



# Listen to Carers

**Report on a Nation-wide Carer Consultation**

*The Carers Association*

*In Partnership with*

*Caring for Carers Ireland and Care Alliance Ireland*

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## Preface

The role of the family as a caring unit has been the subject of much discussion and debate in recent years due mainly to changes in work patterns and in the role of women in society. An increasing number of carers, be they caring for small children, dependent parents or people with disabilities, either by necessity or choice, are now working outside the home. The provision of care services in the community is presenting new challenges as population ageing and longer life expectancy inevitably result in greater demands on both family/community and hospital/institutional caring systems. New and expanded support services are, therefore, needed in order to guarantee adequate care services and to improve the quality of life of family carers.

While the provision of family care at home is desirable for many reasons and is the preference of most people, it can not be expected to carry the future burden of supplying the majority of care services unaided. The reality is that enabling people with high level of needs to remain in their own homes is resource intensive. Also, the opportunity costs of family care must be factored into the debate.

The absence or inadequacy of good-quality residential care and comprehensive community support services means that family care in the home is the only available solution to many people. This model is further reinforced by the dislike of residential care solutions (other than occasional respite care) among the Irish public.

While the expansion of supports for family carers in recent years is a welcome and necessary development, the support system continues to be rooted in a residualist model of social welfare provision. Instead of expanding the State's responsibility for support service provision, the policy in Ireland has been geared towards supporting the home-based (and, in practice, predominantly female) carer. Changes in some benefits over the last decade or so have focused on providing greater income security for some carers. However, such developments continue to be on the basis of income maintenance supports and do not deal with the issue of payment for caring. In other words, marginally improved (means-tested) social welfare payments are used to enable people to stay at home and perform care work. Carer support in terms of service provision also continues to be inadequate to meet needs. These matters need to be addressed as a matter of urgency.

While supporting care in the home is a relatively cheap policy option (subsidising family care work at home being considerably lower than the cost of state-provided care), it may not be viable long-term solution. As the number of family carers declines with increasing female labour market participation, there will probably not be a sufficient number of people in future to look after older people and people with disabilities at home. This potentially emerging scenario requires an innovative and ambitious response.

It remains to be seen whether the call of duty and social pressure to provide care will prove stronger than the personal and financial rewards of work outside the home. So far policy reform in Ireland has done little to enable people to combine the two. The outcome of this is likely to be greater reliance on long term residential care which is the less attractive option and also likely to be more expensive.

Given the preference of most people for care in their own home, and the budgetary limitations on service funding, there is a strong argument for investment in support services for family carers. Such support services should be geared towards ensuring that carers (and potential future carers) are in a position to make choices regarding the extent to which they are involved in care work and in employment outside their care-giving role. In practice, this would mean that carers could combine care work and paid work outside the home with the help of support services that they could rely on to take over the care work when necessary. In terms of actual policies, this would require significant expansion of flexible, mostly home-based services, such as respite, home help, occupational therapy, physiotherapy, chiropody, social work and counselling services. These different services need to be designed to facilitate both the continuation of home care in the long term and the provision of opportunities for carers to maintain their own health and to engage in activities outside their caring role.

The current care in the home situation is marked by a lack of clarity and consistency regarding entitlements to support and the respective responsibilities of the State and individuals. This makes it very difficult for individuals and families to plan care in a rational manner. The time is ripe for clearly articulating the respective responsibilities of the family and the State in respect care provision for dependent people. It is only when this task is completed can the needs of family carers be adequately identified and addressed. As a society, we owe no less to the many dedicated, committed and over-worked carers and to the people for whom they care.

## **Acknowledgements**

The Carers Association would like to acknowledge the support, assistance and contributions of many individuals and groups in the completion of this report. In particular, we would like to thank the Equality Authority for part funding this project under the European Year of Equal Opportunity for All. We would like to thank our partners in this project Care Alliance Ireland and Caring for Carers Ireland for their help and participation and also the Work Research Centre who conducted the report particularly Sarah Delaney (Senior Research Consultant) and Kevin Cullen (Centre Director).

These thanks are also extended to the numerous numbers of Voluntary Organisations and representative groups who shared their valuable insight and thoughts with us and also officials from Department of An Taoiseach, Department of Social and Family Affairs, Department of Health and Children, Department of Finance and the HSE. Our own staff especially Karen Phelan and Karen Gearon who worked endlessly to make this project a success, and a special thanks to all those who participated as workshop facilitators.

Our main gratitude goes to all the family carers who participated in the forums around the country many of whom we know had to make military style planning operations just to get the few hours off to attend the forums. We thank you for your selfless and never ending commitment and we have no doubt your contribution will bring about greater recognition and support for Irelands 160,000 family carers.

## **Executive Summary**

This report presents the results of a nationwide Carer Consultation exercise that took place in October and November 2007. The consultation was led by the Carers Association in partnership with the other main carer organisations, Caring for Carers Ireland and Care Alliance Ireland. Part-funding for the Consultation was provided by the Equality Authority as part of its activities for 2007's European Year of Equal Opportunities for All.

The Consultation was intended to provide an up-to-date perspective on the experiences and concerns of carers across the country. It presents some timely insights into what issues need to be prioritised in the forthcoming national Carer Strategy. The focus was on family carers, people who provide care and support for family members or relatives who need help because of frailty in old age, disability or long-term illness.

A total of 428 carers attended the 8 consultation sessions that were held across the country, representing a broad spectrum of carers and caring circumstances.

### **An urgent need for action**

The consultation identified an urgent need for action to support the 160,000 family carers in Ireland today. There were a number of key messages that need to be heard and given priority attention in the formulation of the Carer Strategy.

### **The key message**

The overarching message is that carers are very dissatisfied with their current situation. Many are over-burdened, feel unrecognised and un-appreciated, and are unable to have any life of their own. As a result, the sustainability of family care in Ireland is under severe threat. It will become increasingly jeopardised unless the fundamentals of carer policy in Ireland are given a new direction and impetus, one that fits with the realities of life in Ireland today.

A very definite conclusion from the consultation is that carers in Ireland are seeking and need a whole new relationship and interface with the state and support services to maintain them in their caring role. In this regard, it is encouraging that the consultations identified a genuine capacity and willingness on the part of carers to think about their situation from a service development point of view and to engage with policy-makers and the relevant service provider agencies in the formulation of the revamped approach that is so badly needed. This must be capitalised upon and brought to bear in the development and implementation of the Carer Strategy.

The core of the issue is about providing the supports that enable caring responsibilities to fit as comfortably as possible within the overall life situation of carers. On the one hand, this means putting in place the supports that enable people to care when required and desired, without major loss of income - a choice that is increasingly less attainable now that dual income households and lifestyles are required

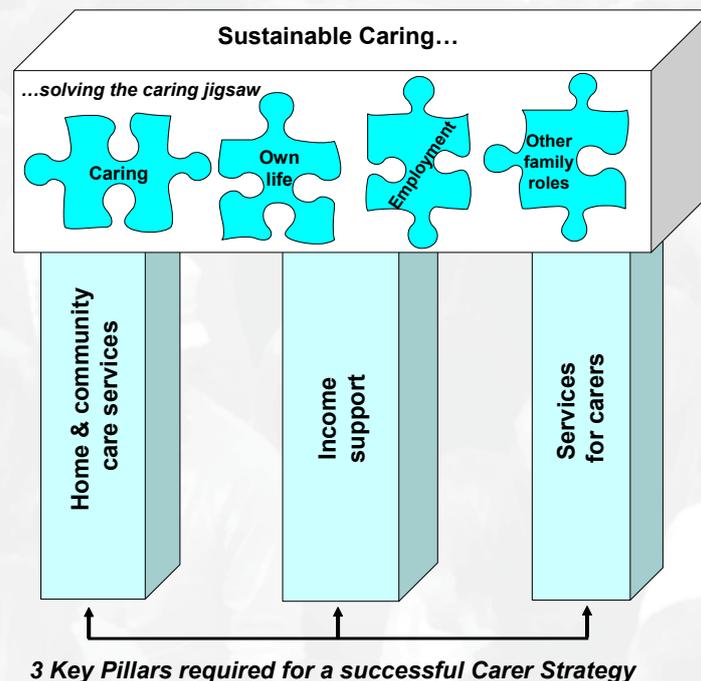
for a normal standard of living. On the other hand, it is about putting in place the supports that give carers the opportunity to continue to have a life of their own when caring responsibilities arise, including retaining one's employment on a part-time or even full-time basis if possible.

The Strategy must also take into account the fact that carers comprise a very heterogeneous group. They include women and men, even if women are still the majority. They encompass the full spectrum of income brackets, from rich to poor. Caring is carried out by all age groups throughout the life cycle, including children. Some carers combine caring with paid employment and others do not. Some embrace caring responsibilities willingly and gladly; others may be reluctant because of the feared impact on their lives but have no choice.

### Three pillars for the Carer Strategy

Three pillars are required to support the type of Carer Strategy that is needed:

- a fair shouldering of the caring responsibility by the state
- adequate income support for carers
- a range of support services that target and meet carers' needs.



### Fair shouldering of the caring responsibility by the state

A fair shouldering of caring responsibility by the state means overhauling the current approach to allocation of community and home care services as it relates to carers. A substantial re-orientation of policy is required, so that community and home care services are provided on the basis of a shared model of care. The current 'residual' approach, where the state steps in when all else fails is neither sustainable nor equitable. Further development of home and community care services and a new and

radically different approach to allocation of services will therefore need to be given a central position in the Strategy for it to succeed.

In each individual case a 'package' of care should be negotiated and agreed, combining state and family inputs as appropriate to each set of circumstances. Service allocations should be based on need, taking into account the needs and aspirations of all family members including carers. Under such a model, families will continue to provide the bulk of care, as they do in all countries, but without an automatic presumption of availability to care and within a much more transparent and equitable framework than is currently the case.

There is an important 'public-private mix' dimension to equitable policy in this area. This is because, although often overlooked, there is in reality a mixed economy of formal care service provision in Ireland. On the one hand, there are publicly-provided or publicly-funded home and community care services, which are primarily oriented towards low income individuals and households. On the other hand, there are tax reliefs that families can avail of to help them with the costs of purchasing care services privately. A fair model of sharing of caring responsibilities between state and family will need to take this mix into account.

## **Adequate income support provisions**

Improvement of social protection provisions for carers has been the most visible aspect of carer policy in Ireland over recent years. Most recent budgets have afforded carers on carers allowance more sizeable increases than other social welfare payments, reflecting a certain degree of recognition of the special contribution that carers make. Despite these improvements, the consultations heard much dissatisfaction with income support for carers. The current provisions do not yet reflect a variety of recommendations made in reports by the Equality Authority and by the Oireachtas Joint Committee<sup>1</sup>, as well as in submissions by carer organisations.

The Carer Strategy will therefore need to devote special attention to further reflection and policy development in this area. The interactions between health and social service, social protection and employment policies will need to be examined in this context. For example, better income support might free up more family time for caring and thus reduce public expenditure on formal health and social care services; better provision of health and social care services might free up more employment time for carers and thus reduce the overall carer payments costs to the exchequer.

## **Support services that target and meet carer's needs**

Although supporting family carers in their caring roles has been at the core of stated carer policy in Ireland, the consultations suggest that much of the fine words have not been implemented in reality. Again and again, carers report being kept at arms length by public services and generally being left to cope with their responsibilities on their own. The consequences are evident in the poor picture of health and well-being of carers that emerges from a recent large-scale survey of carers in Ireland.

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*Equality Authority (2005) Implementing equality for carers; Oireachtas Joint Committee on Social and Family Affairs (2003) Report on the Position of Full-time Carers.*

The general lack of services and supports for carers is compounded by the absence of a requirement for the health and social services to directly take carers needs, in their own right, into account in assessing care needs and allocating care services.

Support services that target and meet carer's own needs must therefore be addressed as the third key pillar of the Carer Strategy. The sustainability of family care in Ireland will depend on this.

## Specific recommendations arising from the Consultations

The following is a summary listing of the specific recommendations arising from the Consultations. These provide a core set of issues that need to be addressed in the Carer Strategy.

Theme	What needs to be done
Community and home care services	<ul style="list-style-type: none"> <li>• Re-orientate the overall approach to a model based on shared state and family contributions</li> <li>• Ensure that carer availability is not taken for granted in service allocation decisions</li> <li>• Implement responsive and 'carer-friendly' customer services</li> <li>• Develop and implement a protocol for co-working between health and social service staff and family carers</li> </ul>
Services and supports for carers	<ul style="list-style-type: none"> <li>• Put in place a comprehensive and responsive information service for carers</li> <li>• Develop and roll-out a nationwide programme of education and training for carers on caring skills etc.</li> <li>• Develop and implement the necessary protocols to ensure that carers needs are identified and met</li> <li>• Provide more and better respite services for carers</li> </ul>
Income support for carers	<ul style="list-style-type: none"> <li>• Examine models for income support for carers in other countries and develop an Irish approach based on international best practice</li> <li>• Disentangle the objectives of basic income support and financial recognition in carer payments, and improve both dimensions</li> <li>• Develop and implement the necessary social protection provisions to eliminate the inequalities faced by carers in relation to pensions and other areas</li> <li>• Ensure that all carers are reached, including the less visible</li> </ul>
Theme	What needs to be done
Employment and work-life balance	<ul style="list-style-type: none"> <li>• Develop a co-ordinated and integrated approach, linking health and social care, employment and income support policies</li> <li>• Implement the community and home care infrastructure that is needed to support working carers</li> <li>• Further develop Carers Benefit to provide more flexibility with security for carers who must take time out from work</li> <li>• Ensure that working carers have a high visibility and attention within the work-life balance initiatives under <i>Towards 2016</i></li> <li>• Improve return-to-work supports for carers</li> </ul>
Social inclusion	<ul style="list-style-type: none"> <li>• Give specific attention to carers in Social Inclusion policy and measures</li> </ul>
A carer-friendly society	<ul style="list-style-type: none"> <li>• Develop and implement a public awareness campaign on carers and caring</li> <li>• Put in place structures to support families who are faced with caring responsibilities, including advice, counselling and mediation</li> </ul>

## 1 Introduction

This report presents the results of a nationwide Carer Consultation exercise that took place in October and November 2007. The consultation was led by the Carers Association in partnership with Caring for Carers Ireland and Care Alliance Ireland. Part-funding for the Consultation was provided by the Equality Authority as part of its activities for 2007's European Year of Equal Opportunities for All.

The Consultation was intended to provide an up-to-date perspective on the experiences and concerns of carers across the country. It presents some timely insights into what issues need to be prioritised in the forthcoming national Carer Strategy. The focus was on family carers, people who provide care and support for family members or relatives who need help because of old age, disability or long-term illness.

### Profile of participants

A total of 428 carers attended the 8 consultation sessions that were held across the country.

Location	Date	Participants
Dublin	October 22	43
Waterford	October 26	55
Cork	October 31	65
Limerick	November 2	65
Tullamore	November 5	83
Dundalk	November 9	17
Galway	November 12	55
Sligo	November 16	45
<b>Total</b>		<b>428</b>

The attendees comprised a broad spectrum of carers, including carers caring for older people, for non-elderly adults, and for children with special needs.

About one-half of participants were in receipt of carer payments and one-half were not. The majority who took part were women (who still provide the bulk of caring in Ireland), although about 15% were men. There was some participation by working carers, although overall only a minority of participants were combining care and employment and, where they were, it was mainly part-time employment.

### Consultation approach

Two main methods were used to gather information from participants during the consultations.

A short questionnaire was distributed to capture background information about the composition of those taking part and also asked participants to list the main issues facing carers today in Ireland and

the actions (by government, service providers and others) that would be most useful in addressing these issues. The most frequently identified issues and actions are listed in order of occurrence in the following Box.

**Priority issues and actions identified from the participants' questionnaire**

**Issues**

- Inadequate income support
- Lack of support for carers (from government, service providers, family and others)
- Insufficient respite services
- Lack of home and community care services
- Stress, exhaustion, depression

**Actions**

- Address the financial needs of carers
- Improve home and community care services
- Develop comprehensive respite service for carers
- Actions to encourage more recognition and respect for carers, and more support for carers, from all relevant parties

The main part of each consultation session involved facilitated discussion groups, with each group addressing the same set of topics as listed in the following Box.

**Topics addressed in the discussion groups**

• Services and supports	• Information services
• Carers health and wellbeing	• Work-life balance
• Remuneration for carers	• Social inclusion
• Education and training	

**Structure of the report**

The remainder of the report presents the results and conclusions from the Consultation, organised according to the 6 main themes that emerged from the questionnaire responses and the discussion groups:

- Community and Home Care Services
- Services and Supports for Carers
- Income Supports for Carers
- Employment and Work-life Balance
- Social Inclusion
- A More Carer-friendly Society

## 2 Community and Home Care Services

One of the biggest difficulties for carers is the lack of sufficient home and community care services for older people, people with disabilities and people with long-term illness in Ireland. Here the main issue concerns fairness in the sharing of care responsibilities between family and state.

### 2.1 Issue: Sharing care between family and state

An effective and fair strategy for carers must be based on a shared model of state and family contribution to care, not a simplistic 'one-or-the-other' approach. Leaving it all to the family is not a viable option.

Sufficient availability and accessibility of good quality home and community care services is essential for sustainable family care. The international evidence suggests that this is the key ingredient of a successful approach, enabling families to continue caring for longer and encouraging contributions by more family members.

The challenge of balancing state and family roles in care is not unique to Ireland, and is one that has been grappled with in many other countries. Some countries have historically made clear the respective responsibilities of state and family in providing care for those in need. In other countries, such as Ireland, this has been and continues to be something of a 'grey area'. The ambiguities, ambivalences and inequalities that can result from this have been well documented by the Equality Authority in its report on Implementing Equality for Carers in 2005.

### 2.2 Carer Consultation Results

The 'grey area' of interaction between state and family responsibilities in the provision of care was one of the biggest problems highlighted in the carer consultation exercise.

Themes from the Consultation	
• Not enough home and community care services	• Long delays
• Leaving it to the family - carers taken for granted	• Fragmentation and insufficient co-ordination
• An 'arms length' approach to carers	• Lack of respect for carers

#### Not enough home and community care services

A recurrent theme from carers was the lack of sufficient access to home help, home nursing and other essential health and social care services in the home, and also to day care facilities in the community. Availability of services was reported to vary widely depending on where in the country one lives.

Home help should be available to all carers and PHN should call on a regular basis.

I never see a public health nurse nor do I know who she is.

Provide more access to chiropodist, more occupational therapy for each area.

Home help services are one of the essential components of the home care infrastructure, aiming to provide regular help with cleaning, cooking, laundry, shopping and other practical activities of everyday life for those who need it. However, carers reported problems with levels of availability of home helps ('patchy at best') and with the quality of care provided. In addition, the time of day the home help is scheduled may often be unsuitable and the service was seen as being too inflexible. Wider issues around the role of the home help service and what it is intended for also require clarification.

Public health nurses are another key component of the home care infrastructure, providing basic nursing care in the community as well as advice and assistance to their clients. In addition, they often play a crucial role as a point of access and referral to other community care services. As in the case of the home help service, however, carers reported variability in the availability and quality of the public health nursing service depending on what part of the country one lives in. The nurses were described as overstretched and, as a result, being selective about who they visit. If a household appears to be coping then carers felt that they would be down the list for a public health nurse visit.

Other community and home care services were also reported to be in short supply, including occupational therapists and chiropodists.

### **Leaving it to the family – carers taken for granted**

Compounding a general lack of sufficient services, it seems that carers are often 'taken for granted' by Health Service Executive (HSE) services in decisions about allocation of home care services. Applications for home help or other supports may be rejected because of a presumption that there is a family carer available to do the job, without a full assessment of the family situation and open consideration of needs and constraints of all relevant parties. Such an approach is the antithesis of a 'shared' model of care and can be grossly unfair on families in general and carers in particular.

An honest assessment of the needs of people in need of care...

They know that we cannot walk away.

...an honest effort to provide facilities for these people of acceptable standards.

Sadly, it seems that the experiences of many carers have been of unwillingness to recognise needs by the health and social services.

## 'Arms length' approach

The recognition given to the role of family carers in the Health Strategy and other documents is not being reflected in the day-to-day experiences of carers. Carers reported difficulties in contacting HSE services in the first place. Where contact was established, reluctance to provide information about entitlements and sometimes even downright unfriendliness was reported.

They don't want you to know.

## Long delays

Many carers reported long delays in gaining access to essential services, such as occupational therapy, home care equipment or home adaptation grants. This can result in years of unnecessary suffering for carers and those that they care for. In addition, carers report long waits before being told that they will not be given services that they have applied for, again causing unnecessary delays in seeking alternative solutions.

Waiting for months to see if eligible for grant for house improvement.

Trying to get an OT sooner to the house without waiting months...everything you want you have to wait for months.

Anything you look for there is at least 18 months waiting.

## Fragmentation and lack of co-ordination

Fragmentation and lack of co-ordination of community and home care services was also a big concern for carers. Lack of communication between different services was a commonly reported problem.

More [respite] services all working together not apart.

Carers had a positive view of the new idea of home care packages that would meet their needs in an integrated manner. However, the consultations heard of a general lack of availability of sufficiently resourced care packages as well as considerable ambiguity and variability in what is currently being offered under the “package” concept.

### Lack of respect for carers

The relationship between carers and health and social care staff was also a source of considerable distress for carers.

Carers must have the respect of government and health services. There is no value placed on them for their contribution to society.

It seems that the role of the family carer is not well understood nor is it formally recognised and integrated into a joint approach to care provision. This can be demoralising and de-motivating for carers, as well as being a source of un-necessary tensions in what are often already very difficult circumstances for carers.

### 2.3 Implications for the Carer Strategy

There are a number of key topics that need to be included in the Strategy for Carers if the issues raised in the consultations are to be properly addressed.

Key Topics for the Carer Strategy	
• A ‘shared’ model of care	• ‘Carer-friendly’ customer service
• Service access and allocation criteria	• Protocol for co-working with informal carers

#### A shared model of care

If the Strategy is to be underpinned by a continued reliance on a strong input from family carers, then the perspective and approach must be one that sees the state and family as having shared responsibilities to care. This means that in each individual case a ‘package’ of care should be negotiated and agreed, combining state and family inputs as appropriate to each set of circumstances. As has been frequently emphasised in other contexts<sup>2</sup>, the service user and his or her family must be placed at the centre of care and service allocation decisions.

<sup>2</sup> for example, the National Council on Ageing and Older People and in the Primary Care Strategy

Under a shared model, families will continue to provide the bulk of care, as they do in all countries, but without an automatic presumption of availability to care and within a much more transparent and equitable framework than is currently the case. Getting the right balance between state and family responsibilities is the key challenge here. As noted by carers, the approach must be an 'honest' one, not the problem avoidance that appears to be a frequent response from the health and social services. To support this, there will be a need for clarification of how the needs and circumstances of each party, carer and person cared-for, are to be taken into account in resource allocation decisions.

In addressing this area, the Strategy will need to take into account the fact that state support for care in Ireland is provided both in kind and in cash. There is direct provision of services by public agencies (especially the HSE) as well as sometimes substantial financial support towards the cost of purchasing care services (through the various tax reliefs that are available for medical and care costs). In addition, there was an initiative a few years ago to introduce cash subsidies for private purchase of care services under the 'home care subvention scheme' and an element of this is also to be found in the 'home care packages' approach. The Strategy will need to devise an equitable model for the Ireland of today, one that caters for the realities of the public-private mix that is now a major feature of the care-giving landscape, and one that ensures a fair deal across all income brackets.

### **Service access and allocation criteria**

Following from the above, it is clear that service access and allocation criteria will need to be reviewed as part of the Strategy. Clarity with regard to eligibility and entitlements is a central issue here. A key aspect of this for carers is how the 'availability' of family capacity to contribute to care is to be determined and how this is factored into service allocation procedures.

### **'Carer-friendly' customer service**

It is quite shocking that carers report sometimes unhelpful and even unfriendly interactions with public services when seeking information and support. This runs contrary to the avowed policy priority to support family carers. An important part of the Strategy, therefore, must focus on ensuring 'carer-friendly' customer service throughout the relevant public services.

### **Protocol for co-working with family carers**

Apart from general customer service, the Strategy must also give attention to critical issues at the 'coalface' - the interactions between care services and family carers in day-to-day negotiations about and delivery of care. Again it is disappointing to hear many carers report lack of understanding and respect, and lack of clarity in their role as part of the team. A protocol for co-working with family carers needs to be developed and consistently applied nationwide by all the relevant health and social services.

### 3 Services and supports for carers

A second major theme concerns the lack of services and supports that focus on the needs of carers in their own right. Here the concern is to care for carers as well as those that they care for.

#### 3.1 Issue: Caring for and supporting Carers

Carers need to be given appropriate support for the job if they are to continue to provide the bulk of care in Ireland. Carers also need supports to ensure that they can have a life of their own.

In addition to practical supports in terms of information and training, there is strong evidence of a need for services and supports that address the health and well-being of carers. A major representative survey of Irish carers in 2007<sup>3</sup> found substantial health and well-being issues associated with caring, echoing the international evidence that has been available for some time suggesting that caring can have negative health impacts for carers.

#### Carer Health and Well-being issues in Ireland (2007)

- Carers less likely to be in very good health
- More than one-quarter say their health has directly suffered
- Considerably lower quality of life
- Specific problems
  - Stress / nervous tension (41%)
  - Back problems (26%)
  - Anxiety (23%)
  - Depression (18%)
- Factors contributing to poor health / quality of life
  - No time for own life
  - Lack of sleep
  - Especially burdensome care
  - Lack of support

#### 3.2 Carer Consultation Results

The carer consultations highlighted a number of major issues and gaps in services targeted towards the needs of carers.

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Conducted by Care Alliance, with support from the Combat Poverty Agency and the Department of Social and Family Affairs

## Themes from the Consultation

- Information
  - Accessible information on health and social services
  - Attitudes and skills of customer service staff
- Education and training about caring
  - Practical training for carers
  - Stress management and personal development skills
- Health and well-being
  - Expected to do too much
  - Carers not looking after their own health
  - Access to health services
  - Psychological / emotional support and counselling
- Carer resource centres and support groups
- Needs assessment for carers
- Respite - more respite for carers, including in-home respite

### Information

Although carers had positive views of the general citizens' information services, they reported considerable problems with information provision by the Health Service Executive (HSE). Lack of accessible information points (e.g. a number to call, and one that would be answered!) was one important aspect of this. There was a strong plea for one-stop-shops that would provide access to all relevant information in one place in an accessible manner.

There is also the problem of sometimes unhelpful and even unfriendly customer service, as well as an apparent lack of training of staff. In addition, carers reported that high staff turnover resulted in poor continuity of care and poor communication.

Information should be available at one point locally as regards what people are entitled to.

Need for information provided in a sympathetic manner.

Staff in government departments need to be more customer friendly and empathic.

Carers reported particular problems with lack of accessibility of information in the community care sector and there were also complaints about the lack of information given to carers when the person they

care for is discharged home from hospital.

More generally, accessing information from the HSE about available services and entitlements was described as often being very difficult and anxiety-provoking. Carers felt that the statutory services are reluctant to give out such information, even getting the impression that ‘they don’t want you to know’.

On the ground, public health nurses have a potentially pivotal role to play in providing information and putting carers in contact with relevant services. However, in carers’ experiences many public health nurses are too over-burdened with other duties to fulfil this role effectively.

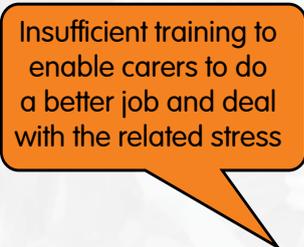
A specific area of difficulty was identified in relation to filling out forms. Carers said the necessary forms were often too complicated and that it was very easy to make a mistake. For those with low levels of literacy, form-filling could be difficult or impossible and in some cases this could lead to carers not applying for benefits that they are entitled to.

The need for information services to understand carers’ needs was emphasised. For example, carers often require information during a traumatic period in their lives, which can make it difficult for someone to retain information. They may need to be able to ask the same question many times and information services need to be responsive to carers in such regards.

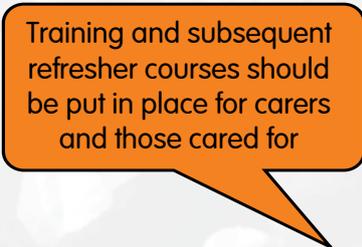
## **Education and training about caring**

A need for education and training for carers about caring was another strong theme emerging from the consultations. One aspect of this concerns training in the practical skills required for caring, such as manual handling, using equipment and personal care. Carers felt that this should be available to all carers on a statutory basis across all parts of the country, provided either directly by the HSE or through channelling funding for this through carer organisations.

Other forms of training that were suggested included personal care and self care. Stress management was felt to be an important element of this, with carers likely to benefit significantly from learning coping skills and stress reduction techniques.



Insufficient training to enable carers to do a better job and deal with the related stress



Training and subsequent refresher courses should be put in place for carers and those cared for

Return-to-work training was also identified as important in order to enable those who have finished caring to re-enter the workforce, and this theme is taken up again in Chapter 5. In relation to this, at some of the consultations the idea was raised that formal care training could be offered to those people who may wish to make a career of caring. There were mixed responses to this, with some carers thinking this to be a good idea, while others said that the last thing they would want to do is continue to care after their original caring role had ended.

More generally, education and training were seen as having additional benefits for carers, such as providing some time away from caring, opportunities for networking with other people, and having somewhere to go for advice. However, significant barriers were identified that prevented carers from accessing education and training.

Transport difficulties were especially a problem for carers who do not have access to a car and who live in rural areas. The lack of a comprehensive rural public transport system means that many carers simply cannot make their way from their home to the training centre.

A very basic issue was the lack of short-term care cover for the time that the family carer would need to leave the home to participate in a course. The carers taking part in the consultations felt they would not be able to commit to a course without being able to access such care cover.

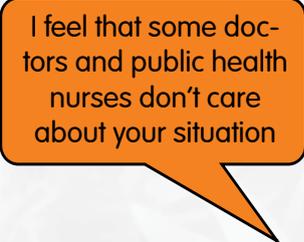
Finally, levels of awareness among carers about training courses for carers seem to be low. It was felt that more publicity needs to be generated at local level about current and future training initiatives.

## Health and Wellbeing

Many carers are in a situation where they are expected to do too much on their own, without support from the health and social services. As the recent survey of carers in Ireland shows, this has negative consequences for their health and wellbeing. Currently carers' health is 'below the radar' and given low priority even though it is of fundamental importance for the sustainability of health and social care in Ireland.

The consultations heard that it is very common for carers to neglect their own health, even when this is being impacted upon by their caring. This, of course, is counterproductive in the long-term because deteriorating health can lead to diminishing capacity to continue providing care over time.

Part of the problem appears to be the tendency for carers to give a low priority to their own health, with this theme being echoed across all the consultation sessions. Carers do not prioritise their health, and neither do government, service providers or the wider community.



I feel that some doctors and public health nurses don't care about your situation



[I was told by my GP] what do you expect...  
...you're a carer!

This de-prioritisation can occur because of lack of time, being caught up in the needs of the person they are caring for or even the fear of discovering a problem that would have to be addressed but having no one else to take their place in caring. The expense of attending a GP, paying for a prescription and other potential costs were also reported to be major barriers for many carers if they do not have a medical card.

A common plea was for the medical card to be automatically available to carers (on the same basis as for those aged over 70 years) and there was strong support also for the implementation of a once-a-year free medical check-up for carers. The concept of an annual medical check-up for carers was seen as very important and participants stressed that the check-up should take account of psychological as well as physical needs.

There should be someone available to call out and see carers are being looked after themselves and are in good health

There's a need for physical, psychological and spiritual health to be addressed.

Medical care for all carers....  
...medical once a year

The high priority that carers give to the need for support with the psychological and emotional challenges of caring is echoed in the high levels of stress and psychological distress found in the carer survey by Care Alliance. The need for dedicated counselling services for carers *and* their families was emphasised, because the children and spouses of carers also experience the impact of caring. A holistic view of health and well-being was regarded as the best approach.

Another area of importance to carers was obtaining up-to-date equipment such as hoists. It was reported that there is currently a long waiting list, which means that many carers are lifting the people they care for unaided, risking injury to themselves.

### **Needs assessment for carers**

Unlike other countries such as the UK, a needs assessment for carers is not yet in place in Ireland. Carers were in strong agreement about the need to develop a comprehensive needs assessment protocol targeting carers directly.

### **Carer resource centres and support groups**

Carers Resource Centres are provided in key towns and cities across Ireland by the Carers Association. There are sixteen centres and two service bases. Each Centre offers a drop-in service as well as dealing with telephone enquiries and personal callers.

They were my crutch at the end of the phone when I was in crisis and I needed them.

The need for extension of the phone-in service ('Careline') to operate on a 24/7 basis was raised - leaving a message on the answering machine when the office was unstaffed was unsatisfactory.

The Carers' Association also run carers' support groups from its Resource Centres. The support groups aim to allow carers to share coping strategies and local information as well as offer emotional support and develop friendships. Support groups also allow carers to access information on their rights and entitlements.

Carers who had attended support groups were positive about the experience. They said it offered them time off from caring, and the opportunity to make friends and get support. However, many carers had not heard about the support groups, especially in areas not covered by a carer organisation. They recommended that the service be extended nationwide.

## Respite

Respite services give carers a period of temporary relief or rest from their caring responsibilities. Carers felt that being able to access day care or respite care is essential to allow them some time away from caring, some time to relax and look after themselves and the other members of their families.

Although carers welcomed the increases that have been made in respite care grants, there was a common plea for further improvements in this area. Carers pointed to widespread variation in the amount and nature of respite care that is available, depending on what part of the country you live in, and also found the service inflexible especially in times of crisis.

More home help needed to give full-time carers a break - would prevent carer from suffering from depression.

Competent, regular, reliable, in home respite service for carers

Many carers mentioned a pressing need for more respite services, to include a mix of both residential and in-home respite care. In some cases, in-home respite is what is desired and preferable as it can reduce disruption and stress for the person cared for, allowing the carer time off without guilt or worry. However, although available in-home respite services were felt to be of good quality, the extent of provision was described as extremely limited. In other cases, residential respite can be more suitable if it is of sufficient quality, for example, in the case of children and adolescents who go away on a residential camp where they can spend time with each other.

Apart from occasional breaks, carers also reported a strong need for regular provision of 'respite' in the form of homecare services that would enable them to get out of the house, attend a course or even go to work. As discussed in Chapter 2, access to such services may be jeopardised by service rationing processes that deny services where a carer is deemed to be 'available'.

We need written care plans...a plan for sufficient and structured relief... every week according to lifestyle of primary family carer

### 3.3 Implications for the Carer Strategy

Provision of services and supports to address the needs of carers in their own right must be given a high priority in the Strategy.

Key Topics for the Strategy	
• Information	• Needs assessment
• Education and training for caring	• Respite
• Health services and other supports for carers	

#### Information for carers

A comprehensive and responsive information service for carers is needed. Particular attention must be given to improving the accessibility and quality of information about health and social services. An action plan for meeting the information needs of older people was published in 2002<sup>4</sup> and this provides a useful framework for improving information quality in health and social services.

#### Education and training about caring for carers

A nationwide programme of education and training on caring skills and how to cope within the role it is needed for family carers. It is essential that the training developed covers both the practical and emotional aspects of caring.

#### Health services and other supports

The Strategy must give particular attention to ensuring that carers' own health and wellbeing needs are specifically addressed. A support structure must be put in place to address threats posed by caring to carers' health. Barriers that prevent carers from looking after their own health need to be removed, including cost barriers. Options raised in the consultations that might be explored include the provision of an annual check-up for carers and wider access to medical cards for carers.

#### Needs assessment for carers

One of the most crucial issues for the Strategy will be to institute a framework that ensures that carers can be directly addressed as clients of the health and social services in their own right. In some countries, such as the UK, carers have an entitlement (in their own right) to an assessment of the needs that arise for them from their carer responsibilities. This approach should be examined as a possible

<sup>4</sup> Ruddle, H, Prizeman, G, Haslett, D, Mulvihill, R and Kelly, E (2002) *Meeting the Health, Social Care and Welfare Services Information Needs of Older People in Ireland*, Dublin: National Council on Ageing and Older People

way forward in Ireland.

In any event, the strategy must implement the necessary protocols to ensure that carers' needs, both health and social, are consistently and transparently taken into account in all service allocation decisions that impinge upon them. The practice of unilaterally factoring-in apparent carer 'availability' in health and social service decisions on whether to allocate home and community care services must be discontinued.

As already discussed in Chapter 2, this must be replaced by a statutory provision that in each individual case a 'package' of care should be negotiated and agreed, combining state and family inputs as appropriate to each set of circumstances.

## **Respite**

Both the concept of 'respite', and the nature and amount of existing provisions in this area need to be reviewed and further developed within the Carer Strategy. On the one hand, there is a continued need for improvement of access to respite breaks for carers. On the other hand, there is a need to examine how the concept of respite fits in relation to more regular or ongoing provision of publicly supported care services. This is currently a 'grey area' at the intersection between publicly supported services targeted towards the needs of the person in need of care and 'respite' services targeted towards the needs of carers. Therefore, as has been identified in the Equality Authority's report on *Implementing Equality for Carers*, the Strategy must be based on a clear articulation of the individual and joint needs (and rights) of carers and of those who receive care.

## **4 Income Support for Carers**

Income support for carers was another major theme arising from the consultations. Here the concern is to ensure that carers have an acceptable standard of living and get appropriate recognition and recompense for their enormous economic contribution.

## 4.1 Issue: Fair recompense

The financial situation of carers has received increased attention in public policy over the last few years, with efforts being made to recognise the special contribution of carers through improvements in the levels of carer payments (Carers Allowance and Carers Benefit) and also in the introduction of the half rate carer payment in addition to another social welfare payment for qualifying carers. There has also been an increase in the hours of employment that a carer may engage in whilst still receiving Carers Allowance.

Other recommendations that have been made by carer organisations<sup>5</sup> and in reports by the Oireachtas Joint Committee<sup>6</sup> and the Equality Authority<sup>7</sup> have not yet been implemented, for example, issues around the means testing of carer payments, eligibility for pensions and other longer-term aspects of social protection for carers, and the linking of carer payments to labour market rates.

Against this background, it is timely to take stock of current perspectives on income support from the point-of-view of carers themselves.

## 4.2 Carer Consultation Results

Issues in relation to income support for carers were raised almost as frequently during the consultations as were issues concerning access to services and supports.

### Themes from the Consultation

<sup>5</sup> Carers Association (2006) *Towards a Family Carers Strategy*

<sup>6</sup> Oireachtas Joint Committee on Social and Family Affairs (2003) *Report on the Position of Full-time Carers*.

<sup>7</sup> Equality Authority (2005) *Implementing Equality for Carers*

- Defining carers
  - Lack of clarity regarding eligibility
  - Eligibility of less visible carers
- Level and duration of payments
  - Insufficient recompense for work being done
  - Carers Benefit not paid for long enough
- Means-testing of payments
  - Should be abolished
  - If not, should be based on carer's means only
- Recent payment changes
  - 'Giving with one hand, taking away with the other'
  - Anomalies that need to be removed
- Security for the future
  - Pension and other social protection entitlements
- Respite care grant
  - Further increases in the grant

## **Defining carers**

There was quite a lot of confusion about eligibility criteria for Carers Allowance and how to go about applying for it. Carers also reported anomalies in defining carers for purposes of determining eligibility for carer payments. For example, carers of people with less visible needs, such as mental illness, may not be recognised as being carers and find it difficult or impossible to obtain the Carers Allowance.

## **Level of payments**

There was a strong view amongst carers that the current levels of the carer payments do not sufficiently reflect the economic value of the work done by carers. Relevant yardsticks for payment levels that were suggested included the minimum wage and home help hourly rates.

Some carers felt that some form of 'wage' for carers would be the best way to properly recognise the contribution of carers and adequately recompense them for this. Everyone agreed with the need for higher levels of financial supports but there were a mixture of views as to whether this should be a wage or compensation payment. In addition, the tax and insurance implications would have to be closely examined.

A more generous payment system to enable carers to participate more in society.

Recognise the role - it's a job 24/7 - and pay as appropriate with benefits.

We need to get more pay for it, if the person was in a nursing home, it would cost a lot more.

In relation to Carer's Benefit, the consultation heard dissatisfaction with the fact that it is paid for two years only. If the need for care still exists beyond this time, carers are unsure what to do.

The Respite Care Grant was generally viewed in a positive light, although an increase in the grant to more accurately reflect the costs of care would be welcomed by carers.

### Means testing

The current means testing of carer payments was seen as very unfair.

It is unjust to tie any funding to private resources rather than the value of the work that is being performed'.

Due to means testing I'm not entitled to anything, in other words I'm worthless...

...but should I mind my next door neighbour I'm entitled to pay. I find it hurtful, and hard to make sense of this

There was a strong view that the payments should be for all carers and not subject to means testing. It was recommended to abolish means-testing for Carers Allowance, as well as for other benefits carers might receive.

For as long as means testing remains, carers felt that it should be based only on the carer's own means and not take into account that of their spouse's. Otherwise, it is of little value in terms of recognition of the contribution that carers are making.

Remove means test - partner's income should not affect carers' income.

Carers allowance should not be means tested or spouse / partner's income taken into account - the person/carer in their own right should be respected and financially assisted

### Recent payment changes

Although carers welcomed the recent increases in the levels of carer payments, for many the experience was one of the government 'giving with one hand and taking away with the other'. It was reported that the implementation of the 'half-payment' had caused significant problems for carers by triggering a

withdrawal of other benefits, such as the medical card. Any changes in payments that can affect other benefits are a very important concern for carers who are in precarious financial situations and dependant on various social welfare and other benefits.

There were also reports of the half-payment not being available to people in receipt of pensions from other jurisdictions such as the UK. These and other anomalies need to be resolved.

## Security for the future

The situation for carers in regard to pension contributions and entitlements was also raised as an important issue of concern. Being unable to work because of caring responsibilities not only affects carers' incomes whilst they are caring but also has longer-term impacts in terms of eligibility for pensions and the amount of pension that they will receive at retirement age.

### 4.3 Implications for the Carer Strategy

Income support for carers must be given a high priority in the Strategy. Arising from the consultations, four key topics need to be given special attention.

Key Topics for the Strategy	
• Adequate financial recognition	• Providing carers with security for the future
• Carers in precarious financial circumstances	• Reaching all carers, including the less visible

#### Adequate financial recognition

The appropriateness of giving financial recognition to the contribution made by carers has already been accepted in the raising of carer payments to levels that are higher than most other social welfare payments. However, the Consultation heard a strong call for more in this area, in particular for caring to be properly financially recompensed for the work that it is and for the enormous economic contribution that it makes. Linked with this is the need for recognition that, under the current system in Ireland, many carers must give up years of, or even the lifetime possibility of paid employment.

The Strategy must include a deep analysis of this issue and present considered proposals for how best to address the matter in the Irish context. Some countries, for example, give family carers the option to apply to the health and social services for a homecare job to look after a family member, paid at the normal rate for homecare workers. Others provide a carer payment that is linked to the hours of employment that are lost due to caring. The Equality Authority's report *Implementing Equality for Carers* provides an analysis of some of the dimensions that need to be considered in this area.

#### Carers in precarious financial circumstances

Another key issue for the Strategy is the development of a system that fairly addresses the range of financial circumstances that pertain across the carer population. A key difficulty in this area was identi-

fied by the Department of Social and Family Affairs as far back as 1998 in its report on the *Review of the Carers Allowance*<sup>8</sup>. The problem is that a number of different objectives have been bundled within the Carers Allowance payment. One aspect is basic income support for carers on the basis of means testing; another is to provide an element of financial recognition of carers (for those who are eligible). The Strategy should review this approach and develop a system that separates out these two dimensions. Specific provisions must be made for carers in precarious financial circumstances and a fair system of financial recognition of the contribution of carers must be applied across the spectrum of carers and their differing financial circumstances.

### **Providing carers with security for the future**

The Strategy must recognise that caring can have lifetime implications for the earning potential of carers. Apart from years of employment that may be lost whilst caring, taking up of caring responsibilities can also have very negative consequences for the lifetime employment careers of carers. The financial impacts are felt not just during the working age years but also at retirement age. The Strategy must therefore give a high priority to the provision of security for the future for carers, particularly through continued social protection contributions during caring years and eligibility for full pensions at retirement age.

### **Reaching all carers, including the less visible**

Finally, the Strategy must address the need to ensure that an even-handed approach is applied so that carers who are caring for people with less visible but still very demanding needs, for example mental illness, are not unfairly excluded from carer payments.

<sup>8</sup> Department of Social, Community and Family Affairs (1998) *Review of the Carer's Allowance*, Dublin: Department of Social, Community and Family Affairs.

## 5 Employment and Work-Life Balance

The historical pattern in Ireland, where the bulk of carers were women who were outside the labour force, no longer pertains. Today, considerably more than one-half of working age carers are in part-time or full-time employment and many carers who are not in employment would like to return to work. Their needs must be given a lot more attention in policy and provisions for carers.

### 5.1 Issue: Giving carers options

The Equality Authority's report on *Implementing Equality for Carers* emphasised that carer policy must address the full spectrum of carers and encompass their varying interests and needs in relation to employment. Some carers who are working outside the home when their caring responsibilities start will wish to continue doing so, whether full-time or part-time; others will wish to take time off for a period and then return to work at an appropriate time in the future. Likewise, some carers who happen not to be working outside the home when their caring responsibilities start will have aspirations to return to work as soon as possible; others may not wish to return to work for the foreseeable future.

All of these situations need to be supported through labour market, social protection and other measures.

### 5.2 Carer Consultation Results

As noted in the introduction to this report, only a minority of participants in the consultations were working carers. This is likely due in part to logistical barriers to participation by working carers (consultations were in the day-time) and in part to a more general lack of visibility of working carers on the carer scene in Ireland. Nevertheless, the consultations did point to some important issues for carers in relation to employment and work.

#### Themes from the Consultation

- Barriers to employment
  - Lack of community and home care services
  - Restricted hours that can be worked with carer payments
- Work-life balance
  - Organisation of work to meet the needs of carers
  - Having a life as well as caring
- Return-to-work
  - Training and other supports for return-to-work

#### Barriers to employment

The lack of availability of sufficient community and home care services often presents an insurmountable barrier to employment for carers. Even where services are available, they are typically not or-

ganised around the needs of working carers. The lack of respite places or short-term care cover was again raised here.

Restrictions on the hours that can be worked by those in receipt of Carers Allowance were also seen to be an important barrier to employment. Although carers felt that the recent increase in the hours of employment allowed was a positive step, in reality, to be practically useful, the limit needs to be raised to at least 20 hours per week.

## Work-life balance

Carers felt that more effort was required to encourage employers to provide flexible working arrangements that meet the needs of employees who have caring responsibilities. Working carers need the flexibility to be able to take time off at short notice in case of emergency, and also need understanding and support from their employers.

The idea of ‘work-life balance’ was also interpreted more broadly by carers to include the achievement of a balance between caring and leisure time. The experience of carers was that there is seldom such a balance, that caring is a job that takes up 24 hours of the day, either in terms of direct caring tasks or in terms of thinking about the person being cared-for and planning tasks for the next day.

Many carers have to combine multiple responsibilities, such as caring for their children and family as well as for the person(s) with specific care needs. The constant juggling that is required can be highly stressful.

## Return-to-work

It was pointed out that many carers find themselves totally unprepared for return to work once their caring role has ended. Current restrictions on those receiving carer payments can effectively prevent carers from accessing many forms of training. In addition, the various practical and logistical barriers already discussed in Chapter 3 in relation to access to training about caring apply equally to accessing training for return-to-work.

## 5.3 Implications for the Carer Strategy

Employment opportunities, work-life balance and return-to-work for carers must be given a high priority in the Strategy. Based on the results of the consultation and the recommendations in the Equality Authority’s report on *Implementing Equality for Carers*, a number of topics need to be given special attention.

Key Topics for the Strategy	
<ul style="list-style-type: none"> <li>• A co-ordinated and integrated policy approach</li> </ul>	<ul style="list-style-type: none"> <li>• Work-life balance for working carers</li> </ul>
<ul style="list-style-type: none"> <li>• An adequate care infrastructure</li> </ul>	<ul style="list-style-type: none"> <li>• Support for return-to-work</li> </ul>
<ul style="list-style-type: none"> <li>• Flexibility with security</li> </ul>	

## **A co-ordinated and integrated policy approach**

A core focus of the Strategy must be to put in place the co-ordinated and integrated approach that is so badly needed across employment, income support and health/social service policies in the Ireland of today. For example, there is a real tension between an employment policy that aims to encourage high employment rates for all groups, including carers, and health and social service policies that depend on the availability of full-time family carers. This is unfair on carers and entirely unsuitable for the modern Irish society, and will become increasingly untenable in the light of lifestyle and demographic developments.

## **An adequate care infrastructure**

The evidence from other countries shows that an adequate care infrastructure is the key to supporting carers to participate in paid employment. This means that the Strategy must give special attention to ensuring that community and home care services are provided in sufficient quantity, and are suitably organised to facilitate the working lives of carers.

## **Flexibility with security**

The Strategy must also deal with the reality that even with a well-developed care infrastructure in place, caring responsibilities will still require time-out from the workforce in many cases. An income support policy is needed that provides flexibility with security for carers whose employment opportunities are impacted by caring, one that minimises the financial penalties for carers both in the short-term and longer-term.

## **Work-life balance for working carers**

The Strategy must also address work-life balance issues for working carers. It should ensure the implementation of the various measures for working carers that have been promised under *Towards 2016*<sup>9</sup> and identified in other reports, including the Equality Authority's report on *Implementing Equality for Carers*.

## **Support for return-to-work**

Improvement of return-to-work supports for carers must also be given a high priority, again based on implementing the commitments in *Towards 2016* and the recommendations in the Equality Authority's report.

9

*Towards 2016: Ten-Year Framework Social Partnership Agreement 2006-2015*

## 6 Social Inclusion

The social inclusion concept brings together a number of dimensions that together can result in a high risk of exclusion from mainstream society for particular groups. Carers are one such group, although this aspect of the caring experience is often not sufficiently recognised.

### 6.1 Issue: A life beyond caring

Caring responsibilities are often very onerous, limiting the time and energy available for carers to have a life of their own. Many carers do not have access to supports to allow them time off from their caring duties to have a social life or to more generally participate in the life of the community and society. The recent survey of carers by Care Alliance found that the majority of carers report major restrictions in their social / leisure lives and that isolation was a problem for many. This results in a lower quality of life, stress and other negative health impacts for many carers.

The fact that carers are often in low income situations - many are at-risk of poverty - is also a major concern. Separately and in combination, the lack of social opportunities and risk of poverty mean that carers are at high risk of social exclusion.

### 6.2 Carer Consultation Results

For purposes of the consultation exercise, social inclusion was defined as ‘a process which ensures that those at risk of poverty and social exclusion gain the opportunities and resources necessary to participate fully in economic, social and cultural life, and to enjoy a standard of living and well-being that is considered normal in the society in which they live’. This definition was taken from the Charter of Fundamental Rights of the European Union. Within this perspective, the consultations focused on a number of specific aspects, including social participation, isolation and lack of support, poverty, and recognition and respect for carers.

Experiences of social exclusion were common amongst the carers who took part in the consultation.

Themes from the Consultation	
<ul style="list-style-type: none"><li>• No life of one's own</li></ul>	<ul style="list-style-type: none"><li>• Poverty</li></ul>
<ul style="list-style-type: none"><li>• Isolation and lack of support</li></ul>	<ul style="list-style-type: none"><li>• Lack of recognition and respect</li></ul>

#### No life of one's own

Many carers report that the 24/7 responsibilities of caring and the lack of supports means that they have no life of their own. Even if they can get out, guilt about leaving the person they care-for on their own or about burdening someone else seems to be a common experience. The lack of opportunities affects all aspects of their lives, including social life and personal development.

Our lives should not stop and stagnate just because we are carers. We are important too!

A few hours to myself at least one day a week, when someone could stay with the person...

## Isolation and lack of support

Carers also commonly report isolation and of being left alone to cope without support from others. Isolation tends to increase the longer one is caring, as it becomes increasingly difficult to maintain relationships with friends and family.

On a practical level, carers pointed out that participating in society is dependent on the very basic ability to leave one's own home.

This is not to do with money; it's to do with getting out of the house.

If there is no cover available, and if the carer cannot access transport, this becomes almost impossible. Participants living in rural areas, especially those without cars, found accessing transport services extremely difficult, and many were effectively trapped in their homes.

Participants came up with some innovative suggestions for solutions to some of these problems, such as telephone or video conferencing, and using the internet and email for networking and support. However, the point was strongly made that technology is no substitute for genuine human contact.

Carers emphasised the necessity of planning ahead for any social event, requiring a lot of elements to be put in place well beforehand, along with the help and support of friends and family. Respite or some other form of care cover is essential and needs to be planned ahead, but it seems that it is currently not possible to get advance notice of the availability of respite care. Out-of-hours care cover at evenings and weekends was also identified as being crucial if carers are to get out of the home and participate in society, but carers reported that this was not available.

## Poverty

Carers who rely only on carer or other social welfare payments for their income are at a high risk of poverty. The consultations suggest that many carers are living in very precarious financial circumstances where even a few euros per week make a huge difference. Caring is a difficult enough role without being compounded by poverty.

## Recognition and respect

Recognition and respect for carers and the carer role are important factors in social inclusion. Sadly, however, the consultations heard that experiences of lack of respect and recognition were commonplace.

Respect for carer as doing an important job.

Recognition of the role played by carers and then valuing their contribution.

Respect the same as other workers, stop taking us for granted.

### 6.3 Implications for the Carer Strategy

Carers need to be given a higher priority and greater attention in Social Inclusion policy.

#### Key Topics for the Strategy

- Give specific attention to carers in Social Inclusion policy

### Carers in Social Inclusion policy

Carers need to be clearly identified as a priority target group within social inclusion policy. Specific measures for carers should be implemented to address the various dimensions of this, including social participation, isolation, poverty and recognition / respect.

## 7 A More Carer-friendly Society

Caring is an issue that cuts across all aspect of society and has relevance for us all. Everyone with a role to play - employers, co-workers, service providers, educational institutions, communities, neighbours and families - must be mobilised to do their bit. There is a pressing need for efforts to promote a more 'carer-friendly' society.

### 7.1 Issue: Everyone doing their bit

The key issue here is the need for an ethos of 'everyone doing their bit' in contributing to and supporting the caring work that needs to be done in our society. Available evidence suggests that the reality in Ireland is far removed from this. Caring responsibilities often end up with just one person in a family, and carers and their needs are often invisible in the workplace, education and community life more generally.

### 7.2 Carer Consultation Results

Many carers reported a lack of carer-friendliness in their own experiences within the family as well as in the wider society.

#### Themes from the Consultation

- |                   |                                    |
|-------------------|------------------------------------|
| • Family dynamics | • Societal awareness and attitudes |
|-------------------|------------------------------------|

#### Family dynamics

The consultations heard that family support is very important for carers. Involvement of other family members can spread the burden of care across more than one person. Some carers reported a lack of sharing of caring within their families and an absence of support from other family members. Lack of awareness and appreciation of what is involved for the carer seems to be an important factor in this. Sometimes also the family dynamics are such that carers who need help may refuse it when offered. In general, there seems to be a widespread lack of understanding of caring and of good role models on how to fairly share caring responsibilities within families.

The need for support in the resolution of financial or other disputes that may arise within families dealing with caring responsibilities was also raised. The possibility of free legal or mediation aid being provided for this was suggested.

#### Societal awareness and attitudes

The problem of awareness and attitudes extends beyond the family. Carers felt that there was a general lack of awareness, understanding and recognition for carers, and even negative attitudes and prejudices in some cases. The need for a public awareness campaign to address this was raised.

### 7.3 Implications for the Carer Strategy

These experiences of carers point to a need for both awareness-raising and family support to be addressed in the Strategy.

#### Key Topics for the Strategy

- |                      |                  |
|----------------------|------------------|
| • Awareness campaign | • Family support |
|----------------------|------------------|

#### Awareness campaign

The Strategy should consider implementing a public awareness campaign on carers and caring. This is something that has been recommended in the Equality Authority's report on *Implementing Equality for Carers* and support in this area has been promised under the 'Towards 2016' social partnership agreement. Such a campaign might include radio and television advertisements<sup>10</sup>, and a module on caring in the school curricula.

#### Family support

The Strategy should also consider how families can be supported in facing the many challenges that caring can pose in the family context. Important issues include fair sharing of caring responsibilities and negotiation about financial or inheritance matters. Advice, counselling and mediation services are needed in these areas.

<sup>10</sup> A useful model for this might be the campaigns to draw attention to the needs of older people and encouraging us all to be aware and do our bit

## **8 Summary of issues for the Carers Strategy**

This nation-wide consultation of carers has identified an urgent need for action to support the 160,000 family carers in Ireland today. There are a number of important messages that need to be heard and given priority attention in the formulation of the Carer Strategy.

The overarching message is that carers are very dissatisfied with their current situation. Many are over-burdened, feel unrecognised and un-appreciated, and are unable to have any life of their own. As a result, the sustainability of family care in Ireland is under severe threat. It will become increasingly jeopardised unless the fundamentals of carer policy in Ireland are given a new direction and impetus, one that fits with the realities of life in Ireland today.

A very definite conclusion from the consultation is that carers in Ireland are seeking and need a whole new relationship and interface with the state and support services to maintain them in their caring role. In this regard, it is encouraging that the consultations identified a genuine capacity and willingness on the part of carers to think about their situation from a service development point of view and to engage with policy-makers and the relevant service provider agencies in the formulation of the revamped approach that is so badly needed. This must be capitalised upon and brought to bear in the development and implementation of the Carer Strategy.

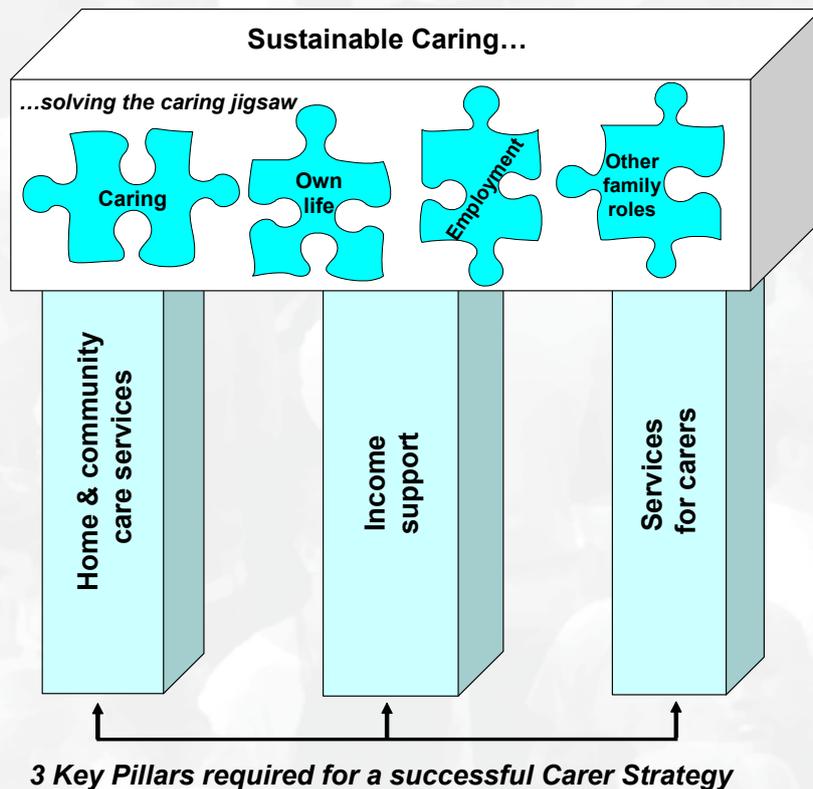
The core of the issue is about providing the supports that enable caring responsibilities to fit as comfortably as possible within the overall life situation of carers. On the one hand, this means putting in place the supports that enable people to care when required and desired, without major loss of income - a choice that is increasingly less attainable now that dual income households and lifestyles are required for a normal standard of living. On the other hand, it is about putting in place the supports that give carers the opportunity to continue to have a life of their own when caring responsibilities arise, including retaining one's employment on a part-time or even full-time basis if possible.

The Strategy must also take into account the fact that carers comprise a very heterogeneous group. They include women and men, even if women are still the majority. They encompass the full spectrum of income brackets, from rich to poor. Caring is carried out by all age groups throughout the life cycle, including children. Some carers combine caring with paid employment and others do not. Some embrace caring responsibilities willingly and gladly; others may be reluctant because of the feared impact on their lives but have no choice.

### **8.1 Three core pillars for the Strategy**

Three pillars are required to support the type of Carer Strategy that is needed:

- a fair shouldering of the caring responsibility by the state
- adequate income support for carers
- a range of support services that target and meet carers' needs.



## **Fair shouldering of the caring responsibility by the state**

A fair shouldering of caring responsibility by the state means overhauling the current approach to allocation of community and home care services as it relates to carers. A substantial re-orientation of policy is required, so that community and home care services are provided on the basis of a shared model of care. The current ‘residual’ approach, where the state steps in when all else fails is neither sustainable nor equitable. Further development of home and community care services and a new and radically different approach to allocation of services will therefore need to be given a central position in the Strategy for it to succeed.

In each individual case a ‘package’ of care should be negotiated and agreed, combining state and family inputs as appropriate to each set of circumstances. Service allocations should be based on need, taking into account the needs and aspirations of all family members including carers. Under such a model, families will continue to provide the bulk of care, as they do in all countries, but without an auto-

matic presumption of availability to care and within a much more transparent and equitable framework than is currently the case.

There is an important 'public-private mix' dimension to equitable policy in this area. This is because, although often overlooked, there is in reality a mixed economy of formal care service provision in Ireland. On the one hand, there are publicly-provided or publicly-funded home and community care services, which are primarily oriented towards low income individuals and households. On the other hand, there are tax reliefs that families can avail of to help them with the costs of purchasing care services privately. A fair model of sharing of caring responsibilities between state and family will need to take this mix into account.

### **Adequate income support provisions**

Improvement of social protection provisions for carers has been the most visible aspect of carer policy in Ireland over recent years. Most recent budgets have afforded carers on carers allowance more sizeable increases than other social welfare payments, reflecting a certain degree of recognition of the special contribution that carers make. Despite these improvements, the consultations heard much dissatisfaction with income support for carers. The current provisions do not yet reflect a variety of recommendations made in reports by the Equality Authority and by the Oireachtas Joint Committee<sup>11</sup>, as well as in submissions by carer organisations.

The Carer Strategy will therefore need to devote special attention to further reflection and policy development in this area. The interactions between health and social service, social protection and employment policies will need to be examined in this context. For example, better income support might free up more family time for caring and thus reduce public expenditure on formal health and social care services; better provision of health and social care services might free up more employment time for carers and thus reduce the overall carer payments costs to the exchequer.

### **Support services that target and meet carer's needs**

Although supporting family carers in their caring roles has been at the core of stated carer policy in Ireland, the consultations suggest that much of the fine words have not been implemented in reality. Again and again, carers report being kept at arms length by public services and generally being left to cope with their responsibilities on their own. The consequences are evident in the poor picture of health and well-being of carers that emerges from a recent large-scale survey of carers in Ireland.

The general lack of services and supports for carers is compounded by the absence of a requirement for the health and social services to directly take carers needs, in their own right, into account in assessing care needs and allocating care services.

Support services that target and meet carer's own needs must therefore be addressed as the third key pillar of the Carer Strategy. The sustainability of family care in Ireland will depend on this.

<sup>11</sup> Equality Authority (2005) *Implementing equality for carers*; Oireachtas Joint Committee on Social and Family Affairs (2003) *Report on the Position of Full-time Carers*.

## 8.2 Specific recommendations arising from the Consultations

The following is a summary listing of the specific recommendations arising from the Consultations. These provide a core set of issues that need to be addressed in the Carer Strategy.

Theme	What needs to be done
Community and home care services	<ul style="list-style-type: none"> <li>• Re-orientate the overall approach to a model based on shared state and family contributions</li> <li>• Ensure that carer availability is not taken for granted in service allocation decisions</li> <li>• Implement responsive and 'carer-friendly' customer services</li> <li>• Develop and implement a protocol for co-working between health and social service staff and family carers</li> </ul>
Services and supports for carers	<ul style="list-style-type: none"> <li>• Put in place a comprehensive and responsive information service for carers</li> <li>• Develop and roll-out a nationwide programme of education and training for carers on caring skills etc.</li> <li>• Develop and implement the necessary protocols to ensure that carers needs are identified and met</li> <li>• Provide more and better respite services for carers</li> </ul>
Income support for carers	<ul style="list-style-type: none"> <li>• Examine models for income support for carers in other countries and develop an Irish approach based on international best practice</li> <li>• Disentangle the objectives of basic income support and financial recognition in carer payments, and improve both dimensions</li> <li>• Develop and implement the necessary social protection provisions to eliminate the inequalities faced by carers in relation to pensions and other areas</li> <li>• Ensure that all carers are reached, including the less visible</li> </ul>
Employment and work-life balance	<ul style="list-style-type: none"> <li>• Develop a co-ordinated and integrated approach, linking health and social care, employment and income support policies</li> <li>• Implement the community and home care infrastructure that is needed to support working carers</li> <li>• Further develop Carers Benefit to provide more flexibility with security for carers who must take time out from work</li> <li>• Ensure that working carers have a high visibility and attention within the work-life balance initiatives under <i>Towards 2016</i></li> <li>• Improve return-to-work supports for carers</li> </ul>
Social inclusion	<ul style="list-style-type: none"> <li>• Give specific attention to carers in Social Inclusion policy and measures</li> </ul>
A carer-friendly society	<ul style="list-style-type: none"> <li>• Develop and implement a public awareness campaign on carers and caring</li> <li>• Put in place structures to support families who are faced with caring responsibilities, including advice, counselling and mediation</li> </ul>