies to address issues of disadvantage and exclusion.

To help overcome social exclusion, Caring for Carers initiated a unique Information Technology project in partnership with the Mid Western Health Board, Ennis Citizens Information Centre and Ennis Information Age Town. Funded by Comhairle, the emphasis is on using Information Technology to improve access to information, advice and advocacy on a broad range of health and social services for a target group of over 1,500 older people. However, mainstreaming of ICT has yet to take place.

Personal Assistants

Personal assistants help people with disabilities to live as independently as possible. The personal assistant agrees the range of tasks with the person with the disability and this varies from one individual to another. Examples of the sort of help that personal assistants may provide include accompanying the person with a disability as he / she goes to social, recreational or vocational activities and interpreting for a person with speech difficulties.

There is no formal scheme to provide personal assistants for people with disabilities in Ireland. Some voluntary organisations, with health board assistance, do organise such a service for individual people. Overall, personal assistants are not widely available or used in Ireland.

4.2 Quality of formal care services and its impact on family caregivers: Systems of Evaluation and supervision, implementation and modelling of both home and other support care services

The public health care system provides both residential and community services for those in need of long-term care. However, whilst stated Government policy is to maintain people in the community insofar as it is possible, in practice, funding arrangements still favour residential care, but the availability of such services has been, and continues to be, subject to budgetary constraints.[22]

Health Boards provide such care for older people in a variety of settings including geriatric, welfare and community hospitals and community nursing units. However, there are insufficient public extended care beds to cater for all those requiring residential care (Mercer Ltd. 2002).

The role of health and social services in caring for older people in the community is underdeveloped. In addition, significant proportions of those in receipt of services reported paying for some or all of the services although they may have been entitled to them without costs.

Although there is some variation in the extent to which formal monitoring and evaluation procedures take place, in the main formal guidelines are not in place. Delaney et al (2001) found that more resources, especially IT systems, need to be provided before proper monitoring and evaluation can take place.

Each health and social care service operates according to a line management arrangement which is deeply embedded in day-to-day service provision. The different services therefore have their own discrete reporting systems, which can lead to a tendency for services to operate in parallel with, rather than in tandem with, each other.

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[22] Sections of the Health (Amendment) (No.3) Act 1996 require that Health Boards (their Chief Executive Officers) do not spend in excess of their annual budgets/allocations.

4.2.1 Who manages and supervises home care services?

The Home Help service is managed by Home Help Organisers and Assistant Home Help Organisers and Supervisors. However, there are not enough Organisers to effectively manage Home Care Workers in Ireland and calls have been made for the appointment of more management staff (Haslett et al, 1998).

4.2.2 Is there a regular quality control of these services and a legal basis for this quality control? Who is authorised to run these quality controls

The formalisation of the level of care given by Home Helps has not so far taken place due to considerable difficulties associated with increased costs of training, supervision and assessment of suitability of personnel. Haslett et al (1998) were commissioned by the National Council on Ageing and Older People (NCAOP) to conduct research into and provide recommendations on how to produce a core, quality service with agreed quality standards. They identified eight pre-requisites to establishing quality control of home care workers:

- Clarification of the nature of the service run by Home Helps
- Reflection of this clarification in training programmes for Home Helps and Home Help Organisers
- Reflection of the core nature of the service in the rates of remuneration and conditions of work for Home Helps
- The drawing up of explicit and agreed criteria for assessment of needs of clients which would apply nationally
- Standardisation of criteria for entitlement, including carefully considering obligations to all older people in need regardless of their means
- Determination of national guidelines for the level of service provision based on assessed needs
- Implementation of an organisational structure for the Home Help Service within the health services
- Understanding of the inter-dependence of the voluntary organisation and the health boards, with mutual recognition of each other's respective role and ethos

However, these pre-requisites have as yet to be implemented, therefore formal quality control has yet to be put in place.

4.2.3 Is there any professional certification for professional (home and residential) care workers? Average length of training?

There is general agreement on the need for training for Home Helps and a requirement that Home Help Organisers receive specific training. Haslett et al (1998) stressed the importance of implementing training of Home Helps as soon as possible. They recommended that training consist of two elements:

- A national standard induction course, to be a basic requirement for all Home Helps
- Appropriate modules to be added on to allow specific groups of Home Helps to cope with specific situations such as dementia and incontinence

The authors recommended that Home Help Organisers attend a national standard training course – to be a requirement for all Organisers and Assistant Organisers.

4.2.4 Is training compulsory?

These recommendations have not been implemented to date.

4.2.5 Are there problems in the recruitment and retention of care workers?

Problems to do with recruiting and retaining staff pose significant difficulties for the health and social community services. Delaney et al (2001) identified staff shortages across services such as public health nursing, social work, psychology, physiotherapy, speech and language therapy and home help. The key factors contributing to this situation were identified as:

- Reluctance to work in the field of older people
- The fact that public health nurses are expected to deal with the entire population from birth to death
- The limited grading structure and remuneration for therapy providers in the community
- The very limited pay and poor working conditions for home helps

4.3 Case management and integrated care

For more than ten years the National Council on Ageing and Older People has advocated strongly for the introduction of Case Management as a key mode of service delivery, and published a report on two pilot projects aimed at improving service co-ordination almost a decade ago (Browne, 1992).

Care Management appeared again in Irish health care literature at the end of the 1990s as a strategy for caring for people with dementia in the Action Plan for Dementia (O'Shea and O'Reilly, 1999). This plan clearly endorsed Care Management as the best approach to care for people with dementia.

In 2001, the National Council on Ageing and Older People published a national report on Care and Case Management for Older People (Delaney et al, 2001). This report reviewed the health and social care practices in Ireland at the time and identified models of best practice within a Care Management framework in Ireland. However, the relationship between health and social services in Ireland remains weak, with social services less developed and subordinate to health services. Since the publication of this last report on Care and Case Management, a number of pilot 'near' case management projects were instigated in the State. In addition, the Health Strategy launched in 2001 (Department of Health and Children, 2001) recommended the introduction of case management to primary and community care. However, mainstreaming of Care or Case Management has not yet taken place.

4.3.1 Are family carers' opinions actively sought by health and social care professionals usually?

Family carers' opinions are informally sought by health and social care professionals, especially GPs, public health nurses and medical social workers, however a formal consultation procedure is not in place.

Mechanisms for active community involvement in primary care teams are being established (Department of Health and Children 2001). Community participation in primary care is being strengthened by encouraging and facilitating the involvement of local community and voluntary groups in the planning and delivery of primary care services. Consumer panels are being developed in each health board area.

In 2003 a Joint Committee on Social & Family Affairs invited submissions from members of the public, professional and voluntary organisations representing Family Carers. First Report (November 2003) Review of the Position of Full-Time Carers. An examination of current welfare policy and practices, statutory, professional and voluntary support structures, education and training opportunities for carers and the long-term effects of full-time caring on the physical and mental well-being of carers. In the Chairman's Preface he stated that he and his colleagues had been moved by the submissions they had received form carers and caring institutions while preparing this Report. The difficulties faced by those caring for people with long term disabilities had been made very real for all of them by the many personal accounts given. The Chairman stated that he waned to put more resources into home care and look for better integrated services that are simple to access.

Following a consultative process which included Family Carers and representative organisations, the Fifth Report of the Fourth Joint Committee on Women's Rights, A Long-term Support Framework for Female Carers of Older People and People with Disabilities: 1996-2011, was published in September 1996. It stated that Government policy should address the long term needs of carers by drawing up a White Paper on caring policy and support for Carers in line with the views of carers and person who need care.

5 The Cost – Benefits of Caring

The GDP for Ireland in 2003 was €96,826 million.

5.1 Percentage of public spending on pensions, social welfare and health

2004 estimates: Health: 6.7 %; Social welfare (includes pensions): 18.5 %; Pensions: 3.2 %.

5.2 How much - private and public - is spent on long term care (LTC)?

Long-term care spending in Ireland as a percentage of GDP between 1992 and 1995 was 0.86. No information is available on the public-private split.[23]

5.3 Additional costs to users for using public health and social services

As stated earlier, health boards may charge discretionary extra costs to users of certain public health and social services. As there is no standard assessment or protocol for means testing, it is impossible to quantify the extent and distribution for these costs.

5.4 Estimated public / private mix in health and social care

Under existing eligibility arrangements, nearly one third of the population can access the full range of public, primary and hospital services free of charge. The remainder are responsible for funding most of their primary care costs. They are however entitled to hospital services as public patients subject to a modest co-payment for in-patient services.

All people are entitled to choose to avail of public hospital services as private patients. About 48 per cent of the population now exercise this option or avail of care in private hospitals through the purchase of voluntary private health insurance. About 2,500 beds (approximately 20 per cent of the total bed complement in public hospitals) are specifically designated by the Minister for use by private patients. In addition, independent private hospitals provide a similar complement of private beds, though focusing more on elective care (Smyth, 2002).

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[23] Source: European Commission (2002) 'Towards a Society for all Ages. Employment, Health, Pensions and Intergenerational Solidarity'. Brussells: European Commission

Consultants have a contractual right to carry out private practice in public hospitals and it is open to medical consultants to combine their public hospital commitment with private practice in public or private hospitals. Under present arrangements 80 per cent of the beds in acute public hospitals may be designated as public while 20 per cent may be private.

5.5 Minimum, maximum and average costs of using residential care

According to a survey carried out in 2000, the average weekly cost of private nursing home care was about 390 euro, with a minimum cost of about €250 and a maximum of about €760 (O'Shea, 2002). It is difficult to relate these figures to average wages in any meaningful manner because of various intervening factors (e.g. whether or not a subvention is provided by the health services and the amount of tax relief, if any, that is available). However, if we take the average cost in 2000 (€390) and apply an estimated average subvention of, say, 35 %, then the net cost might be something of the order of €250 per week. If a further, say, 20 % tax relief was available on this balance, then the average out-of-pocket weekly cost might have been something of the order of €200. This would be somewhere in the order of one-third of average take home earnings.[24]

5.6 Funding of care for older people by the public sector

Currently, formal long-term care (like health care in general) in Ireland is financed publicly from general taxation and privately through health insurance and / or on a directly out-of-pocket basis. Recently, 'equity release' products have become available which enable those who own their own property to release part of its value to pay for care.

5.7 Funding of family carers

See Table 11 Main Developments in Benefits for Carers of Elderly and Older Adults 1990-2001, Daly M & Clavero S published 2002 Institute of Public Administration; also Table 12 Benefits Available for Family Carers.

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[24] Of course the situation is complicated by the fact that a variety of family members, including adult children, can be involved to varying degrees in the payment of nursing home costs.

Table 11: Main Developments in Benefits for Carers of Elderly and Other Adults 1990 - 2001

Year	Main developments
1990	Introduction of Carer's Allowance
1991	Coverage extended to persons in receipt of Disabled Person's Maintenance Allowance or EC Bilateral Agreement pensions
1992	€190.4 income disregard currently applied to a spouse's income to be applied to a couple's joint income. €95.2 weekly disregard to be applied to a single person's income
	Social insurance record preserved for persons moving from insurable employment to Carer's Allowance. To date credits have been awarded on an administrative basis. In addition, credits will be awarded when a person with a gap of two years in their paid or credited contributions was in receipt of homemaker disregards before claiming the allowance
	Free telephone rental, free travel pass for allowance recipients
	Introduction of Home Carer's Tax Allowance
	Tax allowance for employing a carer available for relatives other than spouse
	Extension of Back to Work Allowance to former carers
	€38,092 grant to the Carer's Association towards the cost of producing and distributing an information pack for carers and their families
	Extension of the Employment of a Carer Tax Allowance
1994	Income disregard of €127 in respect of a spouse's income from employment
	Initial income disregard of €2.5 increased to €7.6
	Homemaker's disregard arrangements, preserving carers' entitlement for contributory pension, introduced. Under the new scheme, contribution years spent caring for a child up to 6 years or a frail adult are disregarded in calculating a person's yearly average number of contributions for Old Age Contributory Pension purposes. Up to 20 contribution years may be disregarded
1995	The age limit for children cared for to qualify for homemakers' disregard increased from 6 to 12 years
	Income disregard increased to €190.4 in respect to spouse's income from all sources
	Category of persons being cared for extended to include all persons aged 66 or over, regardless of their source of income (previously confined to carers providing care to people aged 66 or over and in receipt of social welfare payments)
	Free Travel Companion Pass issued to all care recipients
1996	Carers receiving Rent or Mortgage Interest Supplements benefit by up to €36.8 a week
	Review of Carer's Allowance announced
1997	Full-time care requirement relaxed to allow care recipients to attend a non-residential course of rehabilitation training or a daycare centre approved by the Minister for Health and Children
	An additional 50 % paid to persons caring for more than one incapacitated person
1998	Foreign social security disability pensions up to the maximum of Old Age Contributory Pension not to be assessed as means for Carer's Allowance
	Six weeks payment of Carer's Allowance to be paid after the death of a spouse / partner being cared for, who is not getting a social welfare payment
	Free Travel Pass for carers getting Carer's Allowance, allowing carers to travel (free) on their own
	Review of the Carer's Allowance launched in October
1999	Once-a-year payment of €254 automatically paid to all carers to be used for respite care
	All carers providing full-time care and attention to someone over 16 will be eligible to apply for CA regardless income source of care recipient
	Full time carers of children getting domiciliary care (for children between the ages of 2 and 16, severely physically or mentally disabled) entitled to apply for Carer's Allowance
	Carers allowed to work part-time for up to 10 h. and still qualify for the allowance. A carer could earn up to €95 a week and still qualify
	Condition residency relaxed; carers living "next door" to qualify for Carer's Allowance
2000	New social insurance Carer's Benefit, payable for up to 12 months at €112.3 a week
	Annual respite grant increased to €381
	Free electricity allowance and free TV licence extended to recipients of the Carer's Allowance
	Carers made eligible for Back to Education Allowance when caring responsibilities have ceased
	Carers no longer to satisfy '13 paid contribution' rule when claiming Disability Benefit
2001	Carer's Allowance increased by €12.6 for carers agreed 66 years and over and €10 for those aged under 66
	Annual respite care grant increased by €127 (to €507.8)
	Income disregards for means tests for Carer's Allowance relaxed by €63.4 for a single person and €127 for a couple per week
2002	Census Questionnaire: Carers
	Data on carers was derived from answers to Question 23 of the census questionnaire. This asked of persons aged 15 years and over whether an individual provided regular unpaid personal help for a friend or family member with a long-term illness, health problem or disability (including problems due to old age). Personal help includes help with basic tasks such as feeding or dressing. Receipt of "Carers Allowance" was not considered payment for the purposes of this question. "Meals on Wheels" staff were not considered carers for the purpose of this question. The following response categories were given: Yes, 1-14 hours a week; Yes, 15-28 hours a week; Yes, 29-42 hours a week; Yes, 43 or more hours a week; No
2004	Publication of Census Details

5.7.1 Are family carers given any benefits (cash, pension credits / rights, allowances etc.) for their care? Are these means tested?

There are benefits available for family carers. The main forms of benefit are set out in Table 11 below and were discussed in more detail in Chapter 2.

Table 12: Benefits Available for Family Carers

	Carers Benefit	**Carers Allowance**	**Home Carer Tax Credit**	**Employment of a carer tax relief**	**Medical expenses tax relief**	**Domiciliary Care Allowance**
Restrictions	Must not engage in more than 10 hours of employment or training per week; must have a stable recent employment and social insurance contribution history	Must not engage in more than 10 hours of employment or training per week; is means tested and only available to low income households	Only available to married couples and not to cohabiting but unmarried arrangements	Available to tax payers who employ someone to care for a dependant	Available to tax payers who incur medical expenses (including nursing home costs) on behalf of a dependant	Only available to carers of a severely disabled child under 16 years of age.
Who is paid?	Full-time carers	Full-time carers	Carer’s spouse	Tax payer(s) who claim the relief	Tax payer(s) who claim the relief	Carers
Taxable	No	No	N / a	N / a	N / a	No
Who pays?	Department of Social and Family Affairs	Department of Social and Family Affairs	Revenue Commissioners	Revenue Commissioners	Revenue Commissioners	Health Boards
Pension credits	Yes	Yes	N / a	N / a	N / a	N / a
Levels of payment / month	Maximum rate if caring for one person = €558.80 Maximum rate if caring for more than one person = €838.40 For a maximum of 65 weeks	Means tested[25]	Tax credit of 770 euro (max)	Up to approx. 30,000 per annum is allowable	All eligible costs are allowable	Current rate = €179.80 per month
Number of recipients (approx.)	600 (data for 2003)	20,000 (data for 2003)	N / a	400 (data for 2000)	30,000+ (estimated for 2000)	10,000 (data for 2000)

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[25] Maximum rate for carers under the age of 66 caring for one person = €518.40,
Maximum rate for carers aged 66 and over caring for one person = €591.20,
Maximum rate for carers under the age of 66 caring for more than one person = €777.60,
Maximum rate for carers aged 66 and over caring for more than one person = €886.60

5.7.2 Is there any information on the take up of benefits or services?

Women are much more likely to be in receipt of Carers Allowance and Carers Benefit than men, comprising more that four out of five recipients.

5.7.3 Are there tax benefits and allowances for family carers?

There are tax benefits and allowances for family carers, these are outlined in Table 5.1 above and in Chapter 2.

5.7.4 Does inheritance or transfers of property play a role in caregiving situation? If yes, how?

There is little reliable information on this issue. Anecdotally, there has been a perception that such factors played a role in some cases, with an adult child agreeing to become the carer (within their parents' home) on the understanding that they would inherit the home. More recently, the issue of inheritance has emerged in the debate on funding of long-term care and whether the family home and other assets should be taken into consideration and in what ways.

5.7.5 Carers' or Users' contribution to elderly care costs

a. Medical, nursing and rehabilitation services	General access:			Access based on:		
	Free at point of use / wholly reimbursed	Partly privately paid / partly reimbursed	Completely privately paid	Means-tested		Based on severity
				Partly reimbursed	wholly reimbursed	
General practitioner						
Specialist doctor		X		X[26]		
Psychologist		X		X[27]		
Acute Hospital		X		X[28]		
Long-term medical residential care (for terminal patients, rehabilitation, RSA, etc.)		X		X[29]		
Day hospital		X		X[30]		
Home care for terminal patients		X		X[31]		
Rehabilitation at home		X		X[32]		X
Nursing care at home (Day / Night)			X			
Laboratory tests or other diagnostic tests at home		X		X[33]		
Telemedicine for monitoring	N / a					
Other, specify: "home care"	N / a					

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[26] GP Services are free to those in possession of a medical card; some health insurance schemes provide reimbursement for GP expenses; tax relief is available for remaining out-of-pocket expenses

[27] Public Specialist Consultants are free for those in possession of a medical card, otherwise a nominal fee may be charged; private specialist fees are usually reimbursed for those with health insurance; tax relief is available for remaining out-of-pocket expenses

[28] As previous

[29] Most Public Acute Hospital Services are free, however those not in possession of a medical card may be charged a nominal fee (€40 approx); private costs are usually reimbursed for those with health insurance; tax relief is available for remaining out-of-pocket expenses

[30] As previous; nursing home subventions may also apply

[31] As for acute hospital

[32] Public services are free; private services may be covered by insurance, with remaining out-of-pocket costs eligible for tax relief

[33] Public services are free; private services may be covered by insurance, with remaining out-of-pocket costs eligible for tax relief

b. Social-care services	**General access:**			**Access based on:**		
	Free at point of use / wholly reimbursed	Partly privately paid / partly reimbursed	Completely privately paid	**Means-tested**		Based on severity
				Partly reim-bursed	wholly reim-bursed	
Permanent admission into residential care / old people's home		X		X[34]		
Temporary admission into residential care / old people's home in order to relieve the family carer		X		X[35]		
Protected accommodation / sheltered housing (house-hotel, apartments with common facilities, etc.)		X		X[36]		
Laundry service	N / a					
Special transport services		X		X		
Hairdresser at home	N / a					
Meals at home		X		X[37]		
Chiropodist / Podologist		X		X		
Telerescue / Tele-alarm (connection with the central first-aid station)		X		X[38]		
Care aids		X		X[39]		
Home modifications		X		X[40]		
Company for the elderly	N / a					
Social worker	X					X
Day care (public or private) in community centre or old people's home		X		X		

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[34] Means-tested eligibility for Nursing Home Subvention Scheme; tax relief on remaining out-of-pocket costs

[35] May be publicly provided for medical card holders; respite care grant available to help pay for private services; remaining costs may be eligible for tax relief

[36] Tenants in sheltered housing schemes pay rent, however they may qualify for rent allowance

[37] Recipients may be asked to contribute to costs. There is no formal means testing in place.

[38] Not very widely available or used; grant is available to community organisations who may then install equipment without charge for vulnerable older people; private services are also available and must be paid for out-of-pocket

[39] Available aids are free of charge to medical card holders; others generally pay out-of-pocket but costs would often be eligible for tax relief

[40] Both local authority tenants and owner-occupiers may be eligible for the disabled persons grant scheme. Entire costs may be met for local authority tenants. For owner-occupiers, up to 90 per cent of the cost may be granted, generally to a maximum of €20,320. Special housing aid for the elderly is available for home-owners who cannot afford to pay for the improvements or if there is no-one in their household who could do the work.

b. Social-care services	**General access:**			**Access based on:**		
	Free at point of use / wholly reimbursed	Partly privately paid / partly reimbursed	Completely privately paid	**Means-tested**		Based on severity
				Partly reim-bursed	wholly reim-bursed	
Night care (public or private) at home or old people's home		X		X[41]		
Private cohabitant assistant ("paid carer")			X[42]	X		
Daily private home care for hygiene and personal care			X[43]			
Social home care for help and cleaning services / "Home help"		X		X		X
Social home care for hygiene and personal care		X		X[44]		
Telephone service offered by associations for the elderly (friend-phone, etc.)	X[45]				X	
Counselling and advice services for the elderly	X[46]				X	
Social recreational centre		X		X		
Other, specify						

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[41] If available, service is likely to be free for medical card holders; those with private insurance may be eligible for reimbursement; remaining out-of-pocket expenses eligible for tax relief

[42] There is no formal scheme to provide personal assistants. Tax relief is available for employment of a carer

[43] Tax relief available for employment of a carer

[44] Often free for medical card holders but may be some level of charge

[45] Service offered almost exclusively through voluntary sector

[46] Service offered almost exclusively through voluntary sector

c. Special services for family carers	**General access:**			**Access based on:**		
	Free at point of use / wholly reimbursed	Partly privately paid / partly reimbursed	Completely privately paid	**Means-tested**		Based on severity
				Partly reimbursed	wholly reimbursed	
Training courses on caring	X[47]				X	
Telephone service offered by associations for family members	X[48]				X	
Internet Services			X[49]			
Support or self-help groups for family members	X[50]				X	
Counselling services for family carers	X		X[51]			
Regular relief home service (supervision of the elderly for a few hours a day during the week)		X		X		X
Temporary relief home service (substitution of the family carer for brief periods of time, for example, a week)	N / a[52]					
Assessment of the needs	X				X	
Monetary transfers	N / a					
Management of crises	N / a					
Integrated planning of care for the elderly and families at home or in hospital	N / a					
Services for family carers of different ethnic groups	N / a					
Other, specify						

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[47] Service offered almost exclusively through voluntary sector

[48] Service offered almost exclusively through voluntary sector

[49] No reimbursement for Internet Connection costs.

[50] Service offered through voluntary sector

[51] Service either offered free by voluntary sector or are available privately

[52] Respite only available for older people in residential centres. Children with disabilities may be placed with other families during respite.

6 Current trends and future perspectives

6.1 The major policy and practice issues being debated

The many issues on the agenda at present have been discussed at various points earlier in the report. These include:

- recognition and status of carers
- adequate income support and / or payment for caring work
- health and social services for carers and those that they care for
- equality issues for carers
- support for the costs of care
- costs of long term care
- caring in the work-life balance context

6.2 Expected trends in services to support family carers

Changes are likely given the current attention to carers and caring, and the various reports to government that are now on the table. A certain consensus seems to be emerging around the idea of a universal, social insurance based benefit package for those in circumstances where there are caring responsibilities. If implemented, this might take the form of an integrated package, with a choice between benefits in kind (services) or cash, or a mix of the two.

6.3 Role played by carer groups / organisations, "pressure groups"

Historically they have played a key role in getting carer issues onto the agenda and in influencing policy. They continue to have a strong voice and influence.

National Network of Carers Groups

Caring for Carers Ireland National Network comprises of 57 groups for Family Carers throughout Ireland North and South. Meeting on a monthly basis the Network provides a forum for Social Integration information and mutual support. Carer's issues have been brought onto the agenda and influenced policy development. These include Carer's Charter, Carer's Allowance, Carer's Benefit, Carer's Respite Fund and the inclusion of the Census Questionnaire 2002 relative to the position of Carers.

6.4 Tensions between carers' interests and those of older people

Such tensions, if they exist, are not overt in Ireland. Of course, as in all societies, there are human tensions and difficult dilemmas at the family level in this area. Providing informal care is usually a time demanding task, many carers are regularly on-call 24 hours a day and do not get a break. The emotional and social effects of being a carer may also adversely affect physical health; the carers in this study who had poorer health or whose health had deteriorated since they became a carer were also likely to report more psychological symptoms (e.g. anxiety, depression).

A number of previous studies have also found that carers report that their role as a carer has had a negative effect on their physical health. For example a longitudinal study (Evason and Whittington, 1996) found that carers reported a deterioration in physical health over the two years of the study and that the deterioration was attributed to the caring role. Nearly a quarter stated that they sustained some injury through lifting the person. In a study of the Galway area, over a third of carers claimed that being a carer effected their physical health (Syron, 1995).

Although most carers were happy to become a carer, the majority agreed that being a carer has had a profound effect on their social and family life. Very high proportions of carers did not get to go out as often as they would like and did not see their friends, partner or family as often as they would like. Of the carers who did get a break, many worried about the person they looked after and thus would have found it difficult to relax. Some carers mentioned that they were tied down and couldn't get out when they wanted and that they had no freedom and no social life. The social effects of providing care are also highlighted in findings from previous studies. Syron (1995) reported that 42 % of carers found their social life was greatly affected by their role. In a study of carers of people with dementia Connors (1998) found that these carers were even more likely to find it difficult to meet friends socially and pursue their own hobbies and interests. Both Evanon and Whittington (1995) and O'Connor and Ruddle (1988) found that many carers gave up paid employment to take on the role thus missing out on both the financial and the social benefits of employment.

Substantial proportions of carers felt that they did not have enough time to themselves and did not have enough privacy as they would like. This was a particular issue for carers of Alzheimer / dementia patients and for carers who had been providing care for a long period of time. Many carers felt resentful at other members of their family for not sharing the burden of care, young carers were particularly affected by this. Most carers felt that they were valued by the person they look after and were not put down by that person, however very few carers felt that their ring role was valued by the authorities.

Negative emotions were also found to be common among carers in previous studies. For example Connors (1998) found that carers of people with dementia often experienced a sense of bereavement, stress and anxiety. Female carers and young carers were found to be at a higher risk of having poor family support and high levels of depression and anger.

In order to allow informal carers to continue to provide care for individuals in their own homes (a goal articulated in the National Health Strategy and in the Strategy for Services for Older People) it is essential that efforts be made to promote their physical and mental health. It is likely that the negative psychological and social effects of being a carer would in turn effect the individual's physical health and ability to continue to provide care. Carers should get regular opportunities to take a break, safe in the knowledge that their loved one is receiving high quality care. Carers should be encouraged to look after their own health and should be targeted as a special group for health promotion initiatives. Psychological and counselling services should be available to all carers who require them.

Carers should be viewed as a special group at risk of developing mental and physical health problems. They should therefore be targeted in health promotion initiatives.

6.5 State of research and future research needs

There has been quite a lot of research on carers and carer-related issues in Ireland, with data on carers included in the population Census in 2002 for the first time. One area where there is limited information concerns normative attitudes in society towards caring responsibilities, and whether these are changing with social and labour market trends.

6.6 New technologies

Assistive technology services in general are underdeveloped in Ireland. Also, social alarm services are not as widely available or as widely used in Ireland in comparison to a number of other European countries.

There has recently been an innovative pilot study of smart home technologies to support people with dementia and their carers in Europe (WRC, 2003). This study evaluated a variety of technologies, including safety devices for household appliances, monitors for day and night time wandering and other practical supports for everyday issues for carers of people with dementia. Indications from the trials were very positive, especially if the interventions took place at the appropriate (early) stage of dementia progression.

6.7 Comments and recommendations from the authors

The current attention to carer and caring issues by the Equality Authority is bringing together the key stakeholders in the field. It provides an opportunity to address the issues in an integrated and comprehensive manner. Their report is scheduled to be available in early 2005 and it is hoped that it will provide the basis for a coherent policy and range of services and supports for those who are confronted with caring responsibilities.

7 Appendix to the National Background Report for Ireland

no information provided

8 References to the National Background Report for Ireland

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