Equality
Research
Series

Caring, Working and Public Policy

Kevin Cullen, Sarah Delaney and Petrina Duff

THE EQUALITY AUTHORITY
AN tÚDARÁS COMHIONANNAIS

Caring, Working and Public Policy

Kevin Cullen, Sarah Delaney and Petrina Duff

Work Research Centre

FOREWORD

The current Strategic Plan of the Equality Authority establishes carers as a particular focus for our work. It highlights that the family status ground has remained somewhat underdeveloped in our work to date, and commits the Equality Authority to take initiatives that develop a clarity to and a visibility for the equality agenda of carers as a first step in changing this situation. Key activities to realise this ambition include casework on the family status ground, opening up channels of communication with carers and their organisations and research. This report is the first major initiative in implementing this plan. It is the first examination of the relationship between caring and employment in an Irish context and breaks valuable new ground in this regard.

The report explores the choices to be made between caring roles, paid employment and a combination of both. It is based on an understanding of a spectrum of caring responsibilities and a spectrum of employment needs and preferences among carers. As such real choices require initiatives and supports that can be tailored to the circumstances and aspirations of individual carers.

The results highlight inequities in access to health and social services that limit these real choices. These inequities are identified in relation to the carer status per se and in relation to service availability and accessibility. These are seen to limit employment opportunities for carers.

The report establishes the need for further work on these issues. It highlights the need:

- for more information on carers and attitudes to caring
- to investigate service rationing criteria and practice in the provision of health and social services
- to give more attention to methods of needs assessment of carers and of those being cared for
- for more analysis from a rights and equality perspective of the individual and joint rights and entitlements of carers and those that they care for

There is a societal imperative in responding to the issues for carers raised in this report. This imperative is both economic and social and draws from:

- the needs of the workplace of the future which has to recruit from within a diverse labour market, mobilising new sources of labour including carers
- the need to respond to the very difficult experiences of carers. The report notes the high levels of stress experienced by carers with one study finding almost one third of carers with heavy caring responsibilities, had a level of psychological distress that put them at risk of clinically diagnosable anxiety/depression
- the importance of a holistic approach to equality objectives that include an emphasis on affective equality and the domain of caring, access to caring and capacity for caring. Achieving equality requires an interlinked focus on economic, political, cultural and affective objectives

The Equality Authority is committed to further developing our work in this area. An important initiative within which to progress these issues has been the convening of an advisory committee to draft a report on *Implementing Equality for Carers*.

We are grateful to Kevin Cullen, Sarah Delaney and Petrina Duff of the Work Research Centre for their work in preparing this report. They have broken new ground in examining the relationship between caring and employment and they have done so with thoroughness and expertise. They have produced a report capable of generating new understandings of this relationship and new responses to its requirements.

Niall Crowley

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Chief Executive Officer
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July 2004

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EXECUTIVE SUMMARY

‘Carer’ is a term that has come to be widely used to refer to people who provide help and support on a voluntary and unpaid basis to one or more other persons who have difficulties in generally looking after themselves or in carrying out specific activities of daily living because of disability, age or long-standing illness. The term carer is sometimes also used to refer to parents of young children, but they are not the focus of this report. In addition people employed to provide care may be referred to as carers. However, for the purposes of this study the term carer is restricted to those who engage in unpaid and informal caring activities, typically family members or relatives but sometimes friends and neighbours as well.

Although a considerable amount of policy and research attention has been given to carers in Ireland over the last two decades, very little has focused on the interactions between caring and employment. Increasingly, however, carers in Ireland and elsewhere span a wide spectrum both in the types and amounts of care that they provide and in the nature and extent of their involvement in the labour market.

This study on *‘Caring, Working and Public Policy’* aims to assess the Irish situation and changing trends in relation to caring and paid employment and to discuss the implications for public policy in this area. The study was a relatively small-scale one involving desk-based research and analysis of existing data, literature and other documentary sources.

Profile of carers – the 2002 Census found that 148,754 (4.8%) Irish adults are carers, of which 132,183 are of working age (15 to 64). Administrative data reveal that those in receipt of care-related benefits are only a small proportion of the total population of carers.

This overall population includes carers with widely differing levels of caring responsibilities. A small majority (57%) spend one to 14 hours per week in caring. However 40,526 (27.2%) commit 43 hours or more per week.

The Census found that, although more Irish men are getting involved in caring, six of every ten carers are women while women comprise two thirds of those carers who provide 43 or more hours of care per week.

A majority of carers are caring for dependant older people, typically a parent, parent-in-law or spouse. There are also many carers caring for children or adults with disabilities.

Carers and the labour market – up until relatively recently, at least, only about one in four female carers in Ireland were working and their employment rates were considerably lower than their non-carer counterparts. The latest data from the 2002 Census suggest that a significant shift has occurred. It found that 45,464 (55.9%) female carers of working age and 39,690 (78%) male working age carers were in employment.

Carers are more likely to work part-time. In addition working carers typically devote fewer hours per week to caring than those who are not in paid work. This difference is more pronounced amongst women.

Available evidence suggests that only a small proportion of working carers leave work as a direct result of caring responsibilities. Most carers who are not working were in this situation when their caring responsibilities commenced and many would like to be in employment if circumstances were more conducive.

There are now more than 85,000 working carers in Ireland and this figure may grow further in the coming years as a result of increasing female employment rates and population ageing. Carer-friendly work arrangements are therefore becoming of increasing relevance.

The nature of caring – caring experiences and tasks vary greatly depending on particular circumstances in each case. In general, hours spent caring increase in line with the level of dependency of the person being cared for. The level and type of care provided may differ if the carer and person cared for share a home and on the needs of the person cared for with some conditions requiring more intensive care than others.

The financial costs of caring include opportunity costs arising from employment constraints, and extra expenses to cater for everyday and special needs of the person cared for or arising from caring. These often result in financial strain and worry for carers.

In addition caring responsibilities may preclude the fulfilment of a full social life. Indeed, a number of studies have shown that caring can take a toll on the carer's mental, emotional and physical health. Many carers have their own chronic health problems or disabilities.

Combining caring and employment – caring responsibilities may impact on the work of some carers. US studies report effects on work such as taking time off to provide care, leaving early from work and being too tired to work. The impact of caring on working life has been shown to vary by gender and occupational position. In general, individuals in higher occupational positions enjoy greater freedom to control their work schedules. Further to this, access to family friendly working policies may be affected by occupational position or type of work.

Although caring can impose various burdens on carers, the evidence from studies of both working and non-working carers indicates that having the opportunity to continue paid work or to return to paid work after a period of caring is a fundamental requirement for most carers. Apart from employment being a financial necessity and/or an important means of involvement, expression and fulfilment, work can also provide a respite for carers from the demands of caring. This may reduce the likelihood of negative health impacts and improve the well-being of carers. Also, because it can improve and sustain the capacity to care, it may often be of benefit to the person cared for as well.

On the other hand, it has been argued that combining work and care is often more of a juggling act than a well worked-out balance. There is evidence that in some cases the dual role can pose a variety of strains, with negative impacts for the carer and for the carer's work. For those who are being cared for, the practical constraints that work poses for their carers may, in the absence of alternative sources of care, result in negative consequences. Therefore, working carers and those that they care for need to be provided with services and supports that reduce the strains of the dual role.

Carers' needs for services and supports – there is a need for a lot more direct research on the needs of carers in Ireland for services and supports. Nevertheless, on the basis of available information it is possible to provide a broad indication of the types of services and supports that would enable carers to have genuine choices between caring, employment outside the home, or a combination of the two.

To ensure genuine choices are possible, a spectrum of services and supports tailored to the variety of circumstances and preferences of carers must be available, including:

- care services to substitute, as necessary, for family care, delivered in ways that meet the needs of working carers

- appropriate and equitable financial support where such services have to be paid for

- appropriate and equitable income maintenance support for those who must reduce or remain without employment-related income

- protection of employment and career situation during temporary withdrawal or down-shifting

- appropriate and equitable continuity in and protection of social insurance contributions and entitlements

Provision of care services – the basic working model in health and social services policy to date could be described as one where family care is supported, as necessary, by community care and respite services to enable the informal care arrangements to remain sustainable. The services primarily respond to needs as they present themselves rather than proactively looking for unmet needs in the community.

As a consequence of this largely residual model of service delivery and the lack of a statutory basis, care services are under-developed, in short supply and often unequally available across health boards and community care areas. Services are not organised or provided in accordance with the practical needs of working carers. Most of these services are less likely to be provided if there are family members who can provide care and the fact that such potential carer(s) may be working, or may desire to be working, may not necessarily be taken into consideration in this regard. Also, those services that are available are not provided to a time schedule that takes account of the needs of working carers.

Available services for carers, and the conditions of access that are attached to them, do not provide Irish carers with real choices between working and caring or some combination of the two. In fact, there are some potentially direct incompatibilities between employment policy and policy on care services. Put crudely, current employment policy is oriented towards increasing participation rates for all groups, including carers, and current carer policy is predicated on continued availability of informal carers to provide the vast bulk of care and support in the community.

Other supports for carers – important financial and other supports for carers include the following: carer-friendly working arrangements whereby employers can help carers to achieve work-life balance, income maintenance supports, domiciliary care and respite care grants, tax relief for out of pocket costs of care, social insurance credits and information and support services from public agencies and voluntary organisations. Although all these are available to in Ireland to at least some degree, the options and choices available to many carers are often very limited.

For example, while there is an increased recognition that carers need to balance working and caring the financial supports available for those who might wish to, or have to, take time out of employment to care match neither the foregone earnings of most carers nor the market rates for the type of care work they are providing. Carer's Leave does not cater well for those who are in insecure employment and both Carer's Benefit and Carer's Allowance payments are pitched at very basic income support levels. In addition, to be eligible for these income supports requires a more or less complete withdrawal from paid employment and more flexible approaches, such as a significant amount of part-time working, are not facilitated.

Key themes and conclusions – the key themes that have emerged from the study can be summarised as follows:

- Because carers span a wide spectrum, both in terms of their caring responsibilities and in their employment needs and preferences, it is important to avoid stereotyping and to provide a range of services that cater for diversity and enable real choices to be made by carers.

- There appear to be some fundamental inequities in access to health and social services that are related to carer status, per se, arising both at a policy level and in day-to-day delivery of services.

- There are also more general disparities in access to services and supports that can result in inequities in what is available to carers in similar circumstances and with similar needs.

- Separately, and in combination, these carer-specific and more general inequities in access to services and supports result in inequalities in employment opportunities and choices for carers in comparison to other groups and amongst carers themselves.

- On a broader but related level, there is a need for a fundamental discussion and debate on the individual and joint rights of carers and those that they care for, and of families and of family members more generally.

- Finally, there is a need for further research and analysis on specific aspects of all of these issues and sources of inequity.

Recent legislative and other developments in Ireland have begun to put in place a framework within which the needs of carers can be better catered for. It is clear, however, that a lot more needs to be done. There is a pressing need for a major review of health and social service policy in this area, to address both potential inequities arising as a result of carer status, per se, and inequities that can arise for any clients, including carers. There is also a need for a comprehensive review of the main current income supports for carers - Carer's Allowance and Carer's Benefit.

As currently formulated, these provisions support and reinforce a view that people are carers or workers rather than the reality that many people are, or aspire to be, both. The policy approach must therefore focus on supporting equality of choice for carers and equality in relation to the costs associated with each choice.

1

INTRODUCTION AND LEGISLATIVE CONTEXT

'Carer' is a term that has come to be widely used to refer to people who provide help and support on a voluntary and unpaid basis to one or more other persons who have difficulties in generally looking after themselves or in carrying out specific activities of daily living because of disability, age or long-standing illness. The term carer is sometimes also used to refer to parents of young children. However the focus of this report is restricted to carers in the former sense, (although of course many carers in this sense are also parents). In addition, people employed to provide care may be referred to as carers. For the purposes of this study, the term carer is restricted to those who engage in unpaid and informal caring activities, typically family members or relatives but sometimes friends and neighbours as well.

Historically, the main focus of carer-oriented policy and of carer advocacy groups in Ireland has been on carers who, through choice or necessity, give such a degree of commitment of time and effort to caring that it often precludes having paid employment as well. Increasingly, however, carers in Ireland and elsewhere span a wide spectrum both in the types and amounts of care that they provide and in the nature and extent of their involvement in the labour market. The role of state services in this context has recently been identified by Comhairle (2002) as an important challenge for carer policy in Ireland:

> "…opportunities for combining paid employment and caring duties need to be considerably enhanced and developed. Ideally, the network of financial assistance and support services should give carers a genuine choice between caring, employment outside the home, or a combination of the two".

Although a considerable amount of policy and research attention has been given to carers in Ireland over the last two decades, very little has focused on the interactions between caring and employment. In addition, the role of public services in relation to this has received no direct research. This study on *Caring, Working and Public Policy* aims to describe the Irish situation and trends in relation to caring and employment, and to discuss the implications for public policy and services in this area. The study was a relatively small-scale one involving desk-based research and analysis of existing data, literature and other documentary sources. As such, it cannot be comprehensive but rather aims to provide an initial mapping of the challenges emerging in this area.

The fact that carers are explicitly referenced under the family status grounds in the Irish equality legislation was a particular stimulus for the study. This legislation outlaws discrimination in both employment and access to services. This equality perspective informs the analysis of the issues addressed throughout this report.

The remainder of the report presents the results of the study. It begins in Chapter 2 with a presentation of some core issues that provide the backdrop to the analysis. Chapter 3 then presents a synthesis and appraisal of available data on caring in Ireland. Chapter 4 outlines what we currently know about the relationships between caring and labour market participation. Chapter 5 summarises and discusses available research on the nature of caring and Chapter 6 discusses research on those who combine employment and caring.

Chapter 7 then presents an analysis of the needs of carers for services and supports if they are to have genuine choices in relation to caring and employment. This is followed by consideration of how well such choices are supported by current Irish policy in relation to care services (Chapter 8) and supports for carers (Chapter 9). Finally, Chapter 10 draws some conclusions and highlights and discusses some equality issues that are raised by current Irish policy towards carers and by the current provision of services and other supports for carers.

As noted above, carers are explicitly referenced under the family status grounds in the Irish equality legislation. The remainder of this chapter outlines this legislative context.

Employers and service providers have certain obligations under the Employment Equality Act, 1998 and the Equal Status Act, 2000 as employers, educational and training bodies, providers of accommodation and service providers. This legislation aims to promote equality of opportunity and prohibit discrimination on nine specified grounds in employment, vocational training, training or work-experience, access to employment, conditions of employment, the provision of accommodation, service provision and educational establishments. The nine discriminatory grounds are gender, marital status, family status, sexual orientation, religion, age, disability, race and membership of the Traveller community.

Family status is defined in the Equal Status Act, 2000 as

> being pregnant or having responsibility:
>
> (a) as a parent of person in loco parentis in relation to a person who has not attained the age of 18 years, or
>
> (b) as a parent or the resident primary carer in relation to a person of or over that age with a disability which is of such a nature as to give rise to the need for care or support on a continuing regular or frequent basis,
>
> and, for the purposes of paragraph (b), a primary carer is a resident primary carer in relation to a person with a disability if the primary carer resides with the person with a disability.

It is a new ground and should play a central role in making the workplace and the provision of services more family and carer friendly.

The Employment Equality Act, 1998 and the Equal Status Act, 2000:

- prohibit discrimination and indirect discrimination (and discrimination by association by service providers, accommodation providers and educational establishments).

Direct discrimination occurs where one person is treated less favourably on any of the discriminatory grounds that another is, has been or would be treated. Indirect discrimination is discrimination by impact or effect.

Discrimination against carers may constitute discrimination on the family status ground and in certain situations indirect discrimination on the gender ground.

The Employment Equality Act, 1998 and the Equal Status Act, 2000:

- prohibit sexual harassment and harassment on the discriminatory grounds
- require employers, education and training bodies, service providers and accommodation providers and educational establishments to provide reasonable accommodation for people with disabilities unless it costs more than nominal cost
- allow positive action measures:

  (i) under the Employment Equality Act, 1998 in relation to

    (a) the gender ground

    (b) people over 50

    (c) people with a disability

    (d) members of the Traveller community

    (e) training or work experience (provided by or on behalf of the State) for any disadvantaged group (if the Minister certifies that it is unlikely that the group would otherwise receive similar training or work)

  (ii) under the Equal Status Act, 2000 in relation to disadvantaged groups or measures which cater for the special needs of persons
- impose vicarious liability on employers and service providers in relation to discriminatory acts of employees and agents unless the employers and service providers took reasonably practical steps to prevent the discrimination
- contain a number of detailed exemptions

The Employment Equality Act, 1998 and the Equal Status Act, 2000 are being amended to implement the EU Race Directive, the Framework Employment Directive and the Gender Equal Treatment Directive. These Directives will require amendments to the definitions of indirect discrimination. The implementation of the Framework Employment Directive will require employers to introduce a general programme of adjustment measures in order to facilitate participation by disabled persons (unless this would involve the imposition of a disproportionate burden).

The Directives allow positive action measures to achieve full equality in practice. The revised Gender Equal Treatment Directive will require Ireland to promote gender employment equality (this should include employment equality among female carers). The Bill when implemented will prohibit discrimination by association by employers.

2

KEY BACKGROUND ISSUES

This chapter outlines some contextual issues that provide the backdrop to the analysis of the remainder of the study. It looks first at how carers and caring are conceptualised and defined. It then considers the roles of family, state and gender in structuring the provision of care. Finally, it highlights potential tensions between labour market and care imperatives.

2.1 Definitions of Carers and Caring

The term 'carer', as already mentioned in Chapter 1 for the purposes of this report, can be defined as someone who provides assistance on an unpaid basis to one or more family members, relatives, friends or neighbours who have difficulties in looking after themselves or in undertaking daily activities because of disability, age or long-standing illness.

'Caring' is the term used to refer to the actual provision of help and support by a carer to a person in need of care. This may take many different forms ranging from help with shopping and transport to much more demanding and personal care in relation to dressing, feeding, bathing and so on. Such caring may present practical requirements in time and place that are not always easily reconciled with the time and place requirements of employment. Caring also typically includes 'caring about' in the sense of having a strong emotional attachment and interest in the well-being of the other person. Such caring about another person's well-being may be a source of significant worry for some carers when they are not present or available to care because they are out at work.

People have always provided care, especially for family members but also for friends and neighbours, without being called carers either by themselves or by others. The diffusion of the term carer into everyday language and discourse in Ireland can probably be traced initially to the efforts of support and advocacy groups. Organisations such as the Carers Association and Soroptomists have been especially active in Ireland (see, for example, the Carer's Charter published by the latter in 1991). There has also been a formal recognition of a carer role in social welfare provisions with the establishment of the Carer's Allowance in 1990 as a specific welfare payment for those defined as eligible carers and, more recently, in social insurance and employment provisions with the introduction of Carer's Benefit in 2000 and of Carer's Leave in 2001.

There are now various formal definitions of 'carers' in Irish legislative and other instruments, including those that underpin provisions in the social welfare and employment areas and in the Irish equality legislation discussed above. The definition by the Review Group on the Carer's Allowance captures the essence of the definitions in the Carer's Allowance, Benefit and Leave legislation and regulations (Department of Social, Community and Family Affairs, 1998):

> "A carer is defined as someone who provides full-time care and attention, to an older person or a person with a disability, on an unpaid basis."

A key feature of this definition is the requirement that carers should be providing 'full-time care and attention' in order to be a carer. In the review of the Carer's Allowance, the following definition of full-time care and attention was given:

> "Full-time care is defined as care provided to a person who has such a disability that he/she requires frequent assistance throughout the day in connection with normal bodily functions."

Although this requirement for full-time care and attention has since been relaxed to allow up to ten hours engagement in employment or education/training per week, the essence of these definitions remains the same – carers are seen as people who provide such a degree of care as to preclude participation in any significant amount of paid work.

The definition of a carer under the family status ground in the Irish equality legislation appears to restrict the coverage of this ground to carers who reside with the person being cared for, are their 'primary' or main carer and are giving continuing, regular or frequent care. However, although this legislation refers specifically to 'resident' carers, many people provide significant amounts of care for dependants who do not live with them. This has been recognised in the social welfare and taxation regulations. Eligibility for Carer's Allowance and Carer's Benefit extends to those providing full-time care and attention to someone who is not living with them, provided there is a direct system of communication (a telephone or alarm system) between the carer's residence and that of the care recipient and that the care recipient is not already receiving full-time care and attention within his or her own residence from another person. Eligibility for the Home Carer's Tax Credit also extends to people caring for non-resident dependants, provided that they live within two kilometres of the claimant and there is a direct system of communication between the two residences.

The reference to the 'primary' carer in the equality legislation also merits comment. In the organisation of family care for older people, in particular, it is very common to have one family member with most of the responsibility for providing care, sometimes but not always with help from other family members. Intra-familial factors come into play in determining which family member or members become the primary carer, whether the role is adopted voluntarily or involuntarily, and how much and what types of responsibilities are involved. There has been a considerable body of research on the familial processes affecting who becomes a carer (see for example Jani-Le Bris, 1993), with evidence that becoming a carer is not always volitional and that highly gendered factors operate in the assignment of the caring role. Of particular relevance for this study is the evidence suggesting that there may be a tendency for the role to be assigned to the (apparently) most 'available' person. Assessments of availability may be based on physical proximity and/or presumed temporal availability because of (lack of) employment status at the time the caring need arises.

2.2 State, Family and Gender Roles

Caring is a natural expression of familial, inter-generational and social bonds and relationships, and is a commonly experienced stage of the individual or family lifecycle. Most of us will have some experience of caring over our lifetimes. For the majority, caring responsibilities last for a relatively short number of years, for example, when a parent becomes old and frail. But for some they can last much longer, even for the entire adult lifetime, for example, in the case of carers of children or adults with long-lasting illness or disability.

In most developed societies, the state also takes a role in the provision of help to those who are in need of care or support due to illness, disability or old age. In some countries, such as Denmark, the role of the state is to automatically provide care to those who need it without an expectation or obligation that family members will provide care. In other countries, such as Ireland, the role of the state is a residual one, with services often being provided only in the absence of family care.

At the same time, with the exception of the obligations of parents in relation to their children and of the legal responsibility to provide maintenance for a spouse, there are no formal legal responsibilities on families to provide care for dependants in Ireland. As indicated in Table 2.1, this Irish situation is in contrast to the situations in many other countries.

Table 2.1: Family Obligations to Care Between Adults

Legal obligations on extended family	Legal obligations on adult children
Italy, Portugal, Spain	Austria, Belgium, France, Germany, Greece, Luxembourg
No legal obligations no clear state responsibility	No legal obligations clear state responsibility
Ireland, UK	Denmark, Finland, Netherlands, Norway, Sweden

Source: Millar and Warman, 1996

Despite the lack of any legal obligation, family carers provide the bulk of care for older and disabled people in Ireland. This is partly a result of normative cultural expectations, both on the part of carers and of those in need of care, and partly a result of necessity due to the lack of any clear state responsibility in the area. Gender-related factors also play an over-arching role here. While many carers are men, particularly for older dependants and spouses with disabilities, in general caring is culturally constructed as women's work, particularly in Ireland. This has critical implications at a number of levels. To begin with, it means that women make up the majority of carers. As well as this, it has led to a lack of value being accorded to caring work and to a low priority in policy and resource terms.

When this is coupled with the historical lack of encouragement and, indeed, active discouragement of women's labour market participation, it is easy to see how we have inherited a situation in Ireland where, in comparison to many other countries, levels of services to support caring are poor and Irish women carers have been less likely to be in employment. This presents significant challenges in contemporary Irish society, where increasing women's employment rates is a core goal of labour market policy and where dual-income households are becoming more and more the norm.

2.3 Emerging Tensions in Public Policy

Labour market policy in Ireland has undergone profound change in the last 10 to 15 years. It has moved from policies aiming in effect to reduce participation rates (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 engaged in 'home duties', and those at the older end of the working age range. The new model encourages high participation rates for women, with a particular focus on women with children and women in 'home duties'. Incentives have been provided through partial 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. More generally it has been reflected in greater recognition of the caring responsibilities of current employees through the introduction of Carer's Leave and Carer's Benefit. These provisions go some way towards enabling working carers to take time out from work in order to care.

However, the crucial role of an adequate care infrastructure has not received much attention to date. The availability of state-provided care and support services and the extent to which and by what criteria these are rationed can be very influential in determining the choices that are available to the families of those who become dependent due to illness, disability or age. This has clearly been recognised in the case of parenting, where it has been recognised that espousing female labour market participation as an over-riding goal is only valid in the context of adequate childcare provision. An identical argument can also be made in the case of caring for dependants that is the focus of this study.

At present however, the policy approach in Ireland in relation to the provision of health and social care services has been mostly a residual one, whereby public services are provided where family care is absent. The basic working model in health policy to date could be described as one where family care is supported, as necessary, by community care and respite services to enable the informal care arrangements to remain sustainable. The services primarily respond to needs as they present themselves rather than proactively looking for unmet needs in the community.

Clearly then, there are some potentially direct incompatibilities between employment policy and health policy. Put crudely, current employment policy is oriented towards increasing participation rates for all groups, including carers, and current health policy is predicated on continued availability of informal carers to provide the vast bulk of care and support in the community.

2.4 Balancing Labour Market and Care Imperatives?

A key factor that influences analysis and discourse in this area is the relative emphasis given respectively to the labour market and to care. In fact, as has been noted elsewhere, it is quite difficult to articulate a position that gives equal attention to both care and labour market participation in a balanced manner (Murphy, 2003). If the priority is equality of labour market participation, then provision of an adequate and equitable infrastructure of alternative sources of care for dependants that is affordable and of high quality is essential. If the priority is to enable women and men to provide a substantial amount of care themselves, then adequate and equitable social protection is required to cover both short-term and longer-term employment-related income penalties.

Lying somewhere in between these two positions is the notion of a payment or wage for caring. This is something that has consistently been espoused by carer advocacy organisations and has also been proposed within the context of a 'women's model for social welfare reform' (Murphy, 2003). The latter research argued that:

> "It should be a principle of reform that all care that is not "parenting" should be classed as work. Such work could receive a payment. Instead of enhancing and increasing the numbers of care contingencies in the social welfare system, the reform would focus on paying carers for their work." (28)

It is interesting that, in this regard, the historically more traditionalist agendas of the carer advocacy groups coincide with the more feminist and labour-market driven social welfare reform movement. This is a perspective that warrants a lot more analysis and debate, although it is beyond the scope of this report to address it in any depth.

2.5 Conclusions

This chapter began by considering definitions of carers and caring especially as they appear in Irish legislation and policy. Limitations and assumptions in these definitions pose problems, for example lack of acknowledgement of non-resident carers, reinforcement of the assumption of one primary carer in the assignment of carer roles and the requirement that carers should provide full-time care and attention.

Caring will be experienced by almost everyone over their lifetime and state, family and gender roles play a part in structuring the provision of care to those in need of care or support. In Ireland the role of the state is a residual one in contrast to at least some other European countries and family carers, the majority of whom are women, provide the bulk of care.

In addition, there is no co-ordinated approach across relevant policy areas in welfare, employment and health to support carers and, in fact, there are some potentially direct incompatibilities. Current employment policy is oriented towards increasing participation rates for all groups, including carers, and current health policy is predicated on continued availability of informal carers to provide the vast bulk of care and support in the community.

3

PROFILE OF CARERS AND CARING

This chapter begins by presenting a profile of carers in Ireland, including estimates of the overall number of carers and the amounts of care that they provide, age and gender breakdowns of the carer population and a profile of those that carers care for. Administrative data on the numbers of carers in receipt of carer-related payments is also provided and the importance of a recognition of a lifetime cycle of caring is emphasised.

3.1 Survey Estimates of the Prevalence of Carers in Ireland

A number of studies over the last decade and a half 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'Neil 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.

Another source of data on carers comes from the Living in Ireland surveys. Unfortunately the carer aspect of this data has not yet been analysed or compiled in a comprehensive manner in available published material. Where relevant, the limited information currently available from these surveys is also drawn upon in the report.

Although historically there has been a lack of robust information on the numbers and characteristics of carers in Ireland the situation has improved with the publication of the results of the Census of 2002 which included an item on caring for the first time:-

The Census asked:

> 'Do you provide regular, unpaid personal help for a friend or family member with a long-term illness, health problem or disability?'

Respondents who said yes were asked to indicate how many hours caring they provided per week from the following categories; 1 to 14 hours, 15 to 28 hours, 29 to 42 hours and 43 or more hours.

Estimates of the prevalence of carers from the 2002 Census, the Living in Ireland survey and two European surveys that included Irish samples are summarised in Table 3.1.

Table 3.1: Estimates of the Prevalence of Caring in Ireland

Survey	Reference Population	Estimated Prevalence of Carers
Living in Ireland Survey (1994)[1]	Adult Population	6%
European Foundation Survey (1998)[2]	Adult Population (Aged 16-64) 'attached' to the Labour Market	6.3%
European Community Household Panel Survey (1998)[3]	Adult Population (Aged 20-64)	5%
Census (2002)[4]	Adult Population (Aged 15 and Over)	4.8%
	Working Age Population (15-64)	5%

Sources: [1]Cited in DSCFA (1998); [2]Own calculations see Bielenski et al. (2002); [3]Own calculations from data provided in European Commission (2002); [4]CSO (2003) Principal socio-economic results.

These surveys all used somewhat different definitions of caring and had varying reference populations (all adults, adults of working age and so on). However, there is quite a degree of consistency in the finding of around 5 to 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. The latest census estimate would represent 148,754 (4.8%) adults overall and 132,183 (5%) adults of working age (15 to 64 years).

Comparing the prevalence of caring in Ireland with that in the EU overall is made difficult because of different definitions of carers in the various European-wide surveys that have included questions on caring. The European Community Household Panel Survey in 1998, for example, found a prevalence of caring of 6% for the EU overall, with the Irish prevalence just a little below this at 5%. On the other hand, the European Foundation Survey in the same year found a prevalence of 11.4% for the EU and Norway overall compared with a much lower prevalence of 6.3% in Ireland.

It is interesting to note that the prevalence of caring has been found to be a lot higher in UK population surveys. These have yielded estimates of 16% of the working age population in Great Britain (Maher and Green, 2002) and 18% of the working age population in Northern Ireland (Mooney and MacNeill, 2001) being carers. These various cross-country differences could be due to real differences in the actual prevalence of caring, to differences in question wording and therefore in who would classify themselves as carers in the different surveys, or to a combination of both of these factors. If they do reflect real differences in actual prevalence rates then these could result from a variety of factors, including differences in the numbers needing care, in the propensity to care, in the sharing of the caring burden amongst family members, and in the availability and quality of care services.

Unfortunately, there is no available data that would allow the effects of these factors to be quantified for present purposes. Further more in-depth research would be needed to unravel the effects of these factors and determine whether the Irish and EU surveys do in fact underestimate the true number of carers. For present purposes, therefore, the census 2002 estimates are taken as a good indication of the order of magnitude of the phenomenon.

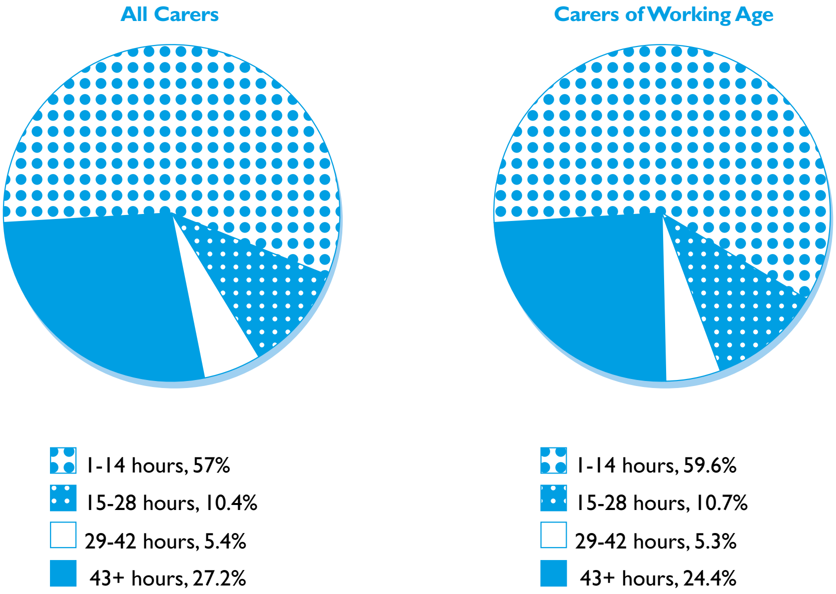
This overall population of carers includes carers with widely differing levels of caring responsibilities. One yardstick often used to indicate the extent of caring responsibilities is the number of hours spent caring per week. Data for the Census in 2002 reveals that there are significant differences among carers in terms of hours spent caring – see Table 3.2. A small majority (57%) spend 1-14 hours per week in caring. However 40,526 (27.2%) carers spend 43 hours or more per week. These percentages only differ slightly among those of working age, being 59.6% and 24.4% respectively (see Figure 3.1).

Table 3.2: Carers Classified by Number of Hours and Gender, 2002

Weekly Hours	All carers	%	Male	%	Female	%
1 – 14	84,862	57.0	34,975	60.8	49,887	54.7
15 – 28	15,409	10.4	5,862	10.2	9,547	10.5
29 – 42	7,957	5.4	3,142	5.5	4,815	5.3
43 +	40,526	27.2	13,501	23.5	27,025	29.6
Total	148,754	100	57,480	100	91,274	100

Sources: Census, 2002

Figure 3.1: Hours Spent Caring by Carers Per Week, 2002



Sources: Census, 2002

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). The grouping of hours of care in the published Census data does not allow the numbers caring more than 20 hours per week to be separately distinguished. However, data from a pilot survey by the CSO in 1999 suggests that almost two in five (39.7%) 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.

3.2 Administrative Data on Carers

Table 3.3 presents administrative data on carers in Ireland who are in receipt of carer-related payments from the Department of Social and Family Affairs and the Department of Health and Children. Women are much more likely to be in receipt of these payments than men, comprising about four in five of those in receipt of Carer's Allowance and an even greater proportion of those receiving Carer's Benefit.

Table 3.3: Recipients of Carer Social and Community Welfare Allowances

Carer's Allowance (April 2003)[1]	20,569
Carer's Benefit (April 2003)[2]	619
Domiciliary Care Allowance (Dec 2000)[3]	10,570

Sources: [1,2]Department of Social and Family Affairs, April 2003, personal communication; [3]Department of Health and Children (2003)

Based on the estimates of the total numbers of carers presented in the previous section, it is clear that the carers included in these statistics represent only a small proportion of all carers. Part of the reason for this, of course, is that many carers are currently in employment and consequently, in the case of Carer's Allowance and Carer's Benefit, do not fall within the categories of carers for whom these payments are intended.

In relation to Carer's Allowance, other factors have also been identified as limiting uptake by those who would otherwise be eligible because of their (lack of) employment status. The means-tested nature of the Allowance, based on household (usually spouse's) income, is one major barrier. In addition, many potential recipients (perhaps half of all applicants) have been ruled ineligible on the grounds of the amount of care being provided (Comhairle, 2002). Those in receipt of any social welfare allowance other than child benefit are also ineligible for the Allowance.

In relation to Carer's Benefit, levels of uptake are clearly very low in comparison to the numbers of working carers overall. Part of the explanation for this may be the relative newness of the provision (first introduced in 2000), although growth has only been around 100 recipients per year since 2001. The very low level of the payment relative to typical wage earnings is likely to be a much more significant disincentive. In addition, many carers are ineligible because of failure to meet the employment and/or social insurance requirements, for example, those with unstable employment histories (casual or seasonal workers, or those on short-term contracts). The prevention of flexible use because of the requirement to take blocks of leave may also be a significant disincentive for those who would prefer a viable part-time working arrangement, for example.

It is also possible that many carers (particularly men) in higher-level jobs may not feel it culturally appropriate to withdraw from employment, even for a limited time, to engage in full-time caring. Finally, another factor may be a preference on the part of most Irish working carers, like their counterparts in the UK and the rest of Europe, to continue working at the same time as they are managing their caring responsibilities rather than to take complete time-out for this.

The number of recipients of Domiciliary Care Allowance is likely to be a less significant under-representation of the total numbers caring for disabled children. The means testing is based on the child's income so that generally only children with significant compensation awards are likely to be ineligible on financial grounds. Also, eligibility for other (social) welfare payments is not affected by take up of this allowance.

Table 3.4 presents data on the numbers in receipt of the main tax reliefs that are directly targeted towards carers.

Table 3.4: Recipients of Tax Reliefs Targeted Towards Carers (1999/2000)

Dependent Relative Credit	20,200
Employment of a Carer Allowance	400
Incapacitated Child Credit	9,600
Home Carer Credit	N/A

Source: Revenue Commissioners, personal communication, May 2003; the numbers of claimants in 2003 are not expected to deviate significantly from these figures

The Dependent Relative Credit is typically claimed by a working person who has a dependent relative but may also be claimed by a dependent parent who is being cared for by a son or daughter living with them. It is actually a very small allowance and historically (until April 2001) its main value for carers was that it was a prerequisite for eligibility for claiming Medical Expenses Relief for expenses incurred on behalf of a dependent. Although the numbers in receipt of this relief are quite substantial they are very small in comparison to the estimated total population of tax-paying carers and/or their spouses.

The Employment of a Carer Allowance is now a substantial allowance at the marginal tax rate. It could considerably expand the options available to working carers by making it more affordable to purchase private care as a substitute for family care. That take up is still low may in part reflect the fact that it was only recently (2002 budget) that the allowance was increased significantly. It may also reflect other factors, such as lack of awareness, limited need for or interest amongst working carers in purchasing private care, or difficulties in sourcing suitable carers given the numbers of potential carers who have now entered alternative employment.

The Incapacitated Child Credit is available to people caring for someone who is deemed to be permanently incapacitated and who acquired the incapacity before the age of 21 (or after this age if in full-time education or apprenticeship type training at the time the incapacity was acquired). The numbers taking up this allowance are very similar to the numbers in receipt of the Domiciliary Care Allowance. Finally, the Home Carer Tax Credit is available to the working spouses of carers but there are no breakdowns available on the numbers of couples claiming this for care purposes as opposed to for parenting purposes.

3.3 Caring Over the Life Cycle

The Census 2002 estimate of 148,754 carers in Ireland provides a static, point-in-time snapshot of the prevalence of caring. It needs to be remembered, however, that although caring responsibilities can sometimes last a lifetime, caring is more typically an episodic phenomenon, arising at one or more periods in mid-life as one's own or one's spouse's parent(s) become dependent. Lifetime likelihood of becoming a carer has not received much research attention although one Norwegian study that looked at this issue found that almost two in five men (38%) and three in five women (59%) in the 55 to 66 years age group reported having had one or more episodes of caring (Lingsom, 1985).

Another aspect of relevance is the actual number of years that are spent caring. There are no reliable Irish data on this aspect, although the Review of the Carer's Allowance in 1998 cited an average of three years spent caring based on administrative data on duration of receipt of Carer's Allowance. This might be an underestimate, however. For example, US data suggests that employed carers report an average of about five years caring, with wide variations depending on individual circumstances (Cullen and Clarkin, 1994). Representative data for Great Britain indicates that just over half of carers there had spent less than five years caring at the time of a survey in 2000 and just under half had spent five or more years caring, with one in five caring for at least 10 years (Maher and Green, 2002). Although these are cross-sectional data reflecting the situation of current carers it does give an indication of the types of timeframe that are involved in caring.

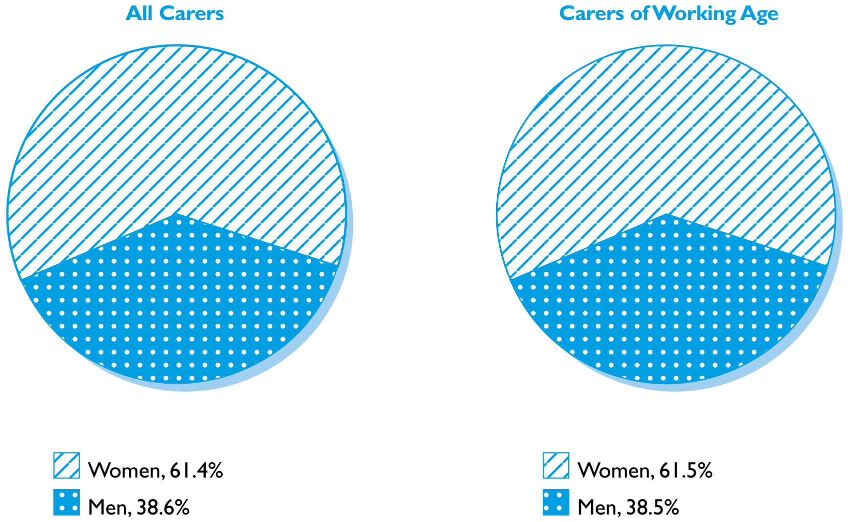
The data for Britain showed that carers of grown up children were most likely to report long-term caring, with more than half of this group reporting caring for at least ten years. Carers of people in the younger age bracket (under 45 years) with an intellectual disability were also more likely to be long-term carers. Carers in these circumstances are therefore particularly likely to experience challenges of balancing caring and employment over an extended period of time.

3.4 Carer Characteristics

Gender

All studies of carers in Ireland have found that women are more likely to be carers than men. While earlier Irish research has found women to comprise about three-quarters of carers, the recent Census found that six out of ten carers were women. This gender breakdown was almost exactly the same for all carers and for carers of working age (Figure 3.2). In Europe overall, studies have found about two-thirds of carers of working age to be women and one-third to be men (European Commission, 2002).It is not immediately clear why the Irish Census data should be significantly different from earlier Irish studies. One possibility is that there has been a fairly dramatic recent trend towards more male involvement in caring, perhaps reflecting some degree of role re-balancing with increasing female employment rates.

Figure 3.2: Gender Distribution of Irish Carers



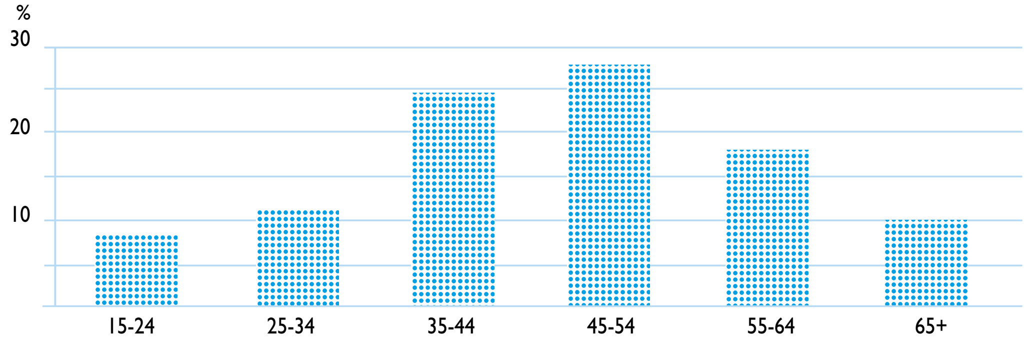
Source: Census, 2002

Although trends in this direction may well be an important factor, it is possible that definitional or methodological differences between the Census and the other survey-based approaches are also involved. This is something that merits further exploration in future research on carers in Ireland. In relation to number of hours spent caring, however, the Census data shows that women comprise 64.7% of carers providing 15 or more hours of care per week in Ireland, and 66.7% of those providing 43 hours or more(see Table 3.2 earlier).

Age

Caring is most commonly a feature of the middle years of life. The Census of 2002 found that more than half of the carers were in the 35 to 54 years age range (Figure 3.3).

Figure 3.3: Age Distribution of Irish Carers

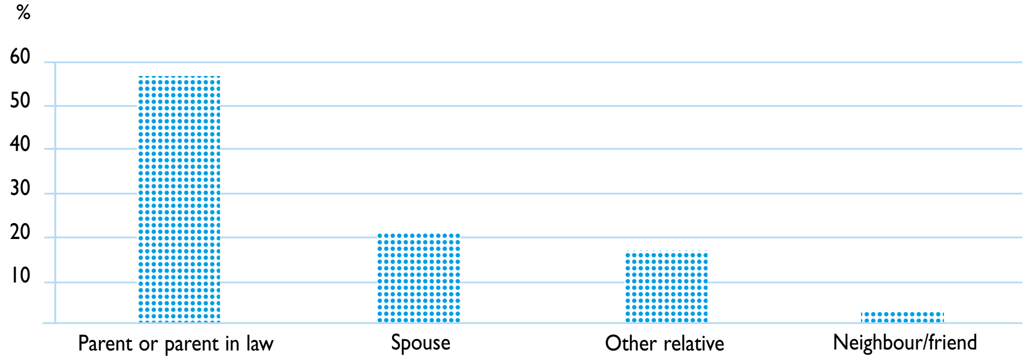


Source: CSO, 2003

Who is Cared For

In relation to who carers are caring for, data from a South Eastern Health Board (2000) survey are broadly indicative of the findings from other Irish studies (Figure 3.4). A little more than 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. Available data also 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 (data from Living in Ireland Survey, 1994, cited in DSFCA, 1998).

Figure 3.4: Who Carers Care For



Source: South Eastern Health Board, 2000

Relationship with Childcare

Finally, it is interesting to look at the numbers of carers in comparison to those who are providing childcare for young children, as well as those who are doing both. Figure 3.5 presents data on this for Ireland from the European Community Household Panel survey of 1998. It can be seen that at any point in time there are a lot more people in Ireland caring for children than there are caring for other dependants. However, the differences in the relative sizes of these groups are a lot smaller in the older age group (50 to 64 years) as the prevalence of caring for children decreases with age whereas the prevalence of caring for other dependants increases.

Women carers are a lot more likely than men carers to be caring for children at the same time as for other dependent people, with more than one third of women carers reporting this dual role. In addition, of course, amongst those who are involved in childcare, women put in a lot more hours than men (European Commission, 2002).

Figure 3.5: Caring and Childcare in Ireland

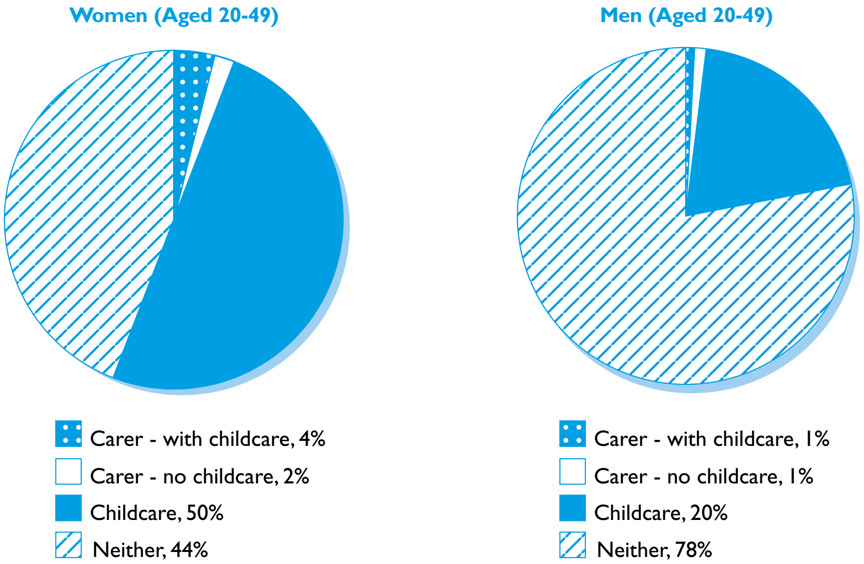
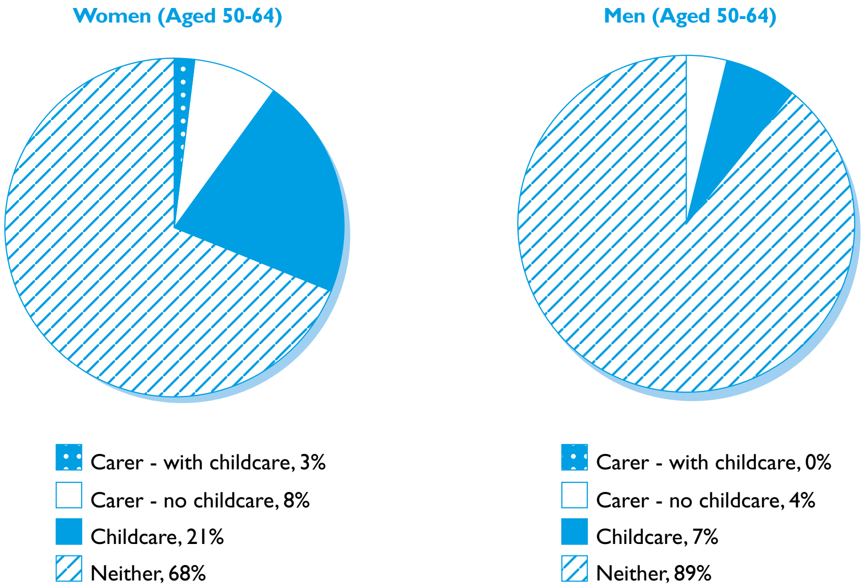


Figure 3.5: Caring and Childcare in Ireland (continued)



3.5 Conclusions

The Census 2002 found that 148,754 (4.5%) of Irish adults are carers. Administrative data reveal that those in receipt of care-related benefits are only a small proportion of the total population of carers.

This overall population includes carers with widely differing levels of caring responsibilities. A small majority (57%) spend 1 to 14 hours per week caring. However, 40,526 (27.2%) commit 43 hours or more per week.

The Census found that, although more Irish men are getting involved in caring, six out of ten carers are women and women comprise two-thirds of those carers who provided 43 hours or more of care per week.

A majority of carers are caring for dependant older people, typically a parent, parent-in-law or spouse. There are also many carers caring for children or adults with disabilities with almost a third of women carers having a dual role caring for children and other dependants.

4

CARERS AND THE LABOUR MARKET

This chapter examines the labour market situation and experiences of carers. It presents an overview of available research on the changing employment status and aspirations of carers in Ireland. It also outlines data on the prevalence of caring among the workforce. Finally it considers the research evidence on the impact of caring on employment decisions.

4.1 Changing Employment Status and Aspirations of Carers

A number of earlier Irish studies based on data from the mid to late 1980s found that carers in Ireland, and women carers in particular, were predominantly not working and a significant proportion did not wish to work. However in the very different labour market conditions of recent years, employment among carers has grown very significantly.

O'Connor and Ruddle (1988) and Blackwell et al. (1992) each surveyed samples of around 200 carers of older people, identified from various rounds of the AFT/ESRI Consumer Survey of Households between 1985 and 1988. Both studies found that just one in ten female carers were working outside the home, while one in two male carers were in employment. However, the Blackwell et al. study found a somewhat higher overall employment rate among carers (22.5%) than the O'Connor and Ruddle study, reflecting a higher share of men in their sample. Blackwell et al. found that employment rates declined as levels of dependency of those cared for increased. Both studies found that only a little more than one in four of non-working carers said that they would like to work if they were not caring. A later study that focused particularly on carers of people with dementia/Alzheimer's disease (Ruddle and O'Connor, 1993) found a broadly similar pattern among this group.

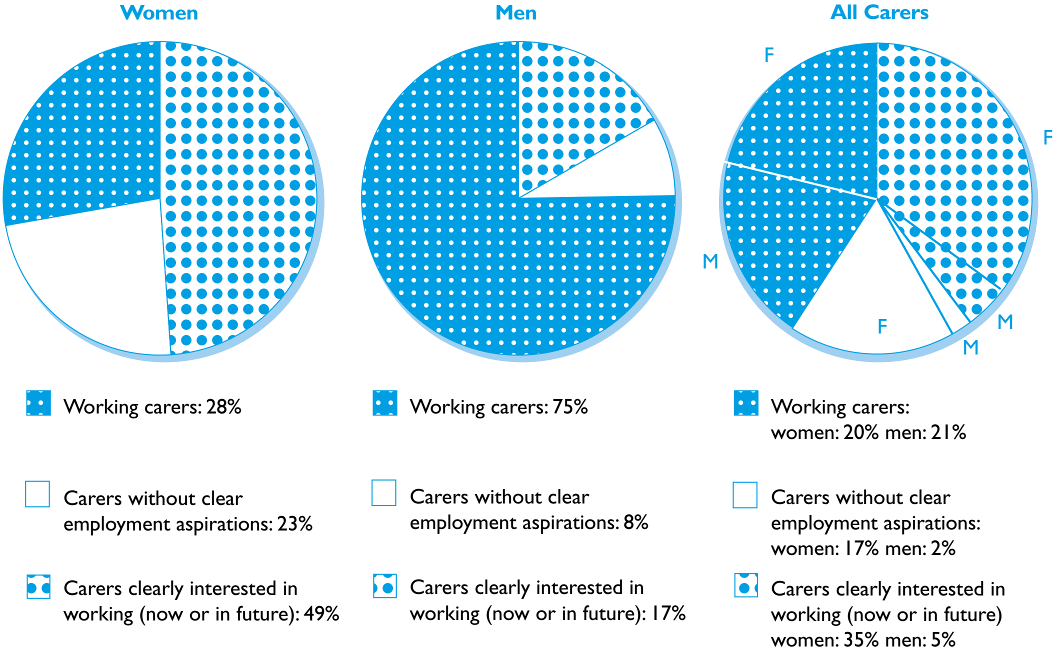
Callan and Wren (1994) found a somewhat higher engagement of carers in the labour market. This study analysed the data on 314 carers of older and/or disabled people from the 1987 ESRI survey on Income Distribution, Poverty and Usage of State Services, of whom 234 were in the 20-59 years age range. They found that the employment rate of women carers (22.9%) in this age range was only a little over half of that of all women (37.9%) in the same age range. Amongst men, the employment rate of carers (69.1%) was only a little lower than that of all men (75.7%).

Obviously the labour market context for these studies was one of mass unemployment and low levels of employment among women in general. It is quite possible, therefore, that the reported disinterest in employment by many carers in these studies reflected a perceived or actual improbability of being able to find a suitable job rather than an absolute lack of interest in employment under any circumstances. Also, women may then have been more likely to see their primary role as that of carer and considering employment might have required a considerable shift of focus. Clearly there have been major changes in the Irish labour market over the last decade and a half including significantly increased female participation rates. This period has also seen changes in the employment experience of carers.

By applying some reasonable assumptions to the data from the European Foundation survey of 1998 (Bielenski et al., 2002) and available data from other studies, it is possible to generate some indicative estimates of the distribution of carers nationally in the 1990s according to their employment status and employment aspirations. Figure 4.1 presents such an overall view of the pattern of relationships between caring and the labour market in Ireland in the 1990s. While this data should be viewed as being indicative rather than definitive, the overall orders of magnitude are probably reasonably accurate. Overall, the indications are that at that time about 40% of Irish carers of working age were working, a further 40% were not currently working but had a clear interest in working either immediately or at an appropriate time within the foreseeable future, and about 20% did not have any clear employment aspirations for the foreseeable future and, in some cases, perhaps forever.

However, the historically highly gendered nature of caring and of relationships to the labour market amongst carers can still be clearly seen from the data in Figure 4.1. Only a little more than one quarter of women carers were working compared with three-quarters of men carers. This suggests that the increase in employment among female carers was relatively small to that point, and much of the increased employment rates may be explained by increased rates of employment among male carers and/or their greater representation among carers. Interestingly, though, these estimates do suggest a significant shift in female carers employment aspirations compared to the situation a decade earlier.

Figure 4.1: Relationships to the Labour Market in Ireland in the 1990s
Indicative estimates for Irish carers of working age[1]



[1] *The following assumptions have been used in making these calculations: about 5% of the working age population in Ireland are carers; 50% of carers with a clear interest in employment are currently working and 50% are currently inactive but interested in working now or in the foreseeable future (European Foundation survey 1998); 6.7% of the population of working age in Ireland do not express an interest in working now or in the foreseeable future (European Foundation survey 1998), comprising 11.2% of women and 2.2% of men; and the prevalence of caring amongst these is estimated at 15% amongst women and 10% amongst men to reflect the older age profile and the more generally higher likelihood of caring amongst this group.*

Source: Own calculations based on data from various surveys.

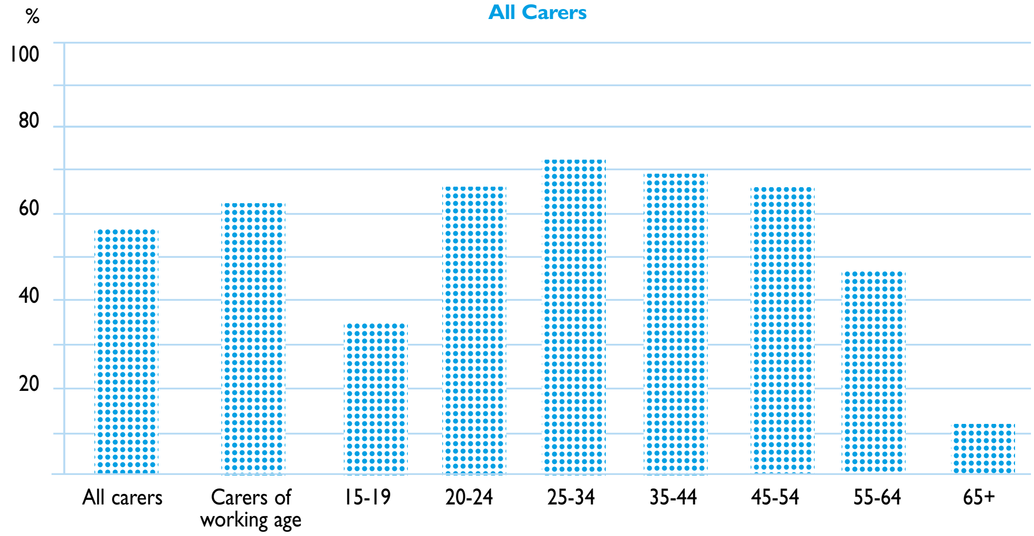
The recently released data from the Irish Census of 2002 shows that the employment rate amongst female carers has increased significantly. Just under half (47.4%) of female carers of working age reported being at work to be their Principal Economic Status compared with 50.9% of all working age women. Three out of four (73.7%) male carers of working age described their Principal Economic Status as at work, which was slightly higher than the 70.7% found among all working age men.

On the more detailed ILO measure of employment, which is now the standard way of measuring labour market participation, 85,154 (64.4%) carers of working age were recorded as employed (Figure 4.2). The Census found that 45,464 (55.9%) female carers of working age and 39,690 (78%) male working age carers were in employment.

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.

Figure 4.2 also includes a profile of ILO employment rates by age. It can seen that the likelihood of carers being in employment drops off particularly in the 55 to 64 age group.

Figure 4.2: Carers' Employment Rates (%) by Age and Gender



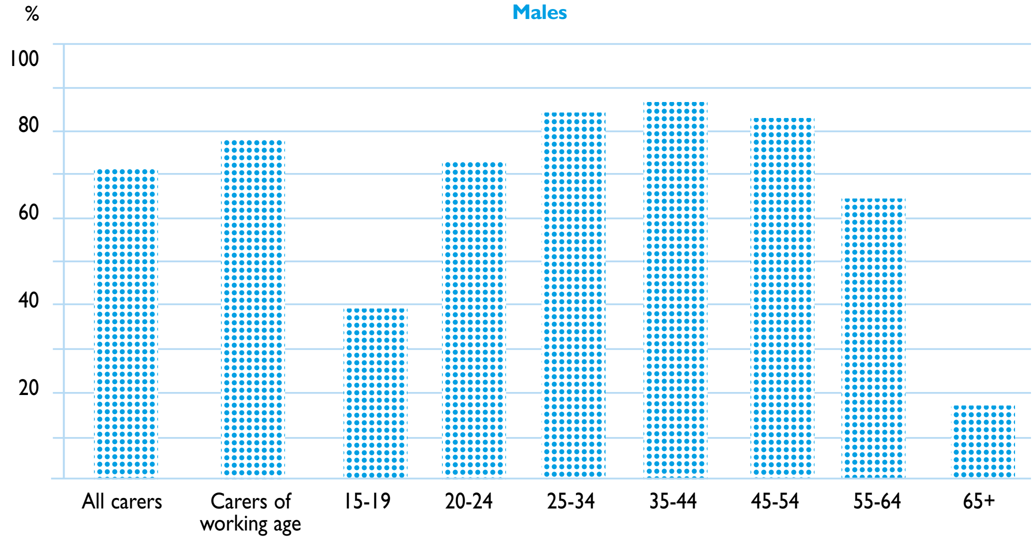
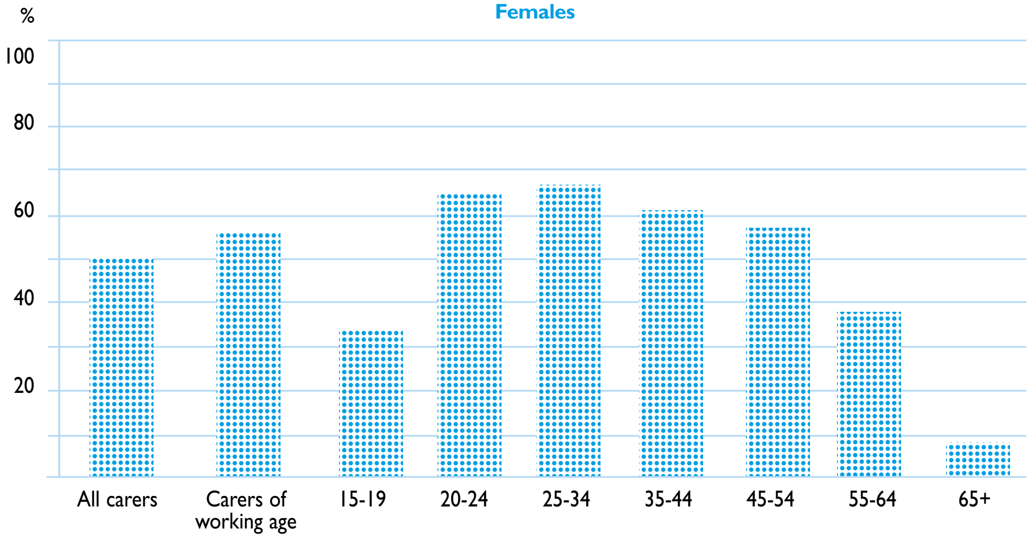


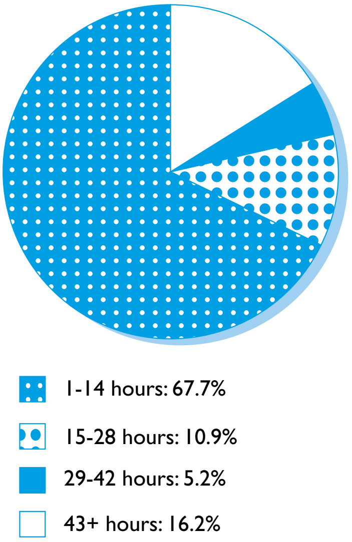
Figure 4.2: Carers' Employment Rates (%) by Age and Gender (continued)



Source: Census, 2002

The majority of working carers (67.7%) report providing between one and 14 hours of care per week but about one in six (16.2%) report that they provide 43 or more hours per week (Figure 4.3). Patterns in this regard were very similar for male and female working carers. Comparing this to the situation for carers as a whole outlined earlier (see Table 3.1 and Figure 3.1). Working carers typically devote fewer hours to caring that those not in work, and this difference is more pronounced among women.

Figure 4.3: Hours of Care Per Week by Working Carers



Source: Census, 2002

4.2 Part-time Working and Home Working

It is also of interest to consider actual and preferred working arrangements, including part-time working and working from home. Flexibility in these aspects of working arrangements may be relevant for carers trying to combine working and caring. Figure 4.4 illustrates that, in Ireland, female working carers are a lot more likely to be working part-time than are male working carers. Overall, just under two in five (39.8%) of female carers were working less than 30 hours per week in 2002 compared with just over one in nine (11.4%) men. For both men and women the rates of part-time working amongst carers seem to be somewhat higher than the rates for the workforce as a whole.

The European Foundation survey of 1998 explored these issues for carers in the EU as a whole. It found that amongst those carers who were working part-time and who wished to remain so, almost two in three (63.5%) cited wanting or needing enough time to care as being a reason for this preference. However, caring was usually just one of a number of reasons (typically including childcare needs) for the part-time preference.

The European Foundation survey also included data on location of work and it is interesting to note that carers in the EU were a lot more likely to be working mainly from home than non-carers. Carers were also more likely to express an interest in working partially or wholly from home but were only very slightly more likely to give combining work and family as a reason for such a preference. Women carers were considerably more likely to cite work family balance as a reason than were men carers.

Figure 4.4: Hours of Paid Work of Irish Working Carers

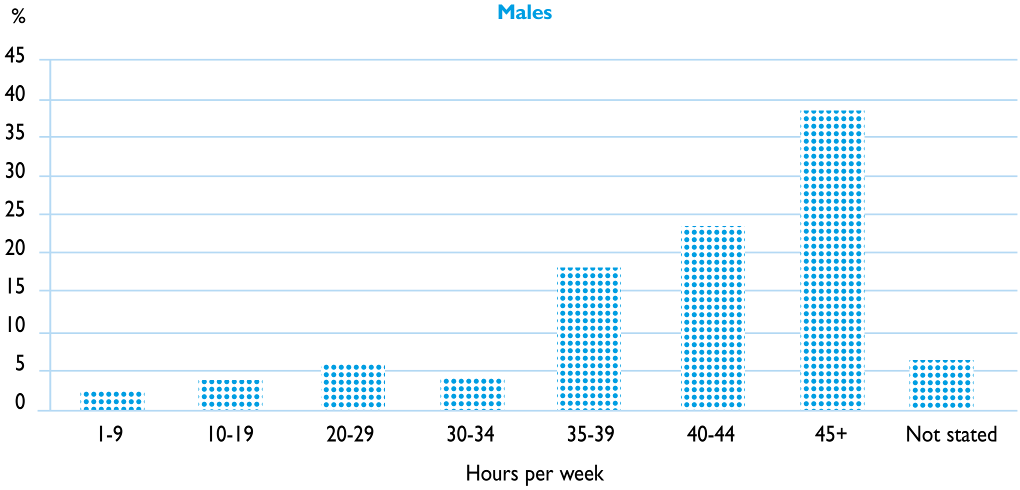
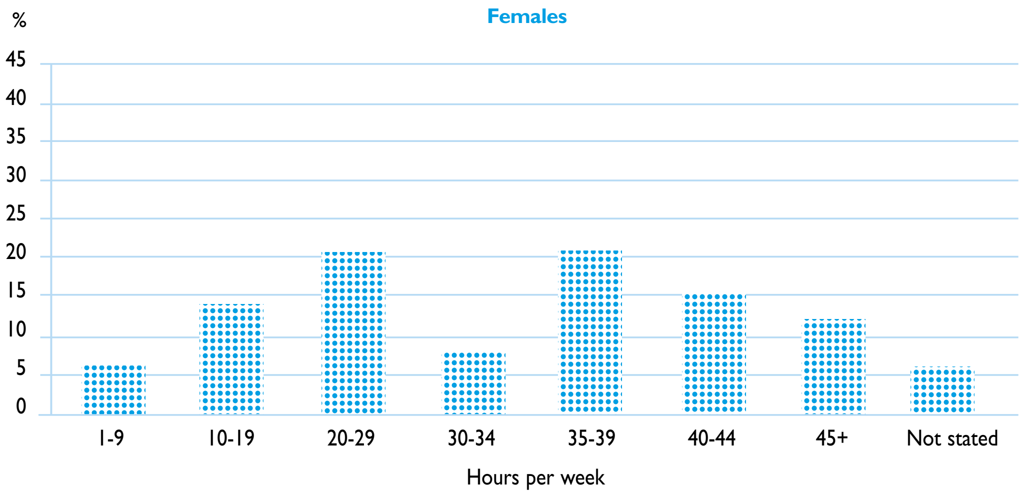


Figure 4.4: Hours of Paid Work of Irish Working Carers (continued)



Source: Census 2002

4.3 Carers in the Workforce

As well as looking at the employment situation of carers it is also of interest to examine the prevalence of caring amongst the workforce. This provides an indication of the extent that caring is a factor to be considered in the work-life balance arena and can help to identify which groups within the workforce are most likely to have caring responsibilities. The European Foundation survey (Bielenski et al. 2002) provided some data of relevance to these aspects. That survey found that carers comprised just over one in ten (10.2%) of the European workforce in 1998 with a much lower prevalence amongst the Irish workforce (4.4%). It is interesting that even with the ten-year time gap, the estimated prevalence of caring amongst the Irish workforce had only marginally increased from the 3.9% prevalence that can be calculated from the Economic and Social Research Institute 1987 survey (Callan and Wren, 1994).

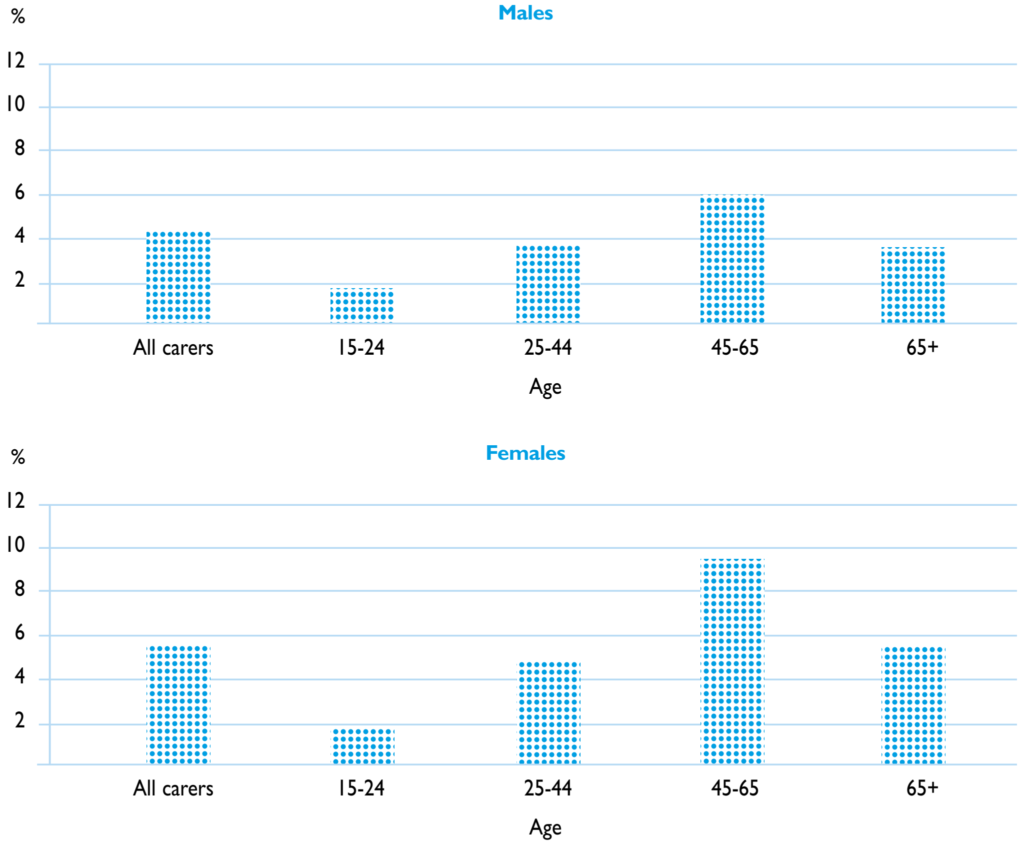
Figure 4.5 presents the most recent data on this aspect from the Irish Census of 2002. The increase since the 1990s in the percentage of the workforce that are carers has not been as dramatic as the apparent increase in the proportion of carers who are working. In fact, the Census finding of 4.7% of the workforce being carers remains close the estimates from the European Foundation survey for 1998.

A number of patterns can be discerned from the data presented in Figure 4.5. First, the percentage of the female workforce that are carers (5.7%) is higher than that of the male workforce (4%). However, because there are more men in the workforce than women, the absolute numbers of male and female working carers are very similar. Second, 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 14 of the workforce overall and almost one in ten of the female workforce in that age range.

Although the prevalence of caring amongst the Irish workforce appears to have been gradually increasing it has yet to reach anything like the estimated more than 10% of the overall EU workforce that are carers from the European Foundation survey of 1998. This may reflect a number of factors. One part of the explanation 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).

There may also be other factors at play within a policy context that does not facilitate a wide range of choices and supports for carers with different employment and caring responsibilities.

Figure 4.5: Percentage of the Workforce who are Carers by Age and Gender



Source: Census 2002

4.4 Impact of Caring on Employment Decisions and Vice Versa

Although there are many Irish carers of working age who are not currently working, it is not necessarily the case that caring is the primary factor influencing this situation. Leane (1995) concluded that available Irish studies suggest a preference on the part of carers to engage in paid employment but a tendency for female working carers to take time off for care giving and for a significant minority to give up work to care for an older person. However, other Irish data in this area shows considerable variation. For example, the proportions of carers reporting that caring duties prevented them from working have ranged from one in six (17%) to more than one in three (37%) (O'Connor and Ruddle, 1988; Ruddle and O'Connor, 1993; Blackwell et al., 1992; *Living in Ireland Survey*, 1996; and South Eastern Health Board, 2000). These variations may in part be due to different populations being targeted by researchers, for different research purposes, and in part to changing patterns over time.

A review of international research on this issue by Deven et al. (1999) concluded that there is evidence that caring does have some impact on labour market participation, leading some carers to leave work and others to reduce their hours of work. McLaughlin (1993) calculated that the effects of caring on employment appeared to begin when the carer was providing 20 hours of care a week and could take two forms: reduction of the employment rate and decreases in the proportion working full-time.

Murphy et al. (1997) argued that, for working women carers in particular, the carer role is added to pre-existing roles and the burden can have many negative implications. Working carers may also have to reduce hours or take less responsible jobs because of care-giving demands and some eventually may have to give up work to care full time (see, for example, Chappell, 1995). However, results from another study (Moen et al, 1994) found that women with both caring and working roles were more likely to stop care-giving than they were to leave their jobs.

In fact, it can be calculated from the European Foundation survey of 1998 that only about one in 40 (2.6%) of those not working but still attached to the labour market had given up work for caring reasons. These figures apply to carers who have not totally withdrawn from the labour market and it is likely that there are also carers amongst those who have permanently left the labour market who have done so because of caring responsibilities, particularly amongst those in the oldest age bands of the working age range. Even if this were so, however, it is clear that overall in the EU, when workers acquire caring responsibilities, they typically remain working and only a relatively small minority withdraw even temporarily from the workforce as a direct result of caring responsibilities.

A series of qualitative studies covering a number of European countries identified some of the factors that may be involved in the employment-related decisions of carers (Jani-Le Bris, 1993). These studies found that for many carers paid work, as well as being a source of income, was also a source of satisfaction and personal enhancement and, interestingly, was also described by some as a method of keeping distance from the care situation.

Motives for stopping or reducing occupational activity were discovered to be quite complex and data from the French and Danish studies indicated that the decision to cease employment was rarely due to caring alone. More important factors cited by carers included the availability of early retirement initiatives, redundancy and having a dissatisfying job, although the absence of satisfactory support services for informal carers could also be a factor for some carers who give up work. In the review by Arksey (2002) the role of factors such as the possibility to opt for 'voluntary' early retirement was also noted. Jani-Le Bris (1993) suggested that women appeared to be more likely than men to give up work in order to care for a family member. However, women generally had a negative view of leaving paid employment to care for a dependent older person. Some of the drawbacks identified by carers included loss of social status, recognition and prestige, loss of work relationships, loss of income and loss of freedom. Evandrou and Winter (1995) conducted a detailed exploration of the socio-economic situation of informal carers. A number of interesting findings were highlighted, including a tendency on the part of younger male carers, in the absence of part-time employment options, to completely exit full-time employment in order to care. Parents of disabled children were also found to be less likely to be in employment and to be more likely to experience lower net earnings than other parents.

Overall, however, the fact that only a small minority of non-working carers appear to leave employment directly because of caring responsibilities suggests that many people assume such responsibilities during periods of the lifecycle when they are not in employment for other reasons, particularly because of current or past childcare commitments. The emergence of caring responsibilities may therefore present additional or new barriers to employment for people in such circumstances. In fact, there is some evidence that being outside the labour force when a caring need arises (for example during child-rearing years) can be a 'risk factor' for becoming a carer. Some studies (see Jani-Le Bris, 1993) have found that such circumstances may be important considerations in the intra-familial negotiation and role allocation processes that occur when families are confronted with a caring need and responsibilities for caring are allocated.

Like others, Evandrou and Winter (1995) noted that not only may carers face employment and income effects related to their caring responsibilities whilst they are caring, they may also do so after caring ends. They argued that some effects may in fact only surface after caring ends, citing a number of studies that show that ex-carers may face difficulties in re-entering the labour market, a drop in living standards due to the loss of care-related allowances, and ineligibility for unemployment benefit. In addition, where carers give up paid employment in order to care, research has indicated that re-entry into the labour market becomes less likely as carers age (McLaughlin, 1991; Askham et al, 1992). Where people do return, ex-carers may face lower pay rates due to less seniority and career opportunities lost.

Indeed, Rimmer (1983) argued that focusing on short-term losses of earnings fails to capture the most serious consequences of leaving the paid labour force in order to become a care-giver. Leaving paid work, reducing hours worked and foregoing career advancement could also have long-term impacts, affecting pension rights, career prospects and future earnings. Similar analyses have been made in relation the long-term consequences for carers in Ireland (O'Shea, 2000). To be complete, therefore, the analysis of the relationships between caring and employment would need to consider both immediate and contemporaneous effects (interactions between current caring and current employment experiences) and longer-term effects (interactions between earlier caring and later employment experiences). Unfortunately, the lifecycle aspects of the interactions between caring and employment are not well covered in available data and research. As Deven et al. (1999) have noted, there is a lack of a 'moving picture' of how many women and men assume care responsibilities at some point in their lives, how long these responsibilities last and how this traverses with their employment histories.

Finally, the analysis of the interactions between caring and employment would need to consider both sides of the caring-employment equation. Caring may have implications for employment and, conversely, employment may have implications for caring. Involvement in employment, whether through desire and/or necessity, may reduce the extent of involvement in caring than would otherwise be preferred. A fully balanced perspective needs to take both aspects into account and focus on how people can be supported to exercise real choices in reconciling caring and employment needs and preferences over the lifecycle. For example, earlier we saw that some working carers would like to reduce their working hours. However, the impact of constraints that employment commitments may pose in relation to whether or not to and/or how to care has received relatively little attention in research to date.

4.5 Conclusions

Up until relatively recently, at least, only about one in four female carers in Ireland were working and their employment rates were considerably lower that their non-carer counterparts. The latest data from the 2002 Census suggests that a significant shift has occurred. It found that 45,464 (55.9%) female carers of working age and 39,690 (78%) male working age carers were in employment.

Carers are more likely to work part-time. In addition working carers typically devote fewer hours per week to caring than those who are not in paid work. This difference is more pronounced amongst women.

Available evidence suggests that only a small proportion of working carers leave work as a direct result of caring responsibilities. Most carers who are not working were in this situation when their caring responsibilities commenced and many would like to be in employment if circumstances were more conducive.

There are now more than 85,000 working carers in Ireland and this figure may grow further in the coming years as a result of increasing female employment rates and population ageing. Carer-friendly work arrangements are therefore becoming of increasing relevance.

5

THE NATURE OF CARING

This chapter examines available research on the nature of caring. There is clearly a lot of variation across caring situations in the levels and types of care that are needed. The amount and type of caring required will vary depending on a number of factors, including the circumstances and needs of the person cared for, the extent to which informal/family care is shared and the extent of availability of formal care services. Carers in some circumstances may experience particularly heavy demands and constraints on other activities, for example, carers of people with very severe physical disabilities and carers of people with behavioural changes of various forms, including dementia.

It is beyond the scope of this chapter to cover all of these areas in a detailed and systematic manner and, instead, the aim is to provide an overview of the levels and types of commitment that caring can involve. This can provide the basis for an analysis of the types of constraint that caring can pose in relation to employment options, and help to identify the types of services and other supports that could alleviate such constraints.

5.1 Amount and Type of Care

Caring tasks can be classified in various ways, for example:

- practical (instrumental): caring may involve practical help with domestic tasks such as preparing and cooking food, cleaning the house, and doing shopping
- personal: caring may also involve the provision of personal care, such as washing and bathing, help with getting dressed, and providing continence care
- monitoring/supervision: caring may sometimes involve monitoring and/or supervision, for example in the case of people with dementia who become forgetful or confused when using appliances (e.g. cookers) or who become disoriented or 'wander' during the day or night
- care management: carers may also provide support through management activities such as liaising with health professionals, co-ordinating care services and organising other informal carers (if they are present)

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 5.1). 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.

Table 5.1: Level and Type of Dependency Amongst Older People Living With Their Principal Carer

	Category of Dependency	%
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

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 5.2 below.

Table 5.2: Average Hours of Care by Level of Dependency and Type of Care

	Level of Dependency						%
Type of care	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	59.4	84.6	62.7	58.8

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 although hours of caring were long, hours of help received by the principal carers in this sample were negligible, with an overall average of 2.4 hours per week.

In this study it was also possible to get some tentative indications of the relationships between carer employment status and the degree of dependency of the person cared for, although numbers were relatively small and conclusions need to be treated with caution. Overall, the percentage of carers in paid employment declined with degree of dependency, and none of the carers of people in the higher dependency categories (D and E) were in paid employment. Amongst those who were in employment, levels of part-time employment increased with increasing dependency and net weekly pay decreased.

Table 5.3: Types of Care Received from Carers

Type of Care Older People Received	From Carers Living With Them %	From Carers Not Living With Them %
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 and Ruddle, 1988

O'Connor and Ruddle (1988) looked at the care provided by carers living with the person cared for and by those living in another household (see Table 5.3). 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.

Ruddle and O'Connor's (1993) study of carers of people with dementia found a greater need for help with personal tasks and a frequent requirement for supervisory care amongst this group.

As noted by Blackwell et al (1992) and others, informal care often, if not always, includes an emotional involvement, since it is most often the spouse or children who are providing care. Therefore, as well as the provision of physical hours of care, caring includes affection, sensitivity, commitment and a willingness to be depended on, and caring activities are sometimes difficult to separate from other relational activities such as companionship and nurturance.

In addition, caring takes place within the context of a complex relationship that may involve not just love and affection but also interdependence, guilt, mutual obligation, domination-subordination and ambivalence. These relational aspects can sometimes add a considerable emotional burden on top of the more practical challenges of caring. In some cases, for example, carers may feel guilty about going out to work or those that they care for may resent the absence of care and attention during working hours. Support services for working carers therefore need to address both the practical and emotional aspects.

5.2 Caring Over the Day and Week

One important practical aspect of caring is the timing of the care needs that the carer must respond to. Whether these are compatible with the time requirements of paid work will be a significant factor affecting employment options and possibilities. A number of Irish studies have explored this aspect of care. It should be noted however that the majority of carers in these studies were not engaged in paid employment.

The O'Connor and Ruddle (1988) study of carers of older people found that most of the carers in the sample (69%) did not have a specific daily schedule of tasks, although there were tasks that they carried out on a daily basis. For the majority (68%), caring started from between eight and ten in the morning. Fifty per cent of carers devoted four to seven hours each day to caring, with some of the carers in the sample who worked outside the home reporting such long hours of caring as well. The Ruddle and O'Connor (1993) study of carers of older people with dementia found that in this case there was a requirement for a higher intensity of caring because of the particular challenges posed by dementia. Caring was reported to be a round-the-clock job for the majority (69%) of their sample. Over half of the carers (54%) devoted between eight and 14 hours each day to caring and for another 23% of the carers, caring took from 15 to 24 hours per day.

In terms of the distribution of caring over the day, differences also emerged from the above two studies. O'Connor and Ruddle (1988) found that caring tasks were spread throughout the day, with a typical pattern of one to two hours spent in caring throughout the morning, again in the afternoon, and again in the evening time. Night time tended to be the only period free for most carers (77.7%). The second study of carers of people with dementia (Ruddle and O'Connor, 1993) found that they typically gave two to three hours caring from morning to mid-day (61%), four or more hours in the afternoon and evening, and less time at night. However, only 39% of carers reported giving no time to caring at night, with the majority (53.6%) reporting that they provided between one and three hours of care at night.

The South Eastern Health Board (2000) study found that almost half of the carers in the sample (47.9%) spent between 16 and 24 hours caring daily, with only 17.4% reporting giving three hours or less. More than half the sample (50.5%) reported providing care overnight; the majority (80.4%) of these reported having to get up one to three times during the night and a smaller number (16.8%) reported having to get up more often to provide care. Eighty-eight percent of respondents reported providing care on all seven days of the week.

These studies provide some indication of patterns of caring over the day and night, and of how these can vary quite widely, although they do not provide any definitive insights into the interactions between the timing of care needs and work requirements. For example, it is not clear in some cases whether care was being provided in a particular pattern during the day because this was what was required or because this suited the carer, or some combination of the two.

5.3 Impact of Caring on Carers

Research on carers in Ireland has identified the financial costs of caring for the carer to be an important yet frequently overlooked factor (O'Connor and Ruddle, 1988). Apart from costs associated with employment constraints this research also drew attention to the extra expenses that can be involved in providing for the special needs of the person cared for (for example, extra heating costs, special diets and so on). O'Shea (2000), however, noted the complexity that can be involved in estimating the extent of expense that can be directly attributed to the caring role. For example, if the carer lives with the person cared for it is often difficult to estimate how much extra money is spent to feed and heat the person being cared for. On the other hand, some carers may need to buy more expensive convenience foods, take taxis shopping, or pay for services such as decorating that they no longer have time to do themselves because of the restrictions of the caring role.

Other studies have also identified financial issues as being significant. Blackwell et al. (1992) reported that more than one in three carers (37%) experienced financial strain and the South Eastern Health

Board (2000) study found that a similar proportion of carers (38.5%) experienced financial worries as a result of providing home care. Apart from financial costs caring can often have social costs as well. Some carers may find themselves housebound much of the time, especially when the person being cared for is immobile or confused. Reflecting this, both O'Connor and Ruddle (1988) and Ruddle and O'Connor (1993) found that many carers reported caring affected their social life to some degree. These carers felt less able to leave the house, went out in the evening less frequently, and found themselves too tired to engage in social activity.

O'Connor and Ruddle (1988) also investigated experiences of strain in terms of physical and emotional wellbeing, family relationships, financial circumstances, free time and personal and social life. They found that emotional strain was the most evident impact on carers. Two-thirds of carers (66%) found the changes in the older person upsetting and one in three (30%) found problems such as incontinence or memory loss difficult to cope with. Over one third of the carers reported having felt completely overwhelmed with worry about the person being cared for. Twenty-five per cent indicated that caring had involved major emotional adjustments.

Ruddle and O'Connor (1993), in their detailed exploration of the experience of strain among carers of people with dementia, found that 38% of carers experienced 'a great deal' of stress in caring with a further 19% describing themselves as experiencing 'quite a lot' of stress. Sources of stress included never being able to get away from caring, aggression of the person with dementia, need for constant surveillance, feeling under pressure to get things done and seeing the changes and deterioration as the condition progresses.

Blackwell et al. (1992) found that almost one third (29.5%) of carers in their study had a level of psychological distress that put them at risk of clinically diagnosable anxiety/depression and this was a lot higher than the one in six (16.5%) of the general population reporting similar symptoms. In terms of specific strains associated with caring, the most frequently cited were the experience of caring as confining (65%) and the physical efforts required (46%). Finally, the South Eastern Health Board (2000) study found that whereas the vast majority (89.3%) of carers rated their emotional health as having been very good (40.7%) or good (48.6%) before becoming a carer, these ratings fell to 19.2% and 40.7%, respectively, following engagement in the care-giving role.

In relation to physical health, O'Connor and Ruddle (1988) found that 68% of the carers in their study reported that they suffered from some chronic health problem themselves, with 24% reporting being in poor health. Almost one third (30%) believed that their health had suffered due to the demands of caring. Ruddle and O'Connor (1993) found a slightly more optimistic picture, with only 11% of respondents rating themselves as having poor or very poor health although 38% of the carers did say that they had experienced health problems. In this context it is important to note that while many of those cared for are people with disabilities, many carers are also people with disabilities.

The South Eastern Health Board (2000) study found an even more negative situation, with a significant proportion of carers reporting deterioration in their physical health since taking up a care-giving role. While 83.2% described their physical health as very good (45.3%) or good (37.9%) prior to becoming a carer, only 56.8% reported this to be the case after becoming a carer.

Taken together the results of these studies suggest that many carers may have health problems themselves, whether due to their own advanced years, the stresses and strains that may result from caring or some combination of the two. As well as the practical constraints that may result from caring, such problems may pose additional barriers to employment for carers.

5.4 Conclusions

This chapter drew on the Irish literature describing experiences of caring which indicates that caring experiences and tasks vary greatly but can be categorised to include practical/instrumental assistance, personal care tasks, monitoring and care management.

In general, hours spent caring increase in line with the level of dependency of the person being cared for. For some carers the experience of caring is characterised by long hours and frequently includes caring seven days a week care and caring at night, including getting up at night to provide care. The level and type of care provided may differ if the carer and person cared for share a home and on the needs of the person cared for with some conditions requiring more intensive care than others.

We have seen that the financial costs of caring, including opportunity costs arising from employment constraints, and extra expenses to cater for everyday and special needs of the person cared for or arising from caring, often result in financial strain and worry for carers. In addition caring responsibilities may preclude the fulfilment of a full social life. Indeed, a number of studies have shown that caring can take a toll on the carer's mental, emotional and physical health. Many carers have their own chronic health problems or disabilities.

6

COMBINING CARING AND EMPLOYMENT

This chapter looks in more detail at the practical issues arising for those who combine, or who would like to combine, caring and paid work. Available research on the experiences of working carers is reviewed, including the types of impacts that caring can have on the carer's work and the possible impacts of combining working and caring for the physical and psychological well-being of the carer. In fact, there is very little Irish research available on this topic. O'Connor and Ruddle (1998) found that about two in five of the working carers of older people in their study had taken time off because of caring responsibilities and about one in six reported negative effects on career prospects. A subsequent study focusing on carers of people with dementia found that the majority of working carers reported difficulties balancing work and caring and almost two in three had to take time off, with one in five having to do this frequently (Ruddle and O'Connor, 1993).

Although direct research on working carers has also been fairly limited internationally, there is some data available on the interactions between caring and employment, and on the implications of combining both roles. Cullen and Clarkin (1994) synthesised the results of (mostly US) research on the topic in the 1980s and early 1990s. The following sections present the main findings of their review, augmented with more recent material collected during the course of the current study.

6.1 Care Provided by Working Carers

Table 6.1 presents some data from the US on the types of care provided by working carers (AARP, 1989). In that study working carers reported providing a wide variety of forms of help and support for those that they cared for, and there was relatively little difference between carers working full-time and carers working part-time in their frequency of reporting carrying out the various types of care tasks. However, both groups of working carers were more likely to report providing instrumental forms of care, such as shopping, transportation and preparing meals, than personal care tasks such as help with bathing, feeding or using the toilet. Nevertheless, significant numbers of working carers did report providing these personal forms of care.

As will be discussed later, some of these types of care, such as help with using the toilet, pose particular logistical challenges in the sense that they involve needs (so-called 'critical interval' needs) that must be dealt with immediately as they arise. It is likely, therefore, that unless the working carers were working from home, there were generally other sources of care available during working hours.

Table 6.1: Care Provided by Working Carers

Type of Care	Working Full-time %	Working Part-time %
Personal		
Walk Around Inside	44	52
Bathe	34	36
Dress/Undress	33	41
Use the Toilet	26	34
Feeding	24	29
None	36	32
Instrumental		
Grocery Shopping	82	78
Transportation	81	78
Housework	75	72
Managing Finances	66	58
Preparing Meals	64	67
Administering Medicine	42	38
None	1	3

Source: AARP, 1989

6.2 Impact of Caring on Carers' Work

Quite a lot of research in the US has concentrated on the impact of care-giving on the working lives of carers. This has included studies on negative day-to-day impacts, on the need for employment adaptation (Sharlach and Boyd, 1989; Franklin et al., 1994) and on impacts on employment and career decisions (Hirst, 1992). Available evidence seems to indicate that about 20% of US employees who care for older people experience workplace problems of some form (Tennstedt and Gonyea, 1994). Examples of the types of impact that have been found are presented in Table 6.2 based on a study of nearly nine hundred employed carers (Sharlach and Boyd, 1989).

The importance of the telephone for working carers can be seen from Table 6.2, with a majority of carers reporting using the phone during working hours to deal with care-related matters. Having the opportunity to take and make personal calls is therefore an important issue for working carers. Many carers do a lot of managing of care for their dependants whilst they are at work and some research has suggested that organising and managing care by others can be as stressful as giving care directly in some circumstances (Neal et al, 1993). This raises the importance of reasonable accommodation of carers by employers.

Table 6.2: Impacts of Caring on Day-to-Day Work

Happened at least once or twice in previous 2 months	%
Used Telephone for Personal Care	70
Used Vacation Time	40
Took Day Off (With Pay)	33
Left Early	33
Too Tired to Work	33
Changed Work schedules	20
Missed Out on Overtime	16
Arrived Late for Work	15
Extended a Break	15
Considered Quitting	9
Took Day Off (Without Pay)	7
Missed a Meeting	5

Source: Sharlach and Boyd, 1989

Other practical solutions used by working carers included using vacation time to make caring contributions, taking time off with or without pay, arriving late or leaving work early, extending a break and changing work schedules. About one in three carers reported being too tired to work on occasion and a small proportion reported specific impacts such as missing a meeting.

The impacts of caring on work can vary considerably by occupational level and by gender. There is general evidence that men tend to organise their family commitments around the needs of their work whereas women tend to organise their work around their family commitments. Also, it has been suggested that executives/professionals are more likely to rearrange their work schedules or decrease their hours of work whereas production workers are more likely to take unpaid leave (Barr et al., 1992), presumably reflecting the different degrees of freedom of the different groups of workers.

6.3 Impact on Carers

Recent research in the UK suggests that the competing demands of caring and work may be more likely to impact on the family and the carer's health rather than on their work (Phillips et al, 2002). This section turns to the issue of the kinds of impacts that combining the dual roles of caring and working can have on the carer.

Studies in this area have looked at various aspects. Some have focused on the opportunity costs associated with time trade-offs (White-Means, 1992; O'Shea, 2000) and other aspects of the financial costs of caring (AARP, 1989; O'Connor, 1993; Caring Costs Alliance, 1996). Others have looked at stress of the caregiver 'burden' (Chiriboga, et al., 1988; Anastas et al., 1990; Sharlach et al., 1991) and gender differences in responses and impacts (Dwyer and Seecombe, 1991). Others have noted the positive impacts of employment as a respite and source of other fulfilling experiences (Orodenker, 1990).

The main focus in this section is on the immediate, day-to-day consequences for carers of having a dual worker-carer role, especially in relation to physical and emotional stress. In fact, Tennstedt and Gonyea (1994) concluded that overall the results of studies in this area have been somewhat equivocal. Some negative impacts on carers in terms of increased stresses and strains have been reported in the research. However, buffering effects have also been reported, whereby having a paid job provides respite and other positive experiences that can counteract some of the negative impacts of caring. This may particularly be the case where appropriate supports such as flexibility in working arrangements and respite or day care facilities are available (Orodenker, 1990). Similar contradictions have been found in relation to emotional impacts on women working carers, with some studies finding links (Kendig, 1983; Mui, 1992; Harper and Lund, 1990), and others finding no association between work and carer well-being (Stull et al, 1994).

Arksey (2002), in particular, reiterated the beneficial potential of paid work for carers. She quoted extensive research (Briggs and Oliver, 1985; Stoller and Pugliesi, 1989; Phillips, 1994; Scharlach, 1994; Rands, 1997; Kagan et al, 1998) that showed that the benefits of employment extend beyond the provision of an income and pension rights. These studies found that employment had a positive role by helping to maintain social networks, providing temporary relief from the caring role, enhancing self-esteem and offering the opportunity to share concerns with colleagues. It could also have beneficial effects on carers' physical health and on their emotional well-being.

Murphy et al (1997) carried out research on daughters caring for an older parent, with a focus on how the degree of conflict between the working and caring roles can influence the impacts of working and caring for the carer. The analysis was based on Garvin's (1991) definition of role conflict as 'conflict that exists because one occupies two or more positions and the prescriptions for one position conflict with the prescriptions for another'. Murphy et al. found that, when asked how their care-giving responsibilities had affected their work, two-thirds of respondents said they found their work a source of relief and an opportunity for another interest (65%). However, one third said they had less energy for work due to care-giving demands and 29% had repeated interruptions at work.

Amongst the carers studied, just under one in five (18%) reported no ill effects of combining work and caring (these were referred to as 'Unconflicted Workers'). Almost one in three (31%) were maintaining their work role despite at least one adverse effect on their work such as working fewer hours or refusing promotion (these were referred to as 'Conflicted Workers'). Just over one in five (22%) were unable to work or had resigned because of care giving (referred to as those who 'Quit Work') and just under one in three (30%) were not working, but did not attribute this to caring ('Traditional Non-workers'). Those who were conflicted or who had 'quit' work reported higher overload than either traditional non-workers or un-conflicted workers. In addition, those who had quit work reported higher resentment than the other groups, while conflicted workers reported higher resentment than un-conflicted workers.

In relation to workplace factors that could reduce carer role conflict and stress, Jani-Le Bris (1993) did not find evidence of a high degree of flexibility in employment settings for working carers. However, she did identify a number of strategies adopted by working carers to minimise stress, including delegating tasks to other people, employing a daily minder and working part-time (mainly by women) as an alternative to ceasing work entirely.

Most studies of working carers have focused on those caring for older people. Kagan, Lewis, and Heaton (1998), however, analysed detailed accounts of parents from 40 families in the UK who combined employment with care of disabled children. They found that these parents felt that they needed to work not just for financial reasons but also to provide another source of self-esteem that helped them to feel that they were active participants in society. Many of the parents (particularly mothers) found it difficult to combine the working and caring roles. Compromise was almost always required in relation to hopes and aspirations and putting up with some degree of economic hardship was often required. Importantly, this study found that the tensions between work and family did not always ease as the child got older and could continue indefinitely. Available employment options were often seen by the parents in this study as being inflexible and unsuited to their needs, and they often had to undertake casual, insecure and unpredictable work that excluded them from employment rights. In addition, parents were often reluctant to ask for the flexibility they needed, especially if this was regarded as a favour rather than something they were entitled to. On the other hand, some employers were seen as being very flexible and supportive.

Broader research on working carers in the public sector in the UK has looked at how the needs of carers are catered for within family-friendly schemes in the workplace (Phillips et al., 2002). That study found that access to workplace supports was often conditional on the individual's level within the organisation, the type of job that they did and the nature of the work. More generally, the authors made the observation that whilst managers tended to view such schemes as helping workers to 'balance' the conflicting demands of work and home life, carers tended to perceive work-life issues as more of a complex 'juggling' act between the competing demands on their time and energy.

That study also found that the demands of working and caring were felt most forcefully on family life and on the carers' own health, rather than on their work. Importantly for the current study, access to personal home care was felt to be the most helpful type of support but few carers had extensive networks of services and benefits that they could call upon for support.

6.4 Impact on Care

Very little research has examined whether the fact that a carer is in employment may affect the quality of care provided and the well-being of the person being cared for. There are a variety of ways in which such impacts might arise. For example, difficulties may be experienced in carrying out specific aspects of care to a satisfactory level of quality or even at all. In some cases there may also be a move to withdraw to some degree or even completely from the care-giving role. If adequate, alternative care arrangements are not put in place this could result in neglect of the person being cared for.

Apart from this extreme it seems likely that in the absence of alternative sources of care during working hours, some dependants of working carers may experience loss of companionship or loneliness, and some may experience discomforts of various sorts and/or be constrained in relation to what they can do. In some cases, also, the practicalities of combining working and caring may mean that some working carers must leave vulnerable and potentially at-risk dependant people unattended during working hours. Adequate supports for working carers are essential if these types of situation are to be avoided.

6.5 Conclusions

This chapter summarises research on experiences of combining caring and employment roles. For some carers their responsibilities impact significantly on their work. US studies have found that many carers report effects on work such as taking time off to provide care, leaving early from work and being too tired to work. The impact of caring on working life has been shown to vary by gender and occupational position. In general, individuals in higher occupational positions enjoy greater freedom to control their work schedules. Further to this access to family friendly working policies may be affected by occupational position or type of work.

The conflict arising from combining working and caring has the potential to interfere not just with work but also with the quality of care provided. It is vital that adequate supports are in place to provide high quality substitute care when the primary carer works. Crucially, as care is most often provided with the context of family or close friendship relationships it is important to emphasise the emotional context of caring. This is a dynamic which should be considered in the provision of supports to caring arrangements.

Although caring can impose various burdens on carers, the evidence from studies of both working and non-working carers indicates that having the opportunity to continue paid work or to return to paid work after a period of caring is a fundamental requirement for most carers. Apart from employment being a financial necessity and/or an important means of involvement, expression and fulfilment, work can also provide a respite for carers from the demands of caring. This may reduce the likelihood of negative health impacts and improve the well-being of carers. Also, because it can improve and sustain the capacity to care, it may often be of benefit to the person cared for as well.

On the other hand, it has been argued that combining work and care is often more of a juggling act than a well worked-out balance. There is evidence that in some cases the dual role can pose a variety of strains, with negative impacts for the carer and for the carer's work. For those who are being cared for, the practical constraints that work poses for their carers may, in the absence of alternative sources of care, result in negative consequences. Therefore, working carers and those that they care for need to be provided with the services and supports that reduce the strains of the dual role as much as possible.

7

CARERS' NEEDS FOR SERVICES AND SUPPORT

Previous chapters have presented an overview of available research on the experiences of carers in general and of working carers in particular. This chapter begins our discussion of the type of policy responses required. It suggests that the starting point for this must be a clearer commitment to facilitating a combination of working and caring. This requires greater appreciation of the varying needs and interests of carers and of the types of services and supports that meet these needs and enable carers to fulfil their aspirations as regards employment and other areas of life.

7.1 Varying Needs and Interests

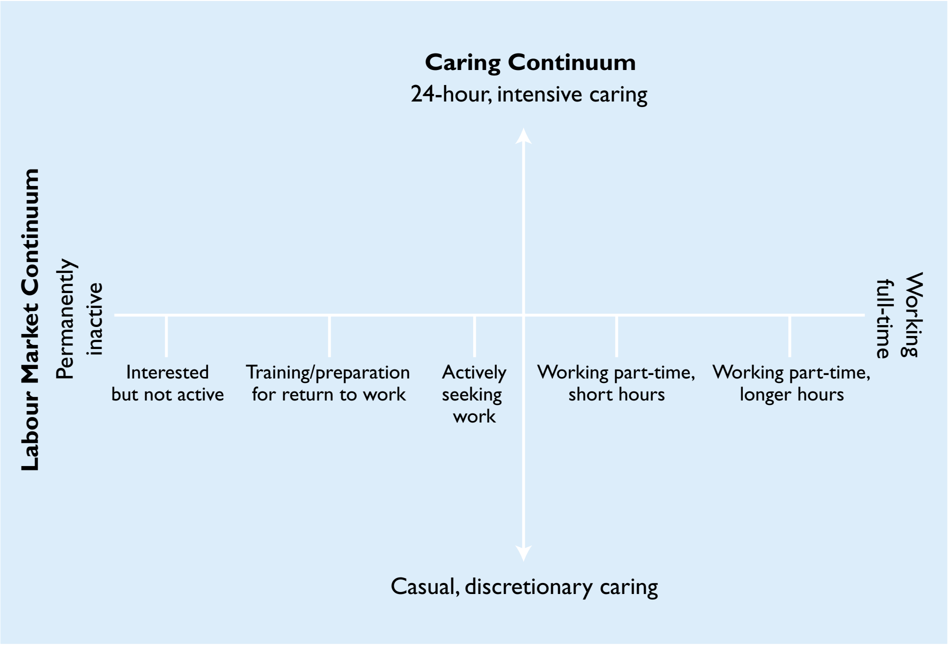
Historically, the implicit constituency and focus of attention of the main carer advocacy and support groups in Ireland has mostly been those people for whom the timing, nature and extent of the care that they provide makes 'carer' their primary socio-economic role. Almost by definition, such a role is viewed as largely incompatible with active participation in the labour market and hence the focus has mostly been on lobbying for a state payment to carers to formally recognise and recompense those in this role rather than on supports to enable working and caring roles to be combined.

The formal definitions of carers in social welfare provisions and, more recently, in social insurance and employment provisions are also largely oriented towards a view of carers as people with very extensive caring responsibilities to the extent that caring may be their main socio-economic role, often precluding participation in paid employment. As we have seen, however, such definitions exclude many people who provide significant amounts of care whilst also engaging in other activities such as paid work. They also tend to reinforce a notion that people are either carers or workers rather than reflecting the reality that, as we have seen, many people combine both roles.

Arguably, therefore, it would be more useful to conceptualise care and employment in terms of two interacting continua (see Figure 7.1). The care continuum ranges from 24-hour intensive caring for people who are very dependent and have extensive needs to more casual and discretionary care provision for people who have less extensive needs and are less dependant or for whom others are providing the bulk of care and support. The employment continuum ranges from permanent inactivity to full time working.

These continua intersect in different places for different people. People can vary significantly in their preferred and actual positions on the two continua and each person needs to be supported to achieve an optimal balance that suits their preferences and circumstances.

Figure 7.1: Caring and Labour Market Continuum Concepts



On the basis of this 'continuum' perspective, the reality of combined working and caring roles may have implications for various aspects of labour market participation and employment. These may include:

- the opportunity to continue working or to seek work, if desired and/or necessary
- the opportunity to discontinue working or not to seek work, if desired and/or necessary
- to be supported in one's caring duties so as not to carry over such a deficit (in terms of stress, tiredness or physical or emotional ill health) as to be unduly affected in terms of the quality of one's working life or unduly at risk of stress from work-life imbalance
- to balance working and caring preferences and needs in a way that best suits the carer's circumstances
- to compete without discrimination and to be considered equally for types of work for which one is qualified
- to compete without discrimination and to be considered equally for work conditions (pay, contractual aspects and so on) for which one is qualified
- to compete without discrimination and to be considered equally for preferred working arrangements (including hours of work, flexibility and so on)
- to compete without discrimination and to be considered equally for promotions and other forms of career advancement
- to avail without discrimination and equally of training and other supports to facilitate return to employment or to the labour market
- to avail of positive action and reasonable accommodation provisions by employers

7.2 Practical Issues for Working Carers

Some carers have continuous caring responsibilities that may arise at any time throughout the day and often the night as well. For others, the critical caring inputs may be needed at regular times, such as preparation for the day or meal times and for some others, the nature of their caring responsibilities may afford more flexibility in when it is done, even if some degree of care may be required every day. For the working carer (or carer who aspires to work) without any support from others, whether from informal or formal sources, the time constraints of caring may thus vary considerably.

For some carers the nature of their caring responsibilities can be such that they have difficulties leaving the home for any substantial length of time. In these cases, the opportunity to work from home may be the only viable option for combining work and care, even if this is not necessarily always a preferred option.

Although many forms of care require the physical, hands-on presence of a carer, some forms may be done remotely. The extent of constraints in terms of having to be physically present with the person cared for can therefore also vary to a certain extent. Regular social contact and support can be provided, at least in part, by telephone. Some forms of supervision can also be supported by telecommunications-based alerting systems that notify the carer if the person being cared for needs help. In addition, for some carers a significant amount of their caring involves management or co-ordination of care by others and this can often be done by telephone from any location, including work.

Where critical caring inputs may be needed at regular times, the logistical issues are similar to those faced by many working parents. Accommodation of carers' constraints in time and place and their need for flexibility may be needed not just in the basic organisation of work but also in the processes that affect status, reward and progression at work. For example, a 'long hours' culture, where staying in late, taking work home and working at weekends, or being available after hours, is seen as an indication of contribution and or commitment, may leave carers at a disadvantage vis à vis their colleagues. Carers may also face difficulties where work-related travel is important. More generally, they may experience disapproval because of absences from work or because of their need for flexibility.

For many people caring has other significant aspects in addition to practical constraints in time and/or place. In some cases there can be a constant worry and distraction when the carer is not with the person being cared for. There can also be specific consequences such as lack of sleep and tiredness when sleep is regularly disrupted, as well as more general health consequences resulting from the physical and mental stresses of caring. Psychological consequences may include burnout and other forms of distress such as depression and anxiety. Finally, there can also be emotional consequences arising from the impacts of caring on relationships. These types of consequence can also pose significant constraints on the carer although they may be less obvious and visible than the more practical ones outlined earlier.

It will be clear from the above that the relevance of various services and supports will vary across carers, depending on their circumstances and preferences. One factor concerns whether or not the carer wishes to continue working whilst caring or to take a break from employment. The availability of affordable substitute care, whether publicly provided or privately purchased, is particularly relevant in the former case. In the latter case, the opportunity to take a break from work with minimum financial and career penalties is particularly relevant. Some other factors that may also play a role in determining the services and supports of relevance under different circumstances are outlined below.

The amount and type of care needed and/or being provided is clearly a relevant factor. This can be assessed in various ways, including:

- number of hours of care (for example, per day or per week)
- temporal aspects and constraints (for example, whether the need for care is on a continuous or intermittent basis)

- locational aspects (for example, whether the carer must be physically present to provide the care or whether it can be done by telephone, alarm system and so on)

Another dimension concerns the actual/desired relationship between caring and working for those who are combining working and caring. Some carers may need and/or prefer clear separation and boundaries between working and caring times and places; for others, a less clear separation and blurring of the boundaries, with caring during working times and/or places, or vice versa, may be acceptable or even preferred. In the first case, substitute care services during working hours and/or adjustment of working hours to accommodate caring needs are the main options for balancing work and care. In the second case, three modes or levels of caring may be involved in varying combinations:

- proximate care (where the carer is in the same place as the person needing care, for example, working at home and providing simultaneous care)
- remote care (where the carer is at another location and provides care with the support of telecommunications in some form, for example, keeping in touch with or monitoring the person being cared for whilst at work)
- management or co-ordination of care by the carer (where the carer does not actually provide direct care but instead manages care by commissioning and/or co-ordinating others, for example, managing the logistics of care whilst at work)

The care preferences of both the carer and person cared for will be relevant factors in determining what forms of care are most suitable.

7.3 The Need for a Range of Service Options

There have been few studies that have specifically focused on the needs of carers for services and supports to enable them to continue in or return to work. However, it is possible from the analysis of the employment-related experiences of carers, and of what is involved in caring more generally, to identify the types of services and supports that would help carers to fully realise their employment aspirations.

Table 7.1 provides a summary overview of how various services and supports relate to the various circumstances and preferences of carers. This mapping is intended to be indicative rather than definitive. For example, the distinctions between levels and types of dependency are somewhat arbitrary and are used here merely to indicate that different levels of services may be needed to substitute for family care, depending on needs. Nevertheless the mapping provides a useful initial overview of what would be required to enable carers to have a genuine choice in reconciling employment and caring needs and preferences under various circumstances.

Table 7.1: Services and Supports Most Relevant Under Different Circumstances

Carer's preferences for reconciling caring and employment interests	Level/type of dependency of person cared for	Core services and supports needed	Other potentially relevant services and supports
Continue (or return to) work whilst caring, without undue costs in terms of quality of working and non-working life, health and well-being, working conditions and career advancement	High dependency, with critical interval needs	All-day formal care services (to substitute for family care during working hours)	Possibly continuous formal care services to substitute for family care outside of typical working hours, depending on work arrangement Social alarm service Respite services Appropriate and equitable financial support if services have to be paid for
	Moderate dependency, with short interval needs	Regular, daily formal care services (to substitute for family care working hours)	Possibly regular formal care services to substitute for family care outside of typical working hours, depending on work arrangement Social alarm service Respite services Appropriate and equitable financial support if services have to be paid for
	Low dependency, but vulnerable	Social alarm service (to enable help to be summoned in the event of an emergency arising)	Appropriate and equitable financial support if services have to be paid for
Take a relatively short-term (complete) break from current employment to care, without undue costs in financial terms, or in future employment and career and social insurance entitlements	May vary	Income maintenance at acceptable level No employment, career or social insurance penalties	Appropriate support from formal care services Social alarm service Respite services Appropriate and equitable financial support if services have to be paid for
Temporarily reduce working hours to care, without undue costs in financial terms, or in future employment and career and social insurance entitlements	May vary	Income maintenance at acceptable level No employment, career or social insurance penalties	As above

Table 7.1: Services and Supports Most Relevant Under Different Circumstances (continued)

Carer's preferences for reconciling caring and employment interests	Level/type of dependency of person cared for	Core services and supports needed	Other potentially relevant services and supports
Take a longer-term break / remain outside the workforce for a relatively long period to care, without undue costs in financial terms, or in future employment and career and social insurance entitlements	May vary	Income maintenance at acceptable level Equitable social insurance provisions/continuity Support to enter/re-enter workforce (training, phasing out of allowances etc.)	As above
Permanent exit/remain permanently outside the workforce to care	May vary	Income maintenance at acceptable level Equitable social insurance provisions/continuity	As above

7.4 Conclusions

There is a need for a lot more direct research on the needs of carers in Ireland for services and supports. Nevertheless, there is enough information on the needs and circumstances of carers to provide a broad indication of the types of help that would enable carers to have genuine choices between caring, employment outside the home, or a combination of the two. To ensure genuine choices are possible, a spectrum of services and supports tailored to the variety of circumstances and preferences of carers must be available. This spectrum includes:

- care services to substitute, as necessary, for family care, delivered in ways that meet the needs of working carers and those cared for
- appropriate and equitable financial support where such services have to be paid for
- appropriate and equitable income maintenance support for those who must reduce or remain without employment-related income
- protection of employment and career situation during temporary withdrawal or down-shifting
- appropriate and equitable continuity in and protection of social insurance contributions and entitlements

The following two chapters consider the extent to which current Irish policy on care services and other supports provided for carers adequately cover this required spectrum.

8

PROVISION OF CARE SERVICES

This chapter looks at the services likely to be of particular relevance for carers wishing to combine working and caring. It first provides a basic description of relevant services and provisions, distinguishing between services promoting independent living, community care services that substitute for family care during working hours, residential care provision and tax reliefs on the costs of caring. Some key equality issues of relevance for carers are then outlined.

In discussing the infrastructure of care services it is important to remember that, as noted by the Health Strategy's Consultative Forum Sub-Group on Eligibility (2001), although the terms 'eligibility' and 'entitlement' tend to be used interchangeably in everyday usage they are in fact legally distinct. The Health Act (1970) explicitly provides for eligibility for services but it does not explicitly provide that an eligible person is entitled to receive a service. Thus, to be eligible means that a person qualifies to avail of services, either without charge (full eligibility, applying to medical card holders) or subject to prescribed charges (limited eligibility, applying to those without medical cards). The Act does not confer entitlement on an individual to receive a service insofar as this may be taken to mean a legally enforceable right.

8.1 Overview of Main Services

The availability of appropriate health and social services is essential if people are to be enabled to fulfil working and caring roles at the same time. Services do this in a number of ways. Here we distinguish between services promoting independent living, community care services that substitute for family care during working hours, residential care provision and tax reliefs on the costs of caring.

Supporting Independent Living

At the outset it is important to emphasise that services that can help older or disabled people to care for themselves and to live as independently as possible are of central importance for these individuals in their own right, while also reducing the requirement for family members or others to act as carers. The development of personal assistant services is particularly relevant here. Other services which can support independent living include home adaptation, assistive technology and social alarm systems, and a range of preventative services.

Personal Assistants – Personal assistant services, in particular, have been identified by the disabled community as a tool for empowering and enabling independent living. Personal assistants support people with disabilities to live as independently as possible. The disabled person agrees the range of tasks with the personal assistant and this varies from one individual to another. Examples of the sort of assistance that personal assistants may provide include accompanying the person with a disability as they go to social, recreational or vocational activities and interpreting for a person with speech difficulties. As of yet personal assistants are not widely available or used in Ireland. There is no formal scheme to provide personal assistants although some voluntary organisations, with health board assistance, do organise such a service for individual people.

Home Adaptation – Home adaptation services include the various modifications that can be made to help people with mobility or other difficulties to get in and out of the house, move around inside and use the various facilities (kitchen, bathroom and so on). The Disabled Persons Grant scheme is the main service of relevance while the Special Housing Aid for the Elderly scheme also has some relevance in this area.

Assistive Technologies – Assistive technologies 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, switch off of appliances and so on). The Health Act (1970) makes provisions for 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 their 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. 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.

According to the Working Party 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.

Social Alarms – Social alarms are systems that enable nominated agencies and/or family members to be notified in the event of an emergency situation arising for the person in need of care. Such systems can be active (where the person actively triggers the alarm) or passive (where the alarm will signal an event without the need for personal intervention by the person in need of care). These types of alarm system can help working carers both by eliminating the need for constant monitoring in the home and by reducing carer anxiety when outside the home, for example when at work. There are only a few social alarm services provided directly as public services in Ireland. However, the Scheme of Community Support for Older People operated by the Department of Social and Family Affairs provides grants to voluntary and community-based organisations to provide security measures for older people. Although this scheme has increased the availability and take up of social alarm services in Ireland, these services are still very under developed in comparison to the UK and many other countries. Coverage across the country is very patchy and there appears to be a lot of variability in availability and take-up. Also, and more specific to this service, the apparent requirement that recipients of the service are living in vulnerable circumstances (i.e. not with a carer) might exclude coverage of people where the carer was resident but out at work during the day.

Preventative and Other Services – Finally, a range of preventative and other services may also have some relevance. These include occupational therapy, physiotherapy and chiropody services that can help to maintain the independence of older or disabled people. Also of relevance are social work services, particularly where these take on a case management or co-ordination role. The only social work services in Ireland that have a statutory basis are those for children and therefore services for children at-risk are given priority. The provision of social work services to older or disabled people in the home varies a lot across health boards and social work services for older people are particularly limited. The various other paramedical community care services are in short supply and are therefore rationed. Waiting lists operate in many areas.

Community Care Services

Some community care services can provide direct and practical support for working carers because they reduce or eliminate the need to be available for caring during working hours. In this sense they can be viewed as substituting for family care. Such care services may be provided in the home or in the community. Because of the practical nature of the services involved and because, at least in principle, they are likely to be delivered on a regular (e.g. daily) basis, home help (and care assistants), meal services and day care services can be expected to be of particular value. Also, for home help and day care services, each episode of service delivery/usage can, in principle, be of a duration (a few hours or more) that is practically useful from a working carer's perspective.

Home Help and Meal Services – Home help workers provide practical help and support in the home to people with difficulties in performing everyday self-maintenance activities themselves. The home help worker usually helps with normal household tasks although they may also help with personal care. Home help workers 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. Some health boards also provide care assistants whose role focuses more on personal care. The majority (more than 80%) of recipients of home help services are older people but less than one in thirty older people actually receives the 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. Similar to the situation with home help services, the majority (more than 80%) of recipients of meals services are older people but only a small minority of older people actually receive the service.

Despite the fact that they are not legally obliged to provide such services, all health boards either provide a home help service directly or make arrangements with voluntary organisations to provide them. The health boards are not limited in the categories of persons they can assist at home, although priority is given to people with Hepatitis C who have Health Amendment Act Cards, older people, families with small children where the mother is dead or seriously ill and people with disabilities. 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. The service is generally free to medical cardholders. 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. Access to meals services is generally by referral and clients may be asked to contribute towards the costs.

Day 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 activities, such as recreational, sport and leisure facilities, and specialised clinic facilities that provide a combination of medical and rehabilitation services. Centres for older people can be categorised into those that provide a mainly social function and those that also provide medical services.

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.

Residential Care Services

Residential care also needs to be considered as it too can substitute for family care, albeit in a more absolute sense. 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.

Eligibility for publicly provided 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. Dependency is 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. In general, those in publicly provided residential care are expected to pay almost all their modest, means-tested income towards the costs although they are entitled to retain some ‘pocket money’.

Those entering a private or voluntary nursing home must pay the costs involved. In certain circumstances, based again on an assessment of dependency and of means, they may qualify for a health board subvention. The means test for subvention for private nursing home care takes into account the income and assets of both the applicant and his/her spouse, where relevant. Although there are rules for the assessment of means, including income and assets, it appears that there may be considerable variation across health boards in how these are applied. Income of adult children was also sometimes taken into account in the past but the practice was found to be contrary to what was intended under the legislation and associated regulations, and health boards had to make refunds.

Tax Reliefs on the Costs of Caring

Finally, there are a number of tax reliefs that are oriented towards ‘the care of the aged and incapacitated’ (Department of Finance, 2000). As noted by Comhairle, however, the tax credits and allowances which are available do not have any single underlying policy objective and they appear to have developed in a fairly ad-hoc manner (Relate, April 2002).

Tax relief is available for costs incurred on behalf of a dependant (through the Dependant Relative Tax Credit, Medical Expenses Relief and Incapacitated Child Tax Credit), for costs of employing an external carer (through the Employment of a Carer Allowance) and for direct financial support provided to a dependant (through the tax relief on covenanted income). Potentially by far the most significant of these tax provisions are the Employment of a Carer Allowance and the tax relief on health/medical expenses incurred on behalf of a dependant.

The Employment of a Carer Allowance can be claimed if a person, or his/her spouse or relative is permanently incapacitated and he/she employs a person to care for the incapacitated person. This is now a substantial allowance (the maximum was increased to €30,000 in the 2002 budget) that can be claimed at one's highest rate of tax and is quite flexible in that it can be shared between more than one family member. Costs of care for a dependant in approved private nursing homes can be claimed under the health/medical expenses relief scheme. Again, this can be claimed at one's highest rate of tax.

8.2 Issues for Working, Caring and Equality

This section outlines some key issues that arise in respect of care service provision from the perspective of combining working and caring and of equality for carers. These include a general underdevelopment of services, geographical and other inequities in access of services and the impact of carer status per se and of the gender of carers on access to care services. It also notes the lack of balance between community care and institutional care services and inequities in care financing through the tax system.

Underprovision of Services

There is not much official information available either on the real levels of potential demand for care services in Ireland (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. However studies of community and social services suggest that the levels of service provided are likely to be inadequate in many respects.

For example, Garavan et al (2001) asked a representative sample of older people about the health and social services that they received, if any, and whether they had any unmet needs for services. They found that the numbers in receipt of services were low, with about one in seven reporting that they received public health nursing services, one in twenty receiving home help services and much fewer numbers receiving respite care or meals on wheels services. Delaney et al (2001) also explored the perceived availability of services for older people in the community, this time from the perspective of the service providers. All services were described as over stretched or limited, with public health nursing described as being the most available and chiropody as the least available. However in relation to the direct concerns of the current study, there has so far been no direct assessment of the potential demand or need for community care services under circumstances that take the requirements of both carers and their dependants into account.

Equity of Access?

Overall there is an absence of common definitions of service purpose and scope and of common standards of service quantity and quality across health boards and community care areas. Given the absence of standardised eligibility and assessment criteria, inequities may arise in relation to needs and/or the origins of such needs. Finucane et al (1994), for example, found that medical rather than social or other criteria tended to be given the highest priority in determining whether services were needed and/or provided, although in the case of the home help service the level of capacity of the person was also given high priority. It is quite possible, therefore, that people in equal need of support in activities of everyday living may not have the same access to services because of variations in assessment of need

Research has also found significant variations across health boards in the service objectives, organisation, scope and levels of provision of the home help service as well as anomalies in the assessment of need and eligibility (Lundstrom and McKeown, 1994; Ruddle et al, 1997). This means that where one happens to live can be an important factor in determining access to the home help service at all and, if the service is provided, how much service one gets. It can also affect whether or not and how much those in receipt of the service have to pay. Clearly these potential inequities apply directly to the person in need of care. In addition carers may be advantaged or disadvantaged by virtue of where they and/or their dependants live.

Impact of Carer Status

Apart from these more generally applicable factors there are also a number of issues that arise in relation to carer status per se. Services are primarily targeted towards the needs of the person cared for. For most services carer's needs are not generally taken into account in the assessment of need (Finucane et al., 1994; Ruddle et al., 1997), unless the carer is judged to be 'at risk'. However, being 'at risk' relates primarily to the physical and mental health of the carer and, although there has been no direct research on the topic, it is unlikely that the conceptualisation of risk extends to any great extent to opportunity costs in the employment arena.

In fact, there is evidence that the presence of a carer is often taken into account in determining whether or not the service will be provided (Finucane et al., 1994: Ruddle et al., 1997, Garavan et al., 2001). Where there is a carer, a reduced service or none at all may be offered. It also appears that where means testing is applied in deciding eligibility and/or charging policy in relation to home help services the means of the carer and wider family is sometimes taken into account.

Finucane et al., (1994) conducted the only direct study of the provision of health and social services in Ireland from the carers' perspective. They concluded that the services of most relevance were discretionary and over stretched. Priorities and associated rationing criteria were overwhelmingly medical. Where the carer was taken into account it was often only to reduce or withdraw the service if the carer was present. There was little provision of direct services for carers and the needs of carers were not typically taken into account in the provision of services for those that they cared for. There is little evidence that things have changed much in the intervening years.

The same study found that the presence of a carer seemed to be less likely to be a factor affecting access to day centres than it was for home help or meals services. Nevertheless day care centres are not designed to meet the needs either of carers in general or of working carers in particular. It is interesting that even as far back as 1988 (Working Party on Services for the Elderly) 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. However, there is little evidence that policy and provisioning in relation to day care centres has actively sought to address the needs of working carers as of yet. Unlike the situation for childcare, there seems to have been little or no consideration given to the needs of working carers in relation to the general availability of day centres or to their hours of opening.

Although the rationing of services on the basis of the presence of a carer appears to be widespread, there has been no systematic examination of the precise criteria that are being used to decide whether or not a carer is 'present'. It would be useful to know, for example, whether a working carer is considered to be available and whether a non-working carer interested in and/or actively seeking work or preparation for return to work is considered to be available. Also of interest would be information on whether family members who are unwilling to provide care are also considered to be available for purposes of service rationing.

The Role of Gender

Gender is also an important issue in this context. There is some research evidence suggesting that older men may sometimes be more likely than older women to receive services such as home help, based on a perception, real or otherwise, that women are better able to care for themselves than men (Arber et al., 1988). In addition, Finucane et al. (1994) reported anecdotal evidence that similar 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. A direct investigation of the extent to which this type of gender bias is actually operative in practice in service rationing would be useful.

Timeliness

Timely availability of services may be especially important for the working carer, particularly where the onset of caring responsibilities is sudden or where there is a rapid increase in the amount of care required. Given that services are over stretched, with often long waiting lists, it is likely that crucial services may not always be made available and put in place within the time constraints of the carer's employment situation.

Residential Versus Community Care

Presence of a carer also may 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 this case 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. It is interesting to note therefore that the Mercer (2003) report on the future financing of long-term care in Ireland has recommended that any assessment process should encompass an assessment of carers’ abilities and needs as well as those of the care recipient.

In addition to inequities in access to nursing home care that have been well documented elsewhere (see for example O’Shea 2002), there is also the broader issue of a bias towards financing nursing home care rather than home care in the community. Despite an espoused policy orientation towards favouring care in the community, it is often easier to get a free or subsidised place in a nursing home than it is for people with significant degrees of dependency to get any substantial level of support to remain living at home.

In general, most dependant people and most carers prefer to avoid the necessity of moving into nursing home care for as long as possible. Supporting home care is also an espoused health and social service policy priority. It is therefore a considerable anomaly that the health boards provide a substantial subvention towards the costs of nursing home care but nothing commensurate is available in relation to the costs of home care. Equality of opportunity for carers, per se, may also be affected. This would arise, for example, where a carer felt obliged to give up work to provide care in the home in order to avoid the necessity of admission to nursing home care but would otherwise not do this if a quality home care alternative was affordable.

Equity in Tax Relief

As we saw above, the two most significant sources of financial support available under the tax system to help meet the costs of care for a dependant are the tax reliefs for the employment of a carer and for medical costs (including nursing home care) incurred on behalf of a dependant. It is interesting to note that these taxation-based supports do not have the same imbalance in relation to support for institutional care as opposed to community care. Substantial tax reliefs are available for both forms of care. This means that, at least in principle, provisions under the tax system provide more choice for working carers in relation to care alternatives.

However, the fact that such financial supports are linked to (taxable) income in the first place can be viewed as an inequitable treatment of those without taxable income. Also, the fact that the tax reliefs can be claimed at the highest rates of tax make the provisions regressive; those with higher incomes get more financial support. These types of provision mean that choices in relation to caring and working are not the same for people on low and high incomes. Those on higher incomes have more choice in terms of how they provide for the care of their dependants, including whether or not they or their spouse do it themselves or, if not, whether they can afford to purchase private care and what form of such care (in the home or in a nursing home) to opt for.

8.3 Conclusions

The basic working model in health and social services policy to date could be described as one where family care is supported, as necessary, by community care and respite services to enable the informal care arrangements to remain sustainable. The services primarily respond to needs as they present themselves rather than proactively looking for unmet needs in the community. This largely residual model of service delivery and the lack of a statutory basis has resulted in a situation where all community health and social services, including those potentially useful to working carers, are under-developed, in short supply and often unequally available across health boards and community care areas. Also, those services that are available are not provided to a time schedule that takes account of the needs of working carers.

Health and social services are not organised or provided in accordance with the practical needs of working carers. Most of these services are less likely to be provided if there are family members who can provide care and the fact that such potential carer(s) may be working, or may desire to be working, may not necessarily be taken into consideration in this regard.

Available services of potential relevance for carers, and the conditions of access that are attached to them, do not provide Irish carers with real choices between working and caring or some combination of the two. In fact, there are some potentially direct incompatibilities between employment policy and health policy. Put crudely, current employment policy is oriented towards increasing participation rates for all groups, including carers, and current health and social services policy is predicated on continued availability of informal carers to provide the vast bulk of care and support in the community.

Apart from this, there are many sources of potential inequity in relation to access to these services. Some of these relate to carer status, per se, and others arise because of the wide scope for anomalies across carers in terms of equal access for equal need. Finally, there is evidence of a strong push towards the privatisation of care, with particular incentives for high earners to purchase substitute care services. In the absence of widely available and high quality public services this trend may lead to increasing income-related inequities in the levels of support and in the choices that are available across the spectrum of carers.

9

OTHER SUPPORTS FOR CARERS

In addition to the development of the infrastructure of care discussed in the previous chapter, the other main policy area of relevance is the provision of financial and other supports for carers. These include: provisions to facilitate employees to balance working and caring responsibilities through Carers Leave and other work-life balance supports and, crucially, income maintenance supports to compensate for employment income foregone. This chapter provides an overview and discussion of the development of policies in this area. It also briefly considers the important role of information services for carers.

9.1 Caring as a Work-life Balance Issue

Carer-friendly working arrangements clearly have an important role to play in helping carers to balance working and caring. In recognition of this, caring has begun to receive attention alongside the more traditional focus on parenting and childcare within the work-life balance movement. In this context the recent introduction of Carer's Leave is a significant development. In addition, there are a range of supports that individual employers can provide to help employees combine working and caring.

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 employees who are employed directly and those who are 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.

The introduction of Carer's Leave, in combination with Carer's Benefit which we discuss below, has the potential to enable people in employment to take time out to care without having to withdraw from the labour market or to lose their position in it and can also provide some degree of financial cushion during the period out of work. However, Carer's Leave does not cater well for the circumstances of those with insecure employment situations and the restriction to a maximum of 65 weeks may not meet with the requirements of many carers.

Employer Supports

Apart from leave arrangements, there are a range of supports that individual employers can provide to help employees combine working and caring. These include:

- working arrangements (e.g. leave time, flexi time, flexi place, career breaks)
- benefits (e.g. reimbursement plans/long-term care insurance)
- information and referral services (e.g. help in locating services, caregiver support through Employment Action Plans or peer support)
- direct provision of services for older people (e.g. provision of day care facilities)
- practical day-to-day supports (e.g. access to a telephone and, possibly in the future, to web cams and other home monitoring equipment)

There has been no direct research on the availability or take-up of such employer supports in Ireland. Evidence from other countries, however, suggests that there may be a lot of variability across sectors and across employees within a given company. As is the case for childcare, there are various ways in which inequities may arise amongst carers in relation to access to carer-friendly opportunities. These include variations in the availability of such options depending on gender, the type of work and the level of responsibility held by the carer. There is also the question of whether parents may be more favourably served in access to parent-friendly options than are carers in access to carer-friendly options.

Elsewhere, there is a growing body of research and practice in this area. In the UK, for example, there is evidence that the public sector, which employs large numbers of women, is ahead of industry and commerce in developing policies to support staff with caring responsibilities (Institute of Personnel Management, 1990; Forth et al., 1997; Gilhooly and Redpath, 1997). However, research by Ingram and Simons (1995) found that it was the proportion of female managers, rather than of female employees overall, that increased organisations' responsiveness to work-family issues.

Apart from flexible work arrangements, the broader issue of work culture also needs to be addressed as it can be a key factor in shaping carers' choices. Recent research (National Centre for Partnership and Performance, 2003) suggests a very high level of work ethic or employment commitment amongst the Irish workforce and at the same time high levels of stress and of tiredness affecting workers' availability for family life. This might be expected to affect availability for or ability to provide care. Although these are important issues and warrant in-depth research in their own right, their detailed examination is beyond the scope of this report.

Carers who are seeking to return to work 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.

9.2 Financial Supports for Carers

Financial supports also have considerable potential significance for carers and for their degrees of freedom as regards for employment. Such supports reduce the influence of financial factors in making decisions on whether to continue to work (or to take up work) or not whilst caring, or to take up caring or not whilst working. Carer's Benefit and Carer's Allowance are the two main income supports for carers. Other relevant financial provisions include domiciliary care and respite care grants and the Home Carers Tax Credit. Finally this section also considers the provision of social insurance credits for carers.

Carer’s Benefit and Carer’s Allowance

There are two main types of income support provisions for carers; those that are related to social insurance contributions (Carer's Benefit) and those that are not (Carer's Allowance). To be eligible for these payments carers must be caring for someone who needs full-time care and attention and must not engage in more than 10 hours of employment or training per week.

Carer’s Benefit is a social insurance payment payable for up to 65 weeks for each care recipient (it may be claimed more then once, if care needs to be provided to a second person at a different time) to people who give up work in order to care for an incapacitated person. The maximum weekly rate in 2004 is €149.70 if caring for one person and €224.60 if caring for more than one person. The payment when caring for one person is just a little more than the level of other social insurance payments such as disability, unemployment, health and safety and injury benefit, and just a little higher than the Carer's Allowance.

It is not clear why the level of the payment has been pitched at this level, and why it should be different from the others. What is clear, however, is that the benefit is intended as a basic subsistence payment and is not in any way intended to maintain the employment income of most carers during their period of absence from employment.

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 Carers Allowance has three main objectives – to provide income support to full-time carers on low incomes, to maintain people in the community, and to recognise and support the valuable role of carers (DSCFA, 1998). The current maximum weekly rate in 2004 is €139.60 for carers under the age of 66 and €157.80 for those aged 66 years and older where care is provided for one person. Where care is provided for more than one person the maximum rates are €209.40 and €236.70 respectively. As for the Carer's Benefit, the rationale for the particular rate and the differentials between rates is unclear.

The means test for the Carer's Allowance is generally similar to that for other social welfare payments, although in 2004 the first €210 of income for a single person and €420 for a couple is disregarded. Recipients of the Carer's Allowance are not eligible for most other social welfare payments during the period that they are claiming the allowance.

From the perspective of their implications for working and caring, the main relevance of these income support payments is that they can, at least in principle, facilitate a choice to take time out from or to remain out of the workforce in order to care. However, the payments are oriented towards those who basically opt for caring on a full-time basis (although a low level of paid work and of income is allowed) so that those who might prefer income support for reduced but still significant hours of work are not provided for.

In addition there are a number of other features that can be considered to be inequitable. For example, the social insurance contribution requirements for Carer's Benefit make this payment inaccessible for many carers with atypical or precarious employment histories (e.g. casual or seasonal workers, or those on short-term contracts). The prevention of flexible use because of the requirement to take blocks of leave may also be a significant disincentive for those who would prefer a viable part-time working arrangement, for example. The restriction of Carer's Benefit to a maximum of 65 weeks is also a contentious issue, as many carers must continue caring for much longer periods than that.

In relation to Carer's Allowance there is also the crucial issue of the means testing being related to household income, with the consequence that the allowance is often not granted because of the income of the working partner. More generally, there is the broader issue of what should be considered to be a proper recompense for the work done by carers. The Carer's Allowance has received a lot of attention in recent years, with the carer advocacy groups arguing that it should be a payment for caring and therefore should be pitched at a much higher level. Neither of these payments is at a level that would constitute either a market rate for the care work that is provided or a replacement of income from employment. Therefore, in most cases these payments are unlikely to constitute a level of support that offers a real choice for carers in relation to whether or not to discontinue working for a time when caring responsibilities arise.

Domiciliary Care Allowance and Respite Care Grant

While Carer's Benefit and Carer's Allowance are the main income support provisions for carers, a number of other measures also play a role. The Domiciliary Care Allowance is a monthly means tested payment payable by the health board to the carer (usually the mother) of a child with a severe disability who lives at home, with the means test applying to the child's income and not that of the parent(s). The current rate is €204 per month. Recipients of this allowance may also receive other social welfare allowances, including Carer's Allowance, if they meet the requirements. Strictly this is more of a financial support for the cost of care than an income maintenance allowance. It is not clear why such an allowance should be payable to those with a dependant aged under 16 years but not to those with older dependants and this seems to be an important potential source of inequity. Carers who are receiving Carer's Allowance, Carer's Benefit or Domiciliary Care Allowance also get an annual Respite Care Grant (€835 since 2004). The grant is a cash payment that is intended for use to pay for respite care but the carer may use it in whatever way he/she wishes.

Home Carer's Tax Credit

Tax relief for couples where one partner works in the home to care for a dependant can also be considered to be a form of income support or contribution. The Home Carer's Tax Credit, for example, 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 rate tax band was begun. The Home Carer's Tax Credit may be claimed by a married couple where one spouse cares for 'a person who is permanently incapacitated by reason of mental or physical infirmity', as long as the caring spouse does not earn more than a specified income ceiling (€5,080 in 2003). Apart from this earnings cap, the provision does not explicitly impose any restrictions on the extent of engagement in work by carers.

There was a lot of discussion at the time about the equity or otherwise of the move to individualisation. Some took the view that it rectified previous discrimination against two income couples and others argued that it introduced new discrimination against couples where one partner opts to work in the home to care for children or for other dependants. Independent of this aspect there is also the fact that this tax credit is only available to married couples and not to those cohabiting but unmarried, including same sex couples. More generally, there is the fact that the carer's spouse, rather than the carer, actually receives the direct financial benefit.

Social Insurance Credits

Finally, social insurance credits, effectively free PRSI contributions, are also of relevance for some carers who leave or remain outside the workforce to care. 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 to receive the payment. Carers on Carer's Benefit are generally likely to qualify but many other carers may not. This is an area where inequities can accrue and be compounded over the entire lifetime for people (usually women) who spend long periods out of the workforce for childcare and/or caring reasons.

The Homemakers' 'Disregard' Scheme in relation to the calculation of the contributory old age pension also has relevance for such carers. Homemakers who have been caring for children or for an incapacitated dependant since April 1994 may have up to 20 of their homemaking years disregarded in calculating their average contributions for purposes of calculating the contributory old age pension. The definition of an incapacitated person is the same as that which applies to the Carer's Allowance and the homemaker cannot earn more than €38.09 per week (as of April 2002). The provision is not of particular value for those who give up work permanently and is of most benefit for those who work outside the home for a number of years, then spend a number of years caring and then return to the workforce.

9.3 Information and Other Supports for Carers

Information on what services and supports are available has been identified in a number of studies as being of central importance for carers in general. For example, one of the main kinds of support most frequently sought by carers in Ireland is information and advice on health and social services and on welfare entitlements (O'Shea and Hughes, 1994). This may be of even greater significance for working carers given that many may not identify themselves as carers as such and, even if they do, are less likely to be in contact with carer support organisations. Also important are education, training, counselling and more general support services for carers.

Ruddle et al. (2002) found that the most critical need for information may arise at the time of initial onset of illness or disability. From the perspective of the current study, information may be particularly important for working carers where the onset of the need for care is sudden and has not been planned for. Decisions and choices may have to be made quite quickly, both on the employment and caring fronts, and these need to be based on information on what services and supports are available. Equally important, of course, is the responsiveness of services so that supports for the working carer are put in place within a timeframe that fits with the degrees of freedom that the carer's employment situation offers in relation to time off and so on.

Various public 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. No agency currently provides a specific information service targeted towards working carers. Other support services are provided by voluntary sector organisations such as the Carers Association, Soroptomists and those dedicated to particular client groups. Apart from information on services and entitlements, such organisations also provide legal and financial advice, liaison with statutory organisations on behalf of carers, counselling and emotional support, training in caring skills, and other activities such as organising holidays for carers. Services are generally given irrespective of the carers' financial means.

9.4 Conclusions

The provision of financial and other supports for carers include; carer-friendly working arrangements whereby employers can help carers to achieve work-life balance, income maintenance supports, domiciliary care and respite care grants, tax relief, social insurance credits and information and support services from public agencies and voluntary organisations.

Recent developments in Ireland have begun to put in place a framework within which the needs of some carers are being better catered for. However, while there is an increased recognition that carers need to balance working and caring the financial supports available for those who might wish to, or have to, take time out of employment to care match neither the foregone earnings of most carers nor the market rates for the type of care work they are providing. Carer's Leave does not cater well for those who are in insecure employment and both Carer's Benefit and Carer's Allowance payments are pitched at very basic income support levels. In addition, to be eligible for these income supports requires a more or less complete withdrawal from paid employment and more flexible approaches, such as a significant amount of part-time working, are not facilitated.

10

KEY THEMES AND CONCLUSIONS

This final chapter draws some overall conclusions from the data and analysis that has been presented in the report up to now.

These can be summarised as follows:

- Because carers span a wide spectrum, both in terms of their caring responsibilities and in their employment needs and preferences, it is important to avoid stereotyping and to provide a range of services that cater for diversity and enable real choices to be made by carers.
- There appear to be some fundamental inequities in access to health and social services that are related to carer status, per se, arising both at a policy level and in the day-to-day delivery of services.
- There are also more general disparities in access to services and supports that can result in inequities in what is available to carers in similar circumstances and with similar needs.
- Separately and in combination, these carer-specific and more general inequities in access to services and supports result in inequalities in employment opportunities and choices for carers in comparison to other groups and amongst carers themselves.
- On a broader but related level, there is a need for a fundamental discussion and debate on the individual and joint rights of carers and those that they care for and of families and family members more generally.
- Finally, there is a need for further research and analysis on specific aspects of all of these issues and sources of inequity.

10.1 The Spectrum of Caring

To begin with, it is important to reiterate that carers span a wide spectrum of circumstances, preferences and needs. There is a tendency in policy and in public debate to view 'carers', by definition, as people who by choice or necessity dedicate so much time and effort to caring as to preclude paid employment. Although there are indeed many carers in such circumstances there are also many carers who are either currently in paid employment or who would like to be.

Apart from employment being a normative aspiration in its own right, with all of the attendant financial, social and personal benefits that can accrue, there is also evidence that having a job, per se, can be beneficial for the health and well-being of carers. On the other hand, of course, juggling the demands of working and caring can also pose additional burdens and new stresses.

Overall, the conclusion of this study is in agreement with that of Comhairle (2002) – carers should be supported so that they have a genuine choice between caring, employment or a combination of the two. Such genuine choices can be enabled by a mix of:

- Accessible health and social services that provide an alternative to or substitute for family care, either publicly funded or with public financial supports to help ensure the affordability of purchasing such services privately.
- Adequate income support during periods of absence from paid employment in order to provide care.
- Measures to minimise any penalties that might be incurred in relation to employment, career and/or social insurance benefits because of periods outside the workforce for caring purposes, including support for those wishing to return to work after a lengthy absence.
- Availability of flexible and carer-friendly working arrangements.

Finally, a full consideration of the spectrum of caring needs to adopt a long-term, lifecycle perspective. On the one hand, negative career and/or social insurance implications of one or more episodes of caring may be carried through for the remainder of a carer's life. On the other hand, many current carers in Ireland have already been out of the workforce for a long time and face particular difficulties in getting back to work if they so wish. The equality agenda for carers needs to give attention to these aspects of caring as well.

10.2 Inequities Resulting From Carer Status

Inequities resulting from carer status, per se, arise where carers are treated less favourably in comparison to other groups. There are at least two areas where such inequities may arise. One concerns the reduced access to health and social care services where a family carer is deemed to be present. The other concerns the possibility that carers might be treated less favourably than other groups in access to family-friendly working arrangements or other relevant services and supports.

Access to Health and Social Care Services

The main thrust of public health and social service provision in Ireland works in a manner that is often, at best, unhelpful to carers who may wish to continue in or return to work. The model is essentially a residual one at both policy and day-to-day service delivery levels, with services offered as a last resort when families cannot or will not provide the necessary care. Most services are in short supply and are therefore rationed through the application of various criteria for assessing priority of need. If a carer is deemed to be 'present' then services may be and, it appears, often are withheld.

There appear to be no formal criteria or guidelines for service providers in deciding on whether or not there is a carer present. In particular, there seems to be no formal position on whether or not services should be provided when a carer is working or wishes to work. More generally, the organisation of such services as are available does not appear to give much attention to the needs of working carers. For example, the opening hours of day centres and the organisation of home care services are not generally aligned with the working hours of carers.

Access to Family-friendly Work Arrangements

As far as we are aware there has been no direct research in Ireland on the question of whether carers are treated in the same way as other reference groups in relation to access to family-friendly work arrangements. It is possible, however, that the greater visibility of parents and their concerns may result in more favourable treatment in some circumstances. On the other hand, there might be equality issues raised for parents by the absence of parental leave provisions that match those available for carers under the Carer's Leave legislation. The challenge here is to ensure a coherence of approach to all those with caring responsibilities including parenting, harmonising up to best practice in each area. These are matters that are beyond the scope of this study to address any further but they may warrant specific investigation in the future.

Access to Income

There is also the question of whether carers are treated equally in respect of access to income, including income maintenance support and financial support to defray the costs of caring for a dependant. This is a complex area and would require specific and detailed comparisons between the supports provided for carers and for others such as parents under the welfare, social insurance and tax systems. Again, these are matters that are beyond the scope of this study to address any further but they may warrant specific investigation in the future.

10.3 Inequities Amongst Carers

There are a number of aspects of access to services and supports where demonstrable inequities arise amongst carers, not because they are carers per se but because of more general inequities and anomalies that can affect everyone. Some aspects where there is considerable scope for inequities to arise although the actual extent to which these occur in practice has yet to be systematically investigated.

Health and Social Services

To begin with, there are fundamental overarching features of the health and social services in Ireland that make it possible for widespread inequities to arise. There is a significant potential for anomaly to arise between clients with ostensibly similar needs and, indirectly or by proxy, for carers as well. In particular, many of the services lack a statutory basis, there is an unclear linking of eligibility and entitlement, 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. Collectively, these factors can result in inequities and anomalies in who gets access to scarce domiciliary and other community care services and can therefore affect equality in the choices available to carers in relation to employment.

One frequently cited issue is the wide variation across health boards and areas within health boards in terms of what services are available and in the accessibility of the services that are available. Another issue concerns the various anomalies that can arise in relation to access to a medical card and in turn in access to services where eligibility or priority is based on medical card holding. Apart from financial anomalies there is also the potential for age-related anomalies given the automatic entitlement of those aged 70 and over to a medical card.

There are also significant age or lifecycle related anomalies in access to care and other services. This is most obvious in the case of people with severe and long-term physical and/or intellectual disability when they pass beyond the stage of entitlement to education-related care and support. The burden of caring and the constraints on employment opportunities often dramatically increase for carers when access to such day care services ceases.

In addition, there is anecdotal evidence that there may be gender biases in operation in some of the service rationing decisions being made on the ground within the health and social services with males carers and dependants more likely to receive services than female carers and dependants. This is an area that warrants direct investigation by service providers.

Finally, despite an espoused policy orientation towards favouring care in the community, it is often easier to get a free or subsidised place in a nursing home than it is for people with significant degrees of dependency to get any substantial level of support to remain living at home. This means that working carers and those that they care for, in particular, are unlikely to have a genuine choice in relation to the type of care arrangement they would prefer. Because of lack of support for home care, the choice may be between settling for residential care or the carer giving up work.

Financial Supports for the Costs of Care

The two most significant sources of financial support available under the tax system to help meet the costs of care for a dependant are the tax reliefs for the employment of a carer and for medical costs (including nursing home care) incurred on behalf of a dependant. It is interesting to note that these taxation-based supports do not have the same imbalance as regards support for residential care as opposed to community care. Substantial tax reliefs are available for both forms of care. This means that, at least in principle, provisions under the tax system provide more choice for working carers in relation to care alternatives.

On the other hand, these reliefs are only available to those with taxable income and, within this group; their effects are regressive because they can be claimed at the marginal rate. In effect, those with more income can get more financial support for purchasing care privately.

Although beyond the scope of this study, an overall analysis and assessment of equity in access to care services across different groups in society would be very useful. This could include those with and without medical cards, those with and without taxable income and those with taxable incomes that are in different income brackets.

In addition there may be some anomalies in the availability of these tax allowances in non-marital situations – the tax relief in relation to nursing home care seems now to be available for costs incurred on behalf of non-relative 'dependants' but the employment of carer relief is not unless there is legal guardianship.

Income Supports

Neither of the two main income supports for carers in Ireland – Carer's Benefit and Carer's Allowance – provide an option to care full-time without incurring a significant financial penalty in comparison to income that could be achieved through paid employment. Both of these payments are oriented towards those who basically opt for caring on a full-time basis (although a low level of paid work and of income is allowed) so that those who might prefer income support to enable reduced but still significant hours of work are not provided for. For both types of payment there are various other aspects that can be considered to be inequitable.

The social insurance contribution requirements for Carer's Benefit make this payment inaccessible to many carers with atypical or precarious employment histories (for example casual or seasonal workers, or those on short-term contracts). The prevention of flexible use because of the requirement to take blocks of leave may also be a significant disincentive for those who would prefer a viable part-time working arrangement, for example. The restriction of Carer's Benefit to a maximum of 65 weeks is also an issue of contention, as many carers must continue caring for much longer periods than that.

Various concerns have been raised about anomalies and inequities in access to the Carer's Allowance, including inconsistencies in the way that assessments of the need for care are made. In addition, the fact that the allowance cannot be shared pro-rata between two or more carers provides institutional reinforcement for the notion of one primary carer instead of more equitable sharing of care within families.

There is also the basic issue that the means testing for Carer's Allowance is related to household income so that, the allowance is often not granted because of the income of the working partner. There has been a strong lobby for Carer's Allowance and other social welfare payments to be individualised, with eligibility to be determined on the basis of the recipient's means only.

Finally, many recipients of Carer's Allowance are not eligible for social insurance credits for the time spent caring and years spent caring before April 1994 are not taken into consideration in the homemaker's disregard scheme for purposes of calculating contributory old age pension entitlement. These restrictions can result in financial costs long after a caring responsibility has ceased.

Family-friendly Working Arrangements

Although not the main focus of this study, consideration has also been given to the possibilities for inequities in access to flexible work and other family-friendly arrangements that can help carers balance working and caring responsibilities. Equality concerns in this arena include the likelihood that such carer-friendly arrangements are not equally available to all workers, with the possibility of inequities arising because of gender and across occupations and occupational levels.

10.4 Implications for Equality of Access and Participation in Employment

Inequities and anomalies in access to services and to income support can, in turn, lead to inequalities in relation to labour market participation and employment. Inequities in access to care services can result in inequalities for carers in whether they have the possibility to work at all if they want to, in the types of job they can take, in the quality of their working experiences and in their opportunities for career advancement. Inequities and anomalies can also arise in the possibility to take time out from paid work to care without undue penalties, for example, for those with less stable employment or social insurance contribution histories.

Finally, there is an overarching source of inequality arising from the fact that services and supports for carers in Ireland are primarily geared towards an all-or-none approach, one is either a worker or a carer but not both at the same time. This means that carers do not have equality and choices in relation to whether to work, care or combine the two roles.

10.5 Individual and Joint Rights

Analysis of the services and supports that can help carers to balance their caring and employment needs and preferences has also drawn attention to some broader issues concerning individual and joint rights. Some issues relate specifically to the respective rights of carers and those that they care for and other issues are linked to the wider matter of the collective and individual rights of families and family members.

It is beyond the scope of this study to explore these complex and fundamental issues in any great depth and this is an area that warrants direct investigation from an equality perspective in future studies. The remainder of this section therefore focuses on highlighting some of the issues that need to be considered rather than attempting to come up with definitive proposals or solutions to these complex issues and dilemmas.

Carers and Those That They Care For

There are a number of levels at which the respective rights and entitlements of carers and those that they care for need to be considered. Firstly, in relation to health and social services there is the basic question of whether it is the carer, the person cared for, or both that are the clients for a given service or support. In Ireland, the person cared for is almost always the client and there is no provision for assessment of the needs of the carer, per se. Even in the context of respite care, a service ostensibly targeted directly towards carers, it seems that this can sometimes be something of a grey area.

Although it is likely that health and social service professionals do in practice take carers' needs into account in some instances, there are no formal requirements for them to do this. In the UK, in contrast, carers do have a right to have their own needs assessed by the health and social services although the focus of such assessments seems to be more on the health and wellbeing of the carer rather than on wider issues such as employment options.

Secondly, there is the issue of preferences and rights in relation to choosing the type of care to be provided and who provides it. This is an area where a variety of conflicts of interest may arise – between service providers, on the one hand, and clients and/or their carers, on the other hand, as well as between carers and those that they care for. For example, the assumption on the part of the health and social services that the bulk of care for a dependant client should be provided by the family may not be shared either by the client or by the family. Indeed, there is some evidence that this may increasingly be the case in Ireland. On the other hand, the problems that may arise in reconciling the preferences and interests of dependants and their families have been well recognised for a long time, for example, in the case of older people and the issue of admission to long-term residential care.

Both of these are areas need closer analysis. There is a need for representative attitudinal surveys to better understand current norms in Irish society and whether these reflect long-held assumptions of a preference for family care. There is also a need for more legalistic analysis of the respective rights of the various parties and of the circumstances under which these could or should be addressed separately or jointly.

Finally, in relation to cost of care benefits, the question of whether these should be paid to the carer or to the person receiving care needs to be considered. In fact, this is an issue where different stakeholders appear to hold divergent views. In Ireland, it seems that organisations representing carers and those representing older people tend to favour the payment being made to the carer whereas organisations representing people with disabilities tend to favour the payment being made to the person needing care.

Family Rights and the Rights of Family Members

There are also a number of levels at which the issues of family rights and the rights of individuals within families need to be considered. To begin with, there is the issue of rights of individual family members vis à vis one another in relation to whether or not they provide care and how much care they provide. There is evidence that caring responsibilities tend not be shared equally within families and that, historically at least, and particularly in the case of caring for an elderly parent or relative, the bulk of the responsibility has tended to fall on one person, usually a daughter or other female relative.

There is also evidence that such responsibilities tend to be allocated, either actively or by default, because the person that becomes the carer is perceived to be "available" if they are not currently working (perhaps because of young children) or their work is viewed to be of less significance. Although this may not be something that could or should be dealt with in legislation it may nevertheless be an important factor in determining employment opportunities for carers. As such, there is a need for representative surveys in order to ascertain the extent of the issue and to formulate appropriate measures (e.g. publicity campaigns) to address it if necessary.

Apart from this very complex area, there are a number of other issues that are more amenable to direct scrutiny and to rectification where any inequities or anomalies are found. One issue concerns the definition of family per se, and the differential treatment of married, cohabiting and same sex couples under the tax and social welfare codes. This results in anomalies for carers in cohabiting relationships in respect of access to the Home Carers Tax credit and possibly also in respect of the tax relief for employment of a carer and for nursing home costs incurred on behalf of a dependant that is not related by marriage.

Another issue that arises in relation to the rights of family members concerns the lack of individualisation of social welfare payments and some other income supports. Where the carer has a partner, for example, eligibility for the Carers Allowance is means tested on the basis of the partner's income and, in practice, the carer's spouse claims the Home Carer Tax Credit.

Finally, there is the question of the extent to which the income and assets of family members should be taken into account in assessing the state contribution to the financing of long-term residential care. There is a need for further analysis of the merits or otherwise of this from an equality perspective.

10.6 Issues for Further Research and Analysis

The data and analysis presented in this report has enabled identification of the types of services and supports that are necessary to help carers to have equal opportunities in relation to participation in paid employment. It has also provided the basis for an initial assessment of actual or potential inequities and anomalies that can arise for carers wishing to avail of such services and supports. Despite what we know, however, there remain many gaps in our knowledge about caring and employment interactions in Ireland. Four topics, in particular, which warrant more detailed attention and investigation are briefly outlined below.

More Information on Carers and Attitudes to Caring

To begin with, there is a need for a lot more information on carers and their circumstances and on the needs and preferences of carers and those that they care for. Research on carers needs to give attention both to carers who are currently in the workforce and to those who are not in order to get a fuller picture of the variety of employment aspirations and experiences of carers. There is also a need for information on the wider prevailing attitudes in society towards the respective roles and responsibilities of family and state in relation to care.

Investigation of Service Rationing Criteria and Practice

In parallel with this, there is a need for investigation and documentation of the actual rationing criteria that are being applied on the ground in the determination of access to key services such as domiciliary or day care. The extent to which these day-to-day practices may directly or indirectly discriminate against carers, per se, or against particular groups of carers needs to be assessed. More generally, current policies and practices need to be reviewed in relation to how they help or hinder carers to realise their employment aspirations.

Needs Assessment and Equity in Access to Service

One of the key requirements for an equitable system of support for carers and those that they care for is an appropriate, transparent and consistently applied method of assessing needs. In fact, a bewildering array of eligibility criteria and approaches to needs assessment govern access to the various services and financial supports discussed in this report. In addition to this, there appears to be considerable inconsistency in how these are applied across health boards and individual health and social service professionals.

An important issue for an equality agenda for carers, therefore, would be to ensure that an equality perspective was fully reflected in the harmonisation and improvement of needs assessment procedures that affect carers, whether assessing the needs of carers, of those that they care for or both. A key aspect of this would be consideration of what criteria to include in needs assessment. For example, in what ways could or should equality of opportunity and/or opportunity costs for carers be considered and how could they be included in the assessment of needs.

There is also a need for an overall analysis and assessment of equity in access to care services across different groups in society, including those with and without medical cards, those with and without taxable income and those with taxable income who are in different income brackets.

Analysis of Individual, Joint and Family Rights

Finally, there is a need for more analysis from an equality and rights perspective of the individual and joint rights and entitlements of carers and those that they care for, of how families should be defined, and of the rights of families and family members. These issues are fundamental to ensuring that the interests and concerns of all parties are equitably considered.

10.7 Overall Conclusions

The many inequities and anomalies in access to services and supports translate into unequal opportunities for carers with respect to employment. Carers may be disadvantaged in terms of whether or not they can work at all or in the quality of the work that they can aspire to. Such disadvantages can be compounded over the lifetime and have serious consequences for income, career and social insurance and pension entitlements. On the other hand, workers may be disadvantaged in terms of whether or not they can contribute to the care of loved ones when they become dependant.

Recent developments in Ireland have begun to put in place a framework within which the needs of carers can be better catered for. Carer’s Benefit and Carer’s Leave go some way towards enabling working carers to take time out from work in order to care. The equality legislation outlaws discrimination against carers under the family status ground. Taxation provisions now give quite substantial relief towards the cost of purchasing care privately.

From the data and analysis presented in this report, however, it is clear that a lot more needs to be done. There is a pressing need for a major review of health and social service policy in this area, to address both potential inequities arising as a result of carer status, per se, and inequities that can arise for any clients, including carers. There is also a need for a comprehensive review of the main current income supports for carers – Carer's Allowance and Carer's Benefit. As currently formulated, these provisions support and reinforce a view that people are either carers or workers rather than the reality that many people are, or aspire to be, both.

The particular circumstances that people with caring responsibilities end up in may not necessarily and frequently do not reflect their preferences, but instead often reflect the limited degrees of freedom that they have for exercising life choices. The policy approach must therefore focus on supporting equality of choice for carers and equality in relation to the costs associated with each choice.

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