SUPPORT SERVICES FOR CARERS OF ELDERLY PEOPLE LIVING AT HOME

SUPPORT SERVICES FOR CARERS OF ELDERLY PEOPLE LIVING AT HOME

By
Patricia Finucane
Joan Tieman
Geraldine Moane

Chapter Three has been prepared by Joe Larragy, former Research Officer with the National Council for the Elderly

NATIONAL COUNCIL FOR THE ELDERLY
REPORT NO. 40

Price £8.50

Table of Contents

List of Tables

Chapter 3

Chapter 4

Chapter 5

Foreword

Since its establishment, the National Council for the Elderly[1] has maintained a continuing interest in, and commitment to family carers of the dependent elderly. It has described family carers as the backbone of community care. Both numerically and in terms of the hours and intensity of their work, informal carers make by far the most important contribution to the support of the frail elderly living in the community. Without this contribution it would not be possible to realise the first objectives of public policy in regard to the elderly, namely:

- *to maintain elderly people in dignity and independence in their own home;*
- *to restore those elderly people who become ill or dependent to independence at home.*

(The Years Ahead... A Policy for the Elderly, p.38)

The third objective of public policy in regard to the elderly is stated by *The Years Ahead* report as follows, to encourage and support the care of the elderly in their own community by family, neighbours and voluntary bodies in every way possible. The Council would hope that this report on support services for carers of elderly people living at home will be helpful in providing some indication of ways to promote this objective. The support of informal care is best achieved by supporting informal carers themselves. Statutory service providers who aim to enhance the health and well-being of the elderly cannot be fully effective unless they work with and support informal carers.

Though the National Council for the Elderly did not initiate this study it was pleased to give its support to the Catholic Social Service Conference[2] which proposed it and which nominated Sr. Patricia Finucane to undertake the research. The Council wishes to thank the authors of the study, Sr. Patricia Finucane, Dr. Joan Tiernan and Dr. Geraldine Moane together with all the other people associated with the report, for their diligence and dedication in producing it.

---

1 Formerly called The National Council for the Aged

2 Now called Crosscare

The Council would like to particularly thank its former Research Officer, Mr. Joe Larragy for liaising with the authors and for drafting Chapter Three of the Report, *Institutional Services and Informal Care.*

The Council is also grateful to the Consultative Committee established to oversee the project in a consultative capacity. Under the Chairmanship of Dr. Bernard Walsh, the members of this Committee were Mrs. Iris Charles, Ms. Janet Convery, Mr. Jim Cousins and Mr. Frank Goodwin.

We thank Mr. Bob Carroll, Secretary for liaising with the CSSC/Crosscare and the authors and for his advice concerning the project. We also thank our Projects Officer, Ms. Trish Whelan for supervising the publication of the report and Ms. Céline Kinsella and Ms. Carol Waters for their secretarial assistance.

Michael White

Chairman

December, 1994

Authors' Acknowledgements

A number of people and organisations greatly assisted the completion of this work. To them we express our gratitude.

The National Council for the Elderly, especially Mr. Bob Carroll and Mr. Joe Larragy.

The members of the Consultative Committee appointed by the National Council for the Elderly under the Chairrnanship of Dr. Bernard Walsh - Mr. Bob Carroll, Mrs. Iris Charles, Ms. Janet Convery, Mr. Jim Cousins, Mr. Frank Goodwin and Mr. Joe Larragy. This Committee helped with constant advice and support throughout the research process.

The Health Boards through the co-operation of their:

Chief Executive Officers
Programme Managers, Community Care
Area Administrators
Directors of Community Care
Superintendent and Area Public Health Nurses
Community Welfare Officers
Social Workers
Home Help Organisers.

A special word of thanks to the community care personnel in the Mid-Western Health Board for their help during a preliminary study which was carried out in 1991, and to those in Community Care Area 6 of the Eastern Health Board and the Roscommon Community Care Area of the Western Health Board who gave so generously of their time during the pilot study for the project.

V.E.C., Roscommon, who provided information regarding carer projects.

Parish Teams in Aughrim Street and Phibsboro, Dublin.

Members of the National Carers Association in:

Dublin

Roscommon

Clare
Limerick
Tipperary
Cork
Galway.

Soroptimists International of the Republic of Ireland, especially Ms. Mary McMahon and Ms. Judith Ironside whose support throughout was greatly appreciated.

The Social Research Centre, University of Limerick, especially Professor Joyce O'Connor, currently President of the National College of Industrial Relations, who provided guidance and encouragement at the preliminary stage of the project and Ms. Patti Punch whose expertise in the library helped to get the show on the road.

The Department of Psychology, University College Dublin, especially Ms. Mairead Bolger and Ms. Muriel Keegan.

Carers - During preliminary, pilot and main study, carers around the country expressed their appreciation that this study was being done and contributed to the work, by providing interviews, comments and suggestions.

The staff of the Catholic Social Service Conference (CROSSCARE), particularly Bishop Desmond Williams and Fr. William Farrell, and later Dr. Maurice Reidy and Fr. Martin Noone, whose interest in the welfare of older people and carers prompted them to promote and support the study. A special word of thanks to Jackie, Gillian and Brian who were ever ready to type, correct and retype, and also Vonnie and Marie who were always willing to oblige.

Bheirimid fíor-bhuíochas díbh go léir, agus tá súil againn go dtiocfaidh feabhas mór ar sheirbhísí cúnta agus tacaoíchta do lucht curaim, de bharr an tsaothair seo.

Patricia Finucane,
Joan Tiernan,
Geraldine Moane.

CHAPTER ONE

Introduction

Attention to the needs of carers of the elderly has been growing in recent years. There is increasing acknowledgement of the central role played by carers in maintaining dependent elderly people in the community. At the same time there is mounting evidence of the strains of caring, and of the lack of support services which specifically cater for the needs of carers. This study aims to analyse the health care system with the specific needs of the carer in mind. It also aims to make recommendations which would result in a health care system which integrates institutional and community care, and which recognises the key role played by the carer in providing health care.

Government Policy Regarding Care of the Elderly

An increasing emphasis on community care is evident in the government policy regarding the elderly. The basic assumption underlying this policy is that it is more desirable to enable elderly people to continue living at home at an optimum level of health and independence, thus avoiding the need for institutionalisation. The development of this policy can be traced from the 1951 *White Paper* through the 1968 *Care of the Aged Report* and on to *The Years Ahead*, report of the Working Party on Services for the Elderly, published in 1988 and it is further reinforced in the recently completed *Shaping a Healthier Future: A Strategy for Effective Healthcare in the 1 990s* (1994). While the 1951 *White Paper (Reconstruction and Improvement of County Homes)* emphasised institutional care, the *Care of the Aged Report* (1968) recommended a movement from hospital and institutional care for elderly people to care in the community. It also recommended that families should be helped by the public authority to maintain their dependent relatives at home.

The National Economic and Social Council's report, *Community Care Services* (NESC 1987) identified and emphasised the complementary nature of community care. It should, the author argues, provide "a framework of services to families, communities and voluntary organisations to allow them to provide various forms of care".

The NESC report (1987) suggests that unfortunately state intervention tends to be substitutional, that is to say, services are more usually provided when family care is absent or breaks down. A clearer policy of complementarity would involve the provision of practical support for carers in the form of ongoing income maintenance, domiciliary supports, etc. This could make it possible for family carers to continue to care, and prevent the need for more costly and inappropriate substitutional care such as long-term hospitalisation or residential care. This point is again addressed in *Shaping a Healthier Future.* The authors acknowledge that "...community-based services are not as yet developed to the extent that they can appropriately complement and substitute for institutional care or provide adequately for those in the community who are dependent on support" *(Shaping a Healthier Future,* 1994, p.10).

The report of the Working Party on Services for the Elderly, *The Years Ahead* (1988), reiterated and expanded on the initial understanding of community care as formulated in the 1951 and 1968 reports. This report spelt out more clearly the huge contribution made by carers towards the provision of care of the dependent elderly in the community. The authors acknowledged that family carers receive little recognition and insufficient support from statutory agencies. They proposed that attention be specifically directed to carers in their own right. It is disappointing that the recent health strategy does not highlight the central role of carers in the actual provision of care services

The 1991 Programme for Economic and Social Progress (Department of the Taoiseach, 1991) report took on board the recommendations of *The Years Ahead* and promised an ongoing development in services for older people being cared for at home. They explicitly stated that "the priorities for service development under the programme will be to:

- *expand home nursing and other support services for the elderly and their carers living at home;*

- *extend respite facilities to relieve the families caring for dependent elderly at home."*

From these reports it is clear that government policy firmly subscribes to need for support services for carers of elderly people living at home, and gives a definite commitment to provide these services. It is also clear that a policy of community care is dependent on the willingness and availability of family members to provide care.

Factors Affecting the Availability of Carers

A number of demographic and social trends influence the availability of carers for dependent elderly, and the demand for services for the elderly. Three factors relevant to carers are the projected increase in the elderly population, changes in family structure owing to large scale social changes, and the increasing age of carers. These trends have serious implications for the ability and willingness of families to provide care, and hence for the policy of community care.

1. Increase in the Elderly Population

The 1986 Census figures for the Republic of Ireland indicated that 10.9 per cent of the total population were 65 years and over, and 4.1 per cent of the total population were 75 years and over (Blackwell, *et al.*, 1992; Central Statistics Office, 1986).

Furthermore, projections from the Central Statistics Office in 1988 suggested that by the year 2006, 11.6 per cent of the total population will be 65 years and over. Almost all of this increase will be in the category 75 years and over, which is projected to increase by 13.6 per cent. To compound matters, two thirds of the increase - approximately 18,000 people - will be in the over-85 year old sector.

During this period, it is estimated that while the population of elderly will increase by 2.7 per cent, the population as a whole will decline by 3.5 per cent. The fact that the biggest percentage population increase among the elderly is expected in the oldest segment poses questions for family members, voluntary and statutory service providers and society at large. It is generally accepted that as people move along in the ninth decade of life, daily task dependency and health needs increase. So we may expect to find a bigger number of elderly requiring care, either at home or in institutions, in the years to come. It could be argued that since the most rapid population increase in this country in the next 20 years is expected in the 40-60 age group, adequate support will be available for the needy elderly from within the family. But

when we look at the factors affecting family structure, together with the employment situation in this country, it is obvious that this is a tenuous assumption. Serious planning is necessary to provide support services for those who make the decision to care for elderly dependent relatives at home, if policies regarding community care of the elderly are to be fulfilled.

2. Changes in Family Structure

Underlying the above reports is the assumption that family care will be available if and when adequate support services are available. However, consideration of some of the dramatic changes in family structure in Ireland in the past 55 years serves to warn against complacency in this matter (Kennedy, 1989). Ireland's transition from a predominantly rural to an urban society, with its attendant industrialisation, urbanisation, technological advances, economic instability, increased mobility and emigration, have contributed to notable changes in attitudes, awareness and social expectation. The latter half of this century has seen the near-disappearance of the extended family, the erosion of the nuclear family, growth in the number of one-parent families, significant changes in the status, role and expectations of women, dual-parental employment, and decreases in family size (e.g., from 4.0 in 1981 to 2.3 in 1987). All of these factors affect the possibility of future care by family members within the community.

It is widely accepted that family care is, or has been, predominantly provided by women (Blackwell, *et al.,* 1992; Boyd and Treas, 1989; Donovan, 1989; Lang, *et al.,* 1983; O'Connor and Ruddle, 1988). In the past, it was comparatively easy to care for older members within the extended family. Later, with a stronger nuclear family base involving the work-in-the-home wife and mother, family home care was more likely and possible. Now, however, with increasing mobility, a greater participation of women in the workforce, and a change in attitudes towards needs and rights, it is unlikely that family carers will be as plentiful in the future.

3. *The Age of Carers*

Another factor commanding attention is the age of carers. O'Connor and Ruddle (1988) note that carers are getting older. Their study indicated that an estimated 66,300 elderly people were receiving some level of care at home. Half of the carers were in the 40-59 age range, 22 per cent were in their 60s, and 10 per cent in their 70s. As already stated in this chapter, it is projected that by the year 2006, there will be a 3.5 per cent decline in the population as a whole while the over *65* population will have increased by 2.7 per cent.

The above three factors clearly indicate the difficulties of ensuring the continuance of home care for the elderly by family carers. The possibility of buying-in care, even with an increased ability to do so, would not appear to be sufficient to offset the greater and more acute demands forecast. There is a clear need to give more immediate attention not only to the question of carer support, but to the question of providing incentives for carers. Otherwise it may not be possible to avert what O'Connor and Ruddle (1988) foresee, namely, the breakdown of the family care system and an inevitable increase in admissions to institutional care.

The Present Study

The present study was motivated by the dearth of evidence relating to the provision of support services specifically for carers. The study was commissioned by the National Council for the Elderly* (NCE), which has repeatedly emphasised the importance and desirability of enabling older people to live in the community for as long as possible. In accordance with government policy, and with research findings in Ireland, the United Kingdom, and the United States, the Council "has identified the family carers of dependent elderly people living at home as the most important contributors of all to the care of the elderly" (NCA, 1989).

Over the years, the Council has repeatedly advocated support for family carers, and has published a number of studies on care of the elderly, and specifically on carers *(NCA,* 1985; O'Connor, *et al.,* 1988; O'Connor and Ruddle, 1988; O'Mahony, 1986; O'Shea, *et al.,* 1991). These studies of carers, and other studies, which will be reviewed in Chapter Two, provide detailed information on the numbers of dependent older people being cared for by family members, and on the nature and extent of the care provided.

Regarding support services for carers, O'Connor and Ruddle (1988) concluded that "the overall level of service provision is low among the great majority of carers". They found that even though some of the services which would meet the needs of carers were in existence, they were not always reaching the carer, and so were not being used effectively to maintain the informal caring relationships. There was a definite lack of necessary information regarding the existence, availability and means of accessing those services which would help to maintain the older dependent person in the family home or which would provide continuing institutional care when home care was no longer possible. There is a need to ascertain not only the extent to which services are available, but also the factors which influence the take

---

***Prior to 1990 the National Council for the Elderly (NCE) was known as the National Council for the Aged (NCA).**

up of services by elderly and their carers in the community. The necessity for further research in this area was clearly highlighted.

Focus and Specific Aims of the Study

This study focuses on the carer of the dependent older person and on carer-support services. Its objective is to ascertain what support services are actually available for carers of elderly people who live at home. It is aimed at policy makers, statutory service providers, relevant voluntary organisations and carers themselves. It is also hoped that the findings may form the basis for further research in this area.

The specific aims of the study are:

1. To identify current services for informal carers of dependent elderly people in each of the 31 community care areas of the eight health boards;

2. To initiate a detailed database of available support services for family and other informal carers of dependent elderly people living at home;

3. To identify variations in provision of services by community care area;

4. To identify and highlight gaps in service provision;

5. To outline possible initiatives in the provision of carer support;

6. To make appropriate recommendations for policy and practice.

Terms and Concepts Used in the Study

This study focuses on the provision of support services to carers of the elderly living at home. However, it is often difficult to separate services for the elderly from services for carers. Furthermore, while many discussions of health care for the elderly acknowledge the importance of carers, very few approach health care from the point of view of the carer. This section aims to clarify some of the concepts which have, been suggested to facilitate discussion of services from a carer's point of view.

The concept of "community care" often involves the implicit idea that informal care is provided "by" the community, that is, by friends, neighbours and volunteers. However, research, which will be reviewed in Chapter Two,

consistently shows that, in fact, care is provided almost exclusively by one carer, usually a female family member, with little support from others. It is thus more accurate to speak of care “in” the community, or even more specifically, of care in the home.

The term “carer” designates family or other informal carers, in other words, people not officially employed by statutory, voluntary or private commercial bodies. This term includes full-time carers, and part-time carers whose lives are significantly restricted because of their commitment to the responsibility for the dependent older person for whom they care.

“Support services for carers” refer to services which facilitate the carer in caring, which make the life of the carer more tolerable, and which promote the capacity of the carer to continue to care. These include any services which help to support and maintain the informal caring relationship between the carer and the older dependent person at a manageable and acceptable level, and services which help to maintain the elderly person in the community. Support services therefore include most of the community and hospital-based services provided by statutory and voluntary bodies.

A number of different distinctions have been applied to these services. Services are said to be formal (supplied by statutory, voluntary or commercial bodies) or informal (supplied by carers and supporters), to be complementary (supplied in addition to carer services) or substitutional (supplied in -the absence of a carer), to be institutional (based in a hospital or residential unit) or community (provided in the home or community), to be statutory (supplied by statutory bodies) or voluntary (supplied by voluntary organisations), to be direct (supplied to the carer) or indirect (supplied to the elderly person).

In fact, all of these distinctions are ambiguous to some extent, and many services involve mixtures. For example, home help is a community-based service sometimes supplied by statutory and sometimes by voluntary bodies. Voluntary services may be funded by statutory bodies. Hospital-based service providers such as occupational therapists visit the elderly at home as well as providing care in the hospital. Day hospitals are usually attached to hospitals, yet are often seen as community-based.

From the position of the carer, an important distinction is between those services which target and/or directly benefit the “carer”, and those services which target and/or directly benefit the “elderly person”, which may also benefit the carer indirectly. Twigg, *et al.* (1990a; 1990b) refer to the former services as direct services, and to the latter services as indirect services. The distinction between the two is not always clear-cut. For example, public

health nurses (PHNs) are targeted primarily at the elderly person, but also sometimes provide information and training to the carer. Respite care for the elderly has a very obvious impact on the carer. In cases of ambiguity, the question of whether the service is accessed by the elderly person or by the carer is used to categorise the service as a direct service or an indirect service. Although not perfect, this distinction is adopted by the present study as it provides a carer-centred approach to services.

"Direct services" are services which are developed with the needs of the carer in mind, and which are provided primarily to improve the lot of the carers. These services are provided directly to the carer, and may be supplied by statutory or voluntary bodies. In principle, the carer may access them in his or her role as carer. Direct services include:

- financial support for carers, including the Carer's Allowance;
- information and advice services offering the carer information and advice regarding available support services, benefits, training courses, etc.;
- training and education courses for the carer;
- respite for the carer - weekends or short holidays away from the caring situation, or alternatively a weekend at home without any obligations for caring;
- support groups focused on the needs of the carer and offering counselling and therapy sessions.

"Indirect services" are services which are developed for the needs of the elderly dependent person. They are relevant to the carer to the extent to which they impact positively on his or her life. These services include:

- community-based services such as GPs, PHNs, home help, transport services and day centres;
- hospital-based professional service providers such as audiologists, geriatricians and physiotherapists;
- respite care for the elderly person;
- long-stay care for the elderly person.

Key research questions centre firstly around the provision of direct and indirect services, that is, the "availability" of these services. Secondly, they focus on the factors which influence whether elderly people or carers actually receive the services, that is, the "accessibility" of services. These questions are taken up in more detail in the following chapters.

Format of the Report

This report is composed of eight chapters.

- The present Chapter One provides an introduction on the background to the study and deals with demographic and social trends.

- Chapter Two discusses the literature on carers in relation to the study and trends that emerged from this.

- Chapter Three discusses institutional services and informal care. This chapter was prepared by Mr. Joe Larragy, former Research Officer with the National Council for the Elderly.

- Chapter Four details and describes the research design and methodology employed.

- Chapter Five reports the results of the census dealing with indirect support services for carers.

- Chapter Six discusses the results relating to direct services for carers.

- Chapter Seven includes an overview of the study and an examination of key findings and conclusions.

- Chapter Eight - the final chapter - highlights gaps in service provision and makes recommendations for immediate and long-term improvements in support services for informal carers of elderly people living at home, for further research in this field, and for policy and practice.

A full bibliography and appendices are included at the end of the main text.

- Appendix A contains a description of the contents of the indirect census form.

- Appendix B contains a description of the contents of the direct census form.

- Appendix C contains tables from the indirect census.

CHAPTER TWO

General Trends in the Literature Pertaining to Carers of the Elderly

During the past decade or so, the volume of literature on elderly care has grown. Carer stress has attracted increasing academic attention, and a conceptual awareness of the central role of the carer has developed. In the Irish context, a number of studies relevant to care of the elderly in the community, and to carers, have been published. These provide a national profile of carers, and considerable detail about caring activities, carer strain and support needs, and the use of services by the elderly and their carers in the community (Blackwell, *et al.*,1992; Clifford, 1990; Convery, 1987; Noonan, 1983; O'Connor, *et al.*, 1988; O'Connor and Ruddle, 1988; O'Mahony, 1986; O'Shea, *et al.*, 1991).

Irish Studies of Care in the Community

Overview

In their 1988 studies of carers, O'Connor, *et al.* provide us with detailed information regarding carers and the caring process. They discuss the types of support carers need and receive. With regard to services available to carers, they deplore the lack of formal support or recognition for those providing care in the home. They warn that the lack of statutory support services for carers is likely to result in a breakdown of the family caring system necessitating unnecessary admission to institutional care.

O'Shea, *et al.* (1991) agree with this projection, and recommend increased support for informal carers of the elderly. Clifford (1990), although keen to

stress the positive aspects and rewards of caring, concluded that, in practice, little is done for carers by statutory service providers. O'Mahony (1986) emphasises the lack of adequate transport facilities. Blackwell, *et al.* (1992) also advocate more support for family carers through financial assistance, information, advice and training. They outline possible respite options which would make caring less stressful for the carer. They also consider that an extension of the home help and meals-on-wheels services would alleviate the burden of daily tasks. The majority of carers, in their study, express a preference for taking care of the elderly person themselves.

It is important to note that O'Connor, *et al.* (1988), Clifford (1990), and Blackwell, *et al* (1992) all found evidence of a positive attitude to caring in this country. But in O'Connor, *et al.'s* (1988) study it emerged that carers' life satisfaction was negatively influenced by "the perceived amount and extent of care provided". Those giving 24 hour care were less satisfied than those giving day care only or occasional care. These findings confirm the need to provide a quality and range of support services relating to the level of care-burden.

Provision of Informal Care

O'Connor, *et al.* (1988) and Blackwell, *et al.* (1992) outline the extent of the provision of informal care in the community. About five per cent of the total elderly population live in long-stay hospitals or other institutions, with 95 per cent living at home. About 80 per cent of elderly people living at home are fully independent and do not require regular care. Slightly less than one third of the remaining 20 per cent are highly dependent, requiring daily care and supervision, while almost two thirds require some care.

Almost 80 per cent of elderly people who require care have female carers. Carers are usually aged between 20 and 54 (52 per cent of carers) with a further 25 per cent over the age of 65.

Carers provide an average of over 40 hours a week of care, rising to over 80 hours of care in the case of highly dependent elderly people. Carers provide an average of 16 hours a week of help with domestic tasks, and 20 hours a week of supervision, even for the less dependent elderly. They provide an average of seven hours a week of physical care, rising to almost 30 hours of physical care for those who are highly dependent. They receive little or no help with these caring activities from other family members, friends, or neighbours (Blackwell, *et al.*,1992; O'Connor and Ruddle, 1988).

It is clear that caring involves a considerable amount of time and effort, and carers express high degrees of stress and strain. Stresses include physical exhaustion, being isolated and confined, financial strains, emotional upsets, and feeling overwhelmed. Blackwell, *et aL* (1992) found that *29.5* per cent of carers were at risk for psychiatric illness.

Support Services

O'Connor, *et aL* (1988) analysed the level of statutory and voluntary support, and concluded that 68.8 per cent of carers receive low levels of support from these sources, with 22.6 per cent receiving a medium level of support. Those carers who received support were usually satisfied, but overall, 43 per cent of carers found the level of formal service support unsatisfactory. Another finding of O'Connor, *et aL* (1988) was that carers rarely request specific kinds of help from social services.

In a similar vein, Blackwell, *et aL* (1992) found that dependent elderly people living in the community reported receiving very few visits from professional and voluntary services, including OPs, PHNs and home helps, and making very few visits to out-patient and hospital day centres. They report that around 30 per cent of carers expressed a wish for more support from PHNs, chiropodists and physiotherapists, while 20 per cent wished for more support from OPs.

These two studies suggest that medical services are used by relatively few dependent elderly and carers in the community, and relatively few carers request services, or express a wish for more support from medical services. Important questions here are whether the take-up of services may be attributed to low demand, inadequate supply, lack of information, or difficulties gaining access to services.

Carers, in fact, express a clear set of priorities regarding support. Firstly, they wished to receive financial support. Secondly, they sought inforntation, advice and personal support. And thirdly, they expressed a desire to receive more respite and relief care. Thus, the supports that carers express a need for involve finance, advice and information, and respite, rather than medical supports.

These studies therefore provide a clear and detailed picture of care provision, carer strain, and carer support in Ireland. They highlight the need for further analysis of which services are provided, how comprehensive they are, and how they are accessed.

General Trends in the Literature Pertaining to Carers of Elderly People Living at Home and Carer-Support Services

The trends highlighted in the Irish research are also found in the broader literature on carers. In current carer and carer-support literature consistent themes emerge which influence the provision, type, and accessibility of carer-support services in some measure:

- The "Carer" - a Recent and Growing Phenomenon;
- Carer-Identification Failure;
- Carer-Gender - its Effect on Service Provision;
- Family Carers and Support Services;
- Carer-Stress and Support Needs;
- Elderly Spouse Carers - Their Specific Needs;
- The Suitability of Services;
- The Need to Advertise Available Services.

These themes help to elucidate why it is that there is little provision of carer support, and little take-up of the support that is available. Carers are either taken for granted or invisible, especially when they are female and family members. There is little understanding of the needs of carers, especially of the needs of specific groups such as elderly carers. Services are often unsuitable and badly advertised. Finally, carers often do not see themselves as needing or as deserving support.

The "Carer" - a Recent and Growing Phenomenon

A critical assessment of contemporary carer research literature reveals that the concept of the carer is a recent and growing phenomenon. For decades, families had "minded", or looked after, their dependent relatives young and old. However, during the 1980s the term "carer" or "caregiver" came into the language (Noonan, 1983; Twigg, *et al.*,1990a, 1990b). According to Twigg, *et al.* (1990b), "carers" became more visible, from a theoretical point of view. They were, however, still mentioned and referred to by policy makers and service providers in a "taken-for-granted, assumed-there" fashion. In the 1990s, while they still occupy a tenuous and ambiguous position on the periphery of the social care system, it is significant that their existence has at least been recognised and acknowledged (Twigg, *et al.*,1990a).

Twigg, *et al.* (1990b) also discuss the meaning of the term "carer", which they see as a mixed term, lacking a clear analytic definition. They suggest that it

might be “best understood, in terms of a constellation of features rather than a single defining variable” (p.4). Among the features implied in the understanding of caring are:

- The performance of tasks of a supportive and personal care character;
- Family obligation;
- Emotional bonds;
- Co-residence, very often but not always;
- Responsibility for the dependent person.

These inherent elements in the perception of caring explain, to some extent, the expectation of carers often reflected in policies regarding carer-support services. An obligation to perform tasks and responsibility for the dependent person on the part of the carer seems to be taken for granted. In another study, the same researchers argue (Twigg, *et al.*,1990b) that carers are rarely seen as clients or patients. Neither are they perceived as persons with needs and rights. Nevertheless, no matter how unclear perceptions of the carer have been to date, the literature indicates that there is an increasing acceptance that carers are central to the provision of community care for dependent elderly people (Evers, *et al.*,1988; O’Connor, *et al.*,1988; *The Years Ahead*, 1988). Carers may no longer be ignored by policy makers or service providers. If caring for the older person at home is in fact a priority, then attention must be paid to the carer.

The Effect of Carer-Identification Failure and Perceived Support Needs on Provision of Support Services

Although carers now have a name, many still fail to identify themselves accordingly. Subsequently, this identification failure affects the provision of services. It appears, from the literature, that there is a definite link between carer-identification, carer-perception of support needs and the actual provision of services for carers. Words like “ambivalence”, “ambiguity”, “confusion” and “unaware”, recur in relation to carers (Twigg, *et al.*,1990b). It is not surprising then, to hear Twigg, *et al.* (1990b) assert that support services for carers are patchy and uncertain. They hold that the type, nature and extent of services provided depend largely on how the carer is perceived (a) by the carer and (b) by the service providers. If policy makers, service providers and the general public, including carers themselves, are vague about carer-identity (Barer and Johnson, 1990; Clifford, 1990) then services cannot be as responsive or well-targeted as the community care situation appears to require. Since carers often fail to recognise themselves as a categorised group (Tester; 1989; Twigg, *et al.*, 1990a, 1990b) appropriate services are not demanded, nor are available services fully utilised.

Identification failure on the part of carers seems to be due, in some measure, to traditional, cultural and religious factors. Very often carers see themselves as merely continuing to fulfil their relationship role. For spouses who are carers, the caring relationship is experienced as a natural extension of the marital relationship (Wenger, 1990). They continue to care, as they have always done, without accessing even those support services which are available.

Carer-Gender and its Effect on Service Provision

It is generally accepted in the literature that the majority of carers are women (Boyd and Treas, 1989; Brody, 1981; O'Connor, *et al.*, 1988; Pitkeathley, 1989). A sense of duty and almost inevitability seems to dominate the thinking especially of female carers (Aronson, 1990; Clifford, 1990). Submissiveness and resignation on the part of the majority of the caring force is more prevalent, apparently, in countries with strong Catholic traditions, such as Ireland (Clifford, 1990; Giarchi, 1988), Italy (Giarchi, 1988) and Poland (Midre and Synak, 1989) and poses problems in service provision. If carers, to a large extent, accept caring as their lot, and if demands for support services are not made, then financially hard-pressed service providers are unlikely to go out of their way to construct and deliver services. Northern European countries, on the other hand, such as Norway and Sweden, with a strong Protestant background, view self-reliance and ongoing autonomy as particularly valuable (Midre and Synak, 1989). Older people tend to favour state support over family support especially for long-term care (Daatland, 1990). Statutory support services continue to expand in both countries and are increasingly accessed by elderly dependants and their carers.

The gender issue in caring is widely discussed in the British literature. In her 1989 study, Pitkeathley refers to the fact that of the 6,000,000 people caring in Britain at that time, three quarters were women. She contends that often the needs of carers are completely subordinated to the needs of the people for whom they care. What may have begun as a temporary situation for many carers develops into what Twigg, *et al.* (1990a) see as a life-long caring career. While the predominance of women in caring is acknowledged across the literature (Aronson, 1990; Brody, 1981; Donovan, 1989; O'Connor, *et al.*,1988) recent studies indicate that the number of men involved in caring is increasing (Pollitt, *et al.*,1991; Wenger, 1990). However, it is also claimed that where men are carers, the statutory services are more likely to offer more support (Arber, *et al.*,1988; Evers, *et al.*,1988). Thus, carers who are female are penalised by receiving less of the help available. In any case, whatever the gender, carers' needs and the importance of community care support services

are commanding more attention in the literature (Action for Carers, 1988; Centre for Policy on Ageing, 1990; Richardson, *et al.*,1989).

Family Carers and Support Services

The central position of the carer in the provision of community care is being increasingly recognised (Griffiths, 1988; O'Connor, *et al.*,1988; O'Connor and Ruddle, 1988; O'Shea, *et al.*,1991; *The Years Ahead*, 1988). Nevertheless, entrenched social assumptions regarding the existence, availability, willingness and coping capacity of the family carer contribute to the dearth of, and gaps in, support services for carers, internationally. It is generally accepted that support services for carers do not measure up to policy avowals regarding the importance of community care and the need to support those who predominately provide it - namely family carers (Kane, 1989; Twigg, *et al.*,1990). Those services which are provided tend to consider only the needs of the older dependent person - physical, medical, and to some extent, social. They rarely take into account the needs of the carer.

Obviously, carers need to be more assertive in requesting support services. As O'Connor and Ruddle (1988) point out, "Carers themselves have to learn to set limits on the amount of care they provide. They have to learn to ask for the help they need from whatever source, statutory services, voluntary groups or informal services

Carer-Stress and Support Needs - The Need for Different Types of Support at Different Stages of the Caring Sequence

The stresses and demands of care-giving are widely discussed in the literature (Lewis and Meredith, 1988; O'Connor and Ruddle, 1988; Pitkeathley, 1989) and a range of support services suggested. Researchers point out that what begins as a response to a specific situation can unobtrusively develop into a long-term commitment which, in time, assumes the proportions of an unpaid career (O'Connor and Ruddle, 1988; Twigg, *et al.*,1990a). Recent studies repeatedly find that carers report feelings of restriction (Blaclovell, *et al.*,1992; Lewis and Meredith, 1988; O'Connor and Ruddle, 1988; Pitkeathley, 1989; Twigg, *et al.*,1990a). An important point made by O'Connor, *et al.* (1988) which could have a major impact on the type of support services provided for carers, is that carers are not a homogeneous group. Thus caring needs are not uniform or unchanging across the different stages of the caring sequence, and will depend on, among other things, levels of dependency, age, relationship between carer and elderly person, and needs for institutional care (Moane, 1993).

Elderly Spouse Carers - Their Special Needs and Reluctance to Seek Help

The literature also points out that different age groups require different types of support. There is a growing realisation that, for example, elderly spouse carers have special needs. Interventions which may be helpful to a younger carer, e.g., day care, could add to the experienced stress of an older spouse carer. Very often what older spouse carers need is not relief from their dependant but rather relief from tasks, responsibility and sleeplessness, to better enable them to spend more time with their dependant (Wenget, 1990). Wenger (1990) and Twigg, *et al.* (1990b) found that even when experiencing real needs, this group is less likely to ask for help. The caring task can be the main focus of their daily living. Companionship with their spouse remains central to their lives, and fear of separation acts as a constraint in requests for help (Clifford, 1990). This fact again poses problems for service providers. As the population of carers and elderly dependants continues to increase and to get older (Pitheakley, 1989), it will be important not only to make suitable services available on demand, but to devise a method of provision which will approach and sensitively offer services to identified older carers (Pollitt, 1991; Twigg, *et al.*,1990b). Other documented reasons for not seeking help were that elderly carers did not realise that help was available (Cameron, *et al.*,1989; Evers, *et al.*,1988; Lewis and Meredith, 1988) or that they were reluctant to accept help because they were too independent (Montgomery and Borgatta, 1989).

The Suitability of Services

More fundamentally, Thornton (1988) and Lewis and Meredith (1988) assert that services must be shaped to suit individual caring situations. The way forward is to give users what they want in the way they want it. Otherwise, services which exist will not be availed of. Because service providers in Britain are realising that support services will be used only when they are suitable to the needs of the people who use them - namely the carer and the elderly person receiving care - carers' views are being increasingly sought and included in the actual fashioning of services. This concern is further developed in the section *The Experience of Caring in Britain and the United States.* Of interest to us here in Ireland is the proposed inclusion of the consumer or service user in planning and evaluation of health services *(Shaping a Healthier Future,* 1994). Unfortunately however, the carers are still not perceived as clients or patients, a point made by Twigg, *et al.* (1990b) and already referred to in this chapter.

The Need to Advertise Available Services

Reasons postulated for the failure to avail of domiciliary support services are as follows:

- particular services are perceived to be or, in fact, are inadequate and/or inappropriate;

- lack of information - carers simply do not know that specific services exist, or although they know of their existence they do not realise that they can apply for them, or sometimes they do not know how to go about applying for available services;

- carers, especially older carers, are too independent to request or avail to help or are too protective of their privacy.

Because of the number not receiving help, Hedley and Norman, in their 1983 study, suggested that it might be necessary to advertise available services. Cameron, *et aL* (1989), in the Birmingham studies, concluded that service providers need to adapt their approach and improve their method of disseminating information to their prospective clients. This conclusion was also reached by the Centre for Policy on Ageing Panel who compiled the *Community Life* report (1990) and by the general practitioners involved in the King's Fund Carers' Project (King's Fund Carers' Unit, 1989).

The Experience of Caring in Britain and the United States

Some of the experiences of caring and the carer centred programmes which have been developed in Britain and the United States may be of relevance here. In both countries the demographic trends outlined in Chapter One are further advanced, and there is experience both of the breakdown of the care in the community, and of innovative carer centred programmes.

Britain

The publication of the Griffiths Report in 1988 was important in that it focused attention on all aspects of community care and recognised the contribution made by informal carers to care provision. Griffiths' (1988) awareness of the carer was probably helped by the work of the British Carers' National Association, which was the result of a rnerger of two existing organisations - the Association of Carers and the National Council for Carers.

Between them, these organisations had over 30 years' experience of working with and for carers. The British Carers' National Association is highly organised and effective. Through its journal *The Carer* it informs health professionals, policy makers and the general public, and encourages carers to be politically energetic in working for their rights as active participants in community care provision.

In the British literature, models of good practice in caring continue to appear (Challis and Davies, 1986; Kohner, 1988; Richardson, *et al.*,1989; Thornton, 1988; Wilson, 1988). Challis and Davies (1986) make a strong case for case managed community care which in itself is a more enlightened way forward than the administrative-propelled services which had hitherto been the norm. They, in their discussion of the *Kent Community Care Project*, promote the case management concept of co-ordinated, professionally organised programmes of delivery, utilising existing services. Thornton (1988) describes the *In Safe Hands Scheme*, already referred to, which is client-focused, but also in a sense client-based, and shaped to the needs expressed by the carer and delivered to meet the carer's requirements. This is taking a slightly different direction from the case management approach. It may be more likely to identify the gap in service provision or inappropriate services which do exist. In dealing with these questions the *In Safe Hands* project brings the development of carer support a step further.

Phillipson (1990) acknowledges the positive value of the Kent Studies but sees a danger in adopting too circumscribed a view of case management, and like Thornton (1988) and Richardson, *et al.* (1989) believes in the need to be less hierarchical and more client-based. Tester (1989) also promotes the idea of carer involvement in the shaping of services. She refers to the practice in the Bedfordshire Social Services Department, where close contact is maintained between the day unit staff and the older person's carer. Staff recognise the value of the carers' contribution to the day programme through their knowledge of the older persons' needs and capabilities. Richardson, et *al.* (1989) provide several succinct accounts of services for carers and their dependants including:

- Carers' support groups;
- Cross-roads Care Attendant Scheme, serving 80 families;
- Voluntary sitting services, helping 60 families;
- Carers information and referral services;
- An incontinence laundry service.

All in all, the British literature demonstrates a more dynamic development of

definite and accessible practical services. The carer takes a more active centre-stage position even in the actual shaping of services (Centre for Policy on Ageing, 1990).

The United States

In the United States elder care has posed a problem for a number of years. A culture which prizes youth and productivity appears to have difficulty coping with older people approaching or experiencing frailty and dependence (Butler, 1975). There is a perceptible growth in federal support for home and community care, but, due to the huge numbers of needs involved, there are serious gaps in service provision.

It is estimated that 50 per cent of family caregivers are over 60 years of age and that they are predominately women (Boyd and Treas, 1989; Brody, 1981; Donovan, 1989; Lang and Brody, 1983). Montgomery and Borgatta (1989) complain that although policy makers have been slow to acknowledge the predominance of family care, "they have been quicker to recognise the potential negative consequences of a change in this family behaviour". Lang and Brody (1983) suggest a family-focused social policy, for programmes which would address the needs of the family as well as the needs of the dependent elderly person, enabling family members to continue to give care.

The growth in elder abuse, which is well documented in the United States, has been attributed in part to the strain of care-giving (Daniels, *et al.*,1989; Kosberg, 1988; Pedrick-Cornell and Gelles, 1982; Pillerner and Finkeihor, 1988). It is accepted that predominantly the abusers are close family members and/or carers. A disturbing and growing form of elder abuse is the abandonment of elderly ill or dependent elderly by over-stressed family carers (Hey and Carlson, 1991; Nash, 1992).

This highlights the urgent necessity to provide help for carers. Kane (1989) perceives home care as "the crisis of the nineties", noting that many families cannot afford to pay the price for effective home care. Lambert, *et al.* (1990), also concerned about quality care, discuss efforts by gerontology and childcare professionals to provide intergenerational care facilities in order to relieve carers. Such centres, they believe, could provide physical, social and emotional benefits.

Through the United States literature, one gets the impression of huge numbers of dependants, almost overwhelming need, desperation on the part of carers,

depression on the part of frail elderly. Butler's (1975) view of "The Tragedy of Old Age in America" still applies, at least to low-income elderly and their carers. On the other hand, there is also a large population of prosperous elderly people who have a myriad of quality services available to them at a cost, and many advances have been made in care of the elderly.

Programmes to Help Carers in the Workplace

In an effort to maintain satisfactory levels of performance in the workplace a growing number of American corporations are setting up support services for workers who have carer responsibilities. Ingersoll-Dayton, *et al.* **(1990)** describe one such programme for employed caregivers at four work sites in Portland, Oregon. A basic seven-week educational programme was offered to all. Then participants chose between three eight-week options:

(1) Care Planning - a case management approach. The case planner who was a social worker helped them assess their care-giving situations and suggested possible resources;

(2) A support group of peers facilitated by two professionals;

(3) A caregiver "buddy system". Each employee was paired with a coworker experiencing the same type of care-giving situation. Although the success of the venture was rather dubious it did illustrate employer recognition of the difficulty of continuing paid employment and care-giving.

IBM in the United States is, according to Crowley (1990) one of a growing number of Arnerican corporations with elder care programmes. They employ a specialist "to help employees who are struggling to keep up with their jobs while also meeting the demands of providing care for older relatives". She also refers to programmes being offered by *Johnson & Johnson* who have extended their unpaid leave policy from three months to a year to facilitate carer workers.

Honeywell Inc. offer flexible work hours.

Pitney Bowes allows for shift changes and sponsors counselling and discussion groups.

Stride-Rite launched an intergenerational care programme. It extended its childcare facilities to provide care places for dependent elderly as well.

Developments in worker carer-support services may seem less crucial to us here in Ireland because of our huge unemployment rate. Nevertheless, the hope is that developments abroad may supply policy makers here with ideas and models for carer-support services in the community.

Summary and Conclusions

The literature reviewed in this chapter reveals that apart from Britain and to a lesser extent the United States, direct support services for carers are as yet few and far between. This is the situation despite the fact that community care for the elderly - which predominantly means family care - is widely recommended. Statutory service providers target the needs of the older dependent person - not the carer. A fundamental reason for this is that the concept of "the carer" is a recent one and although the word "carer" is increasingly used in the language, carers themselves, the general public, policy makers and service providers fail to recognise those who care as a specific group or as a group needing help or support, or as partners in decision making regarding care.

To a large extent, family care of the elderly has been taken for granted because families - especially women - have traditionally assumed responsibility for their dependent elderly relatives. Now due to social and demographic changes - especially changes in the role and status of women - the former care system is being eroded and supplementary or alternative measures are called for to ensure community care of older people. As stated, studies have shown that, in many cases, carers want to care for their elderly dependants at horne. However, they need practical and personal support in the form of recognition for the long hours they spend in caring, and a range of suitable services which will enable them to continue. The provision of adequate services is all the more important as carers themselves get older while at the same time the level of care required increases with the population growth in the oldest segment of the elderly population.

There is considerable agreement in the literature regarding the stressfulness of caring. What begins as a response to a specific situation can develop into an unpaid career. Feelings of restriction are often reported by carers. Further, stress is experienced differently at different stages of the sequence of caring and by different age groups, requiring different forms of support. The special support needs of elderly spouses are noted and also the importance of advertising services. But, although there is emphasis on the personal and task needs of carers, and repeated recommendations on how to address and meet those needs, little is written about actual direct support services for carers.

It would appear that the peripheral position of the carer in social care consciousness together with the uncritical acceptance of the natural role of the family in caring, contribute to a political reluctance or failure to provide support services for carers of the elderly at family level. Since women have joined the workforce and more workers are, or are likely to be, carers, flexibility and support in the workplace are also needed. Care-giving demands can affect the performance of workers or even force them to leave their employment. Britain and the US are looking at this situation from the point of view of productivity and profits albeit on a small scale as yet, and initiatives are being taken to provide worker carer-support programmes for staff. These developments abroad can alert us to models of good practice in the provision of support services for carers here.

It is clear that the factors influencing provision and use of support services for carers are complex, involving broad social trends and attitudes, as well as specific policy decisions. While, obviously, the implementation of a policy of community care requires action at both of these levels, the present study is focused on the specific level of service availability and accessibility. It is noted particularly that the provision or availability of a service is not sufficient to ensure its adequacy. The service must also be accessible and relevant to the needs of the recipients.

CHAPTER THREE

Institutional Services and Informal Care

This chapter has been prepared by Joe Larragy, former Research Officer with the National Council for the Elderly

Introduction

This chapter examines the interrelationship between institutional services, particularly long-term care, and informal care. In the past, the two have tended to be considered separately but co-ordination of institutional and community care is crucial to the support of the informal carer.

The chapter is divided into three broad headings. We first examine the overall trend in institutionalisation levels among the elderly, taking into account the distinction between long-term care of the elderly and other types of institutional care, such as psychiatric and acute in-patient hospital care. Next we look at long-term care in institutions in more detail: firstly, comparing dependency levels of elderly people in institutional and community settings; secondly, exploring the attitudes of carers and the elderly to institutional placement and, thirdly, examining the effects of institutional placement on carers. We next examine alternative models of long-term care from the perspective of how they relate to informal care. In the last section we discuss aspects of acute hospital care and some issues arising with respect to the acute hospital and informal care.

Trends in Institutional Care for the Elderly

Trends in institutional provision are difficult to establish because of the complex and changing patient mix and care processes which have

characterised various hospitals and homes throughout recent decades. The most general index of institutionalisation we have is provided by the Census of Population. This measure includes all those in short- and long-term institutional accommodation, and in medical and non-medical settings. Between 1966 and 1986 the number of elderly in this category increased from 26,366 (8.16 per cent of those over 65) to 32,877 (8.55 per cent of those over 65) (Central Statistics Office 1969; 1991). Between 1986 and 1991 this number increased to 34,370 (8.53 per cent) (CSO 1993).

Long-Term Care Beds for the Elderly

The allocation of this portion of the elderly between short- and long-term institutional settings is more difficult to estimate. In 1988, according to O'Shea, Donnison and Larragy (1991), there were 19,120 beds providing long-term care for the elderly in the public, voluntary and private sectors, excluding those in acute or psychiatric hospitals (Table 3.1). These bed numbers cover health board geriatric hospital beds (7,005), health board welfare home beds (1,589), long-stay district hospital beds (1,465) and private (5,552) and voluntary (3,509) nursing home beds.

Exactly comparable figures are not available for the 1960s, but the Interdepartmental Committee on the Care of the Aged provided useful figures which showed that in 1966 there were 20,217 elderly people in a range of general, geriatric and psychiatric institutional settings (Department of Health, 1968: 87-88). Of these, 5,027 were in mental hospitals. A further 2,703 were spread across county hospitals (793), regional hospitals (400) and "voluntary and private general hospitals and nursing homes" *(1,510).* The Committee therefore estimated that there were 11,725 elderly people who were in long-term care beds for the elderly, comprising 7,295 in county homes, 960 in district hospitals and 3,470 in "private homes for the aged and similar centres". This is a minimum figure, because an unknown number of the elderly people in the other types of hospital were also in long-term care.

Regardless of where we draw the boundary around elderly people in long-term institutional care in 1966, it is evident that the numbers in long-term institutional settings increased substantially by 1988. In sectoral terms the most significant change between 1966 and the present has been the growth in nursing home provision by over 160 per cent from 3,470 beds in 1966 to 9,061 in 1988. Within the statutory long-stay sector there were more subtle changes: a reduction in the number of geriatric hospital beds and better targeting of these towards the ill elderly; the addition of some 1,500 new beds in welfare homes and re-deployment of many local district hospital beds from maternity, medical and other purposes to geriatric care.

TABLE 3.1: Long-term care beds for the elderly in 1988 by health board area

Health Board	Health Board Geriatric Hospitals	Health Board Welfare Homes	Health Board Welfare Homes	Private Nursing Homes	Voluntary Nursing Homes	Total Beds
E	1,051	197	370	2,055	2,198	5,871
M	639	160	161	223	167	1,350
MW	1,029	123	70	837	89	2,148
NE	1,010	118	0	323	46	1,497
NW	621	260	137	88	208	1,314
SE	918	159	133	928	70	2,208
S	788	169	594	603	731	2,885
W	949	403	0	495	0	1,847
Total	7,005	1,589	1,465	5,552	3,509	19,120

Source: O'Shea, Donnison and Larragy 1991

Acute and Psychiatric Hospital Beds

Among these changes the one least anticipated by policy makers in the 1960s was the increase in private nursing home provision. Growth in this sector was very likely accelerated in the 1980s as a result of public expenditure cutbacks, and a policy of reducing acute bed numbers through improved targeting of resources and shorter lengths of stay. These policies resulted in a decrease in the number of acute hospital beds staffed by consultants from 16,150 in 1981 to 12,100 in 1988 (Dail Eireann, October 1991: 338). Evidence of higher throughput rates and shortening length of stay in acute hospital care over this period was reviewed by Nolan (1991), though his analysis did not cover the 3 trend in age specific throughput rates. Some of these cuts were aimed at improving effectiveness as well as making savings, and it should be noted that between 1976 and 1985 public spending on non-capital health programmes increased by 45 per cent in real terms with a slight increase in the share allotted to acute hospital budgets (NESC, 1987). The bulk of the cuts in service provision were concentrated in 1987-88.

Reduced psychiatric hospital bed numbers may also have contributed to the increase in private nursing home provision. Since the 1960s the number of psychiatric in-patients of all ages has been falling. In 1963 there were 19,801 in-patients, falling to 8,207 by 1991. The number of elderly people in psychiatric hospitals also fell during the 1970s and 1980s (Table 3.2). In 1971 there were 1,313 patients per 100,000 in the *65-74* age group and 1,736 per 100,000 in the over 75 year age group. The corresponding rates in 1981 were 1,229 for the 65-74 age group and 1,608 for those over 75 years. Between 1981 and 1991, with the more radical scaling down of institutional care of the mentally ill, the number of elderly psychiatric in-patients per 100,000 fell to 745 per 100,000 for those aged 65 to 74 and to 1,049 for those aged 75 and over (Moran and Walsh, 1991:16).

TABLE 3.2: Elderly psychiatric in-patients per 100,000 in 1971, 1981 and 1991

In-patients per 100,000	1971	1981	1991
65-74	1,471.7	1,229.3	745.1
75+	1,735.7	1,608.6	1,048.9

Source: Moran and Walsh (1991)

Overall, since 1966, the trend in institutional places has been upwards in absolute and relative terms, with significant sectoral shifts. Although the number of psychiatric beds has been falling for a long time and more recently the number of acute hospital beds has also fallen, increases in throughput and

shorter lengths of stay, as well as more outpatient care, have compensated for this. In contrast, the number of beds dedicated to the long-term care of the elderly has increased, despite developments in community care and a more active beds policy in geriatric care. Census data for the period 1981 to 1986 also points to an increase in the proportion of very elderly in institutions and a fall in the proportion of younger elderly - suggesting at least a degree of targeting of such care. Comparable data are not yet available for 1991. In the 1980s, however, there has also been a decline in the number of acute beds and statutory long-stay beds. This has not been balanced by increased community care services - although these have been increasing - but primarily by rising demand for private nursing home care.

Long-Stay Institutional Services and the Support of Carers

It is commonplace to say that institutional care is a substitute for community care. While this is true, in many practical senses, it ignores the fact that even after institutional admission, the patient may still have valued informal support and continue to be of concern to caring relatives. Admission to a hospital or nursing home, it is widely appreciated, is not an adequate substitute for informal care. Less well appreciated is that institutional providers could achieve a greater degree of complementarity with carers. In this section we examine some of the issues involved. Irish and international experience has prompted the recognition that community care involves more than the addition of community-based services to (or their substitution for) existing institutional arrangements. What is beginning to be understood is that institutional services need to be transformed into an integral part of a system of community care.

In the sub-sections below we will examine this problem from different perspectives. First, we look at comparisons between the numbers of highly dependent elderly cared for informally and in institutions. Secondly, we look at the attitudes of carers, older people and the wider population to institutional care. Thirdly, we look at the effects of institutional placement on carers. Finally, we suggest how the institutional setting could become more valued and more integral to the philosophy of community care.

Institutional and Informal Care Comparisons

In an important study (Blackwell, *et al.,*1992), a common Guttman scale was used to compare samples of elderly in four geriatric hospitals and a national representative sample receiving informal care in the community from a household member. There were five categories of dependency covering nine items of activities of daily living (ADL) ranging from no disability to inability

to feed without help. Some 14.7 per cent of the community sample were in the two highest categories of dependency (D or E) compared to 55.4 per cent of the hospitals sample. In these categories were those who could not bathe, walk outdoors, walk indoors, get in or out of bed, sit or stand, use the toilet wash hands and face and, for those in category E, feed themselves, unaided.

If we could generalise from the dependency profile of the community sample to the estimated elderly population receiving informal care from a household member we would estimate that 8,000 highly dependent elderly people are in receipt of informal care from a co-resident in a private household. In the absence of more comprehensive studies, this is the best indication that can be offered of the scale and location of high dependency care of the elderly at the present time. Nevertheless, it shows that the role of informal care is numerically very significant and therefore crucial in the context of the highest categories of dependency. Carers of these categories of dependent persons could quite readily seek by right substitute institutional care. Yet, despite evidence of the costs incurred and the great stresses they experience, carers appear reluctant to take this course.

Using the dependency profile of the Blackwell, *et al* (1992) geriatric hospitals sample, Larragy (1993), in the absence of any other evidence, has derived an estimate of 10,500 highly dependent elderly in institutional care. However, there were significant differences between the dependency profiles in the four geriatric hospitals, and this makes generalisation to the whole long-term care sector hazardous. The combined proportions in categories D and E in each of the four hospitals was as follows:

Hospital	Category D+E (%)
1	58
2	64.4
3	55.4
4	40.9
All	55.4

Theoretically, therefore, the actual number of highly dependent elderly in institutional long-term care could be somewhere in the range of 7,500 to 12,300, depending on which hospitals are more typical. Nevertheless, compared with any of these estimates the level of care provided to highly dependent elderly by carers at home is still very impressive.

Attitudes of Carers and Others to Institutional Care

Attitudes to institutional care among the elderly are cautious, and contingent on assumptions about the nature of available alternatives. In one survey of people over 75 years in Scotland, 98 per cent agreed that they should be maintained in their own homes as long as possible, though a majority would not have wished that a daughter would give up work to care for them (Salvage, 1986). West and his colleagues (1984a; 1984b) found that, for all but one disability scenario described to respondents, the least desired regimes of care among a general community sample were those involving either family care only or residential care. In most of the scenarios, respondents preferred a mix of community-based formal and informal care. The exception was a scenario involving the elderly mentally ill, in which case two thirds preferred residential care.

In a national sample of Irish people of all ages, respondents were asked where they would wish to be looked after if they ever needed extended nursing care (Swiss Re, 1990). Most (69 per cent) expressed a preference for care at home, while 19 per cent preferred a nursing home. Interestingly, the proportion preferring institutional care increased fairly directly with age from 13 per cent of those under 25 years to 25 per cent of those over *65.* This evidence tends to confirm the views expressed in other surveys.

Campbell, *et al.* (1981) reported that a preference for institutional care became more frequent among elderly respondents who were posed with scenarios involving heavier levels of dependency (e.g., 16 per cent would accept it if unable to prepare a meal, while 52 per cent would if they were incontinent). This appears to reflect their unwillingness to become a burden to their families. On the other hand, Levin and her colleagues' survey of carers of mentally confused elderly found that only a minority, one in five, would definitely or probably accept residential care if it were offered to them (Levin, *et al.*,1989). This minority was much smaller where the carer lived with or was closely related to the car recipient, though even in other cases the preference for institutional placement did not reach a majority. Evidently, carers display a preference to avoid institutional admission, even in the most difficult of situations and may be concerned about the effect of such placement on both the care recipient and themselves. O'Connor, *et al.* (1988) asked co-resident carers what attitude their care recipient would have to long term institutional placement. Three out of five carers said that the elderly person would hate the idea, and three out of 10 that the elderly person would go to give the carer a break. While carers were very likely influenced by their perceptions of what care recipients felt, we do not know what the carers' own feelings were on this matter.

Institutional Placement - Effect on Carers

In the context of more recognition of the role of informal carers researchers are just beginning to pay more attention to the effects of long-term institutional placement of elderly people on their carers. O'Connor *et al.* (1988) reported that 35 of the carers they interviewed had gone through the experience of the care recipient's death or institutional placement within the previous year. We have not yet been able to ascertain the breakdown of cases between death and placement but, among the 35 carers affected, 64 per cent found it difficult to adjust to a new way of life: since 97 per cent experienced loneliness and 94 per cent grief, the majority of cases may well involve deaths (1988: 148-9).

Novak and Guest (1992) compared a sample of carers of dependent elderly people in the community with a sample whose care recipient was admitted to a nursing home. They found that there were some differences between the community and nursing home groups as a whole. The nursing home group had fewer problems with loss of free time, restricted personal development and negative feelings towards the care recipient. However, within the nursing home group, there were differences associated with whether the carer was a spouse or other relative. Spouse carers in this group were less likely than non-spouses to experience reduced physical fatigue and greater personal development. Non-spouse carers, however, while benefiting on most outcome measures, found themselves with greater responsibilities in relation to their work and family life. The authors suggest that two factors - very much higher visiting levels by spouse carers and the fact that their spouse remains the primary focus of their emotional life - account for their continued fatigue and lesser improvement in personal development.

Zarit and Whitlatch (1993) made a prospective study of the carers of elderly people who were subsequently admitted to nursing homes. By re-interviewing the respondents at intervals they were able to study the differences between carers whose care recipients continued to live in the community and carers whose care recipients at some point were placed in institutions. They found that carers in the institutional group were less overwhelmed, tired and pressured following placement, compared to the community group. However, placement did not change the carers' evaluation of their role, nor did it lead to significantly improved feelings of well-being in comparison to the community group. About half of the institutional group of carers experienced high levels of mental health symptoms. The authors concluded that caring continues after placement, as reflected in high levels of visiting. They also noted that the events surrounding the process of admission

itself seemed to be significant, and that this was a key event. They found few changes in the dispositions of carers in the institutional group when they were re-interviewed 18 months after the first post-placement Interview. Overall, concluded that the caring "career" does not stop at the institution's door, but continues in an altered though still stressful way: carers do not give up their role, but shift their responsibilities.

In one of the United Kingdom case management experiments, in Gateshead, researchers firstly found that case management helped to maintain elderly people in the community and improve their quality of life (Challis, *et al.*,1988; Parker, 1990:112-6). They also made a follow-up study of the impact of institutional placement on the carers of elderly people included in the case management group and the carers from a control group comprising elderly people who were receiving the normal community care services. They found improvements on all measures of carer well-being except mental health problems (related to anxiety and guilt) - whether or not the care recipient had been included in the case management group or the control group - when compared to carers of elderly people remaining in the community. It seems fair to conclude that where the possibility of arranging a package of services in the community which supports elderly people has been exhausted, the carer will benefit from institutional placement.

It has been usual to view institutional care as a substitute for informal or community care. The new research cited above indicates that institutional admission does not terminate the caring role completely, though it profoundly modifies it. Providers of institutional care, and of community care, need to be aware of this, and to explore the implications. Community care staff need to provide support for carers and elderly people in relation to the decision to seek institutional admission and the transitional events surrounding admission once a decision has been made. Carers and institutional providers need to become aware of each other's role after admission.

Improvement of Long Term Care

In the past, long-term care hospitals and homes in Ireland, as elsewhere, have tended to be perceived as self-contained entities, separate from the community. Typically, the long-stay institution or nursing home has been perceived as taking over all care functions - accommodation, meals, day-today tasks, personal care, nursing and medical care and decision making - from the individual, who is cut off from his or her carer and other community support networks and services.

Long-stay geriatric units have been characterised by a custodial regime and some still bear the stigma of the county home as the last resort of the "aged poor". In this perspective there is little scope for realising the potential interdependence between institutional and informal care. For many, admission to a geriatric home has connotations of the same loss of autonomy as described by students of "total" institutions such as asylums and prisons (Goffman, 1968): the elderly individuals soon become "inmates", stripped of their former social status and freedom, and subject to rigid routines. Among the worries people have about institutional placement are that they will be forgotten about, lose all remaining scope for personal initiative, or lose touch with many informal sources of motivation, encouragement or advocacy. From research evidence on the effects of institutional admission on carers, we have seen that it is not just the patient who can potentially benefit from institutional reform, but the carer too. Moreover, the staff of institutions may also stand to benefit from providing a more integrated type of care which departs from the custodial orientation of the past. Research on residential care in the United Kingdom shows that the fewer the linkages between the residential home and the outside community the more difficult it is for staff to serve the interests of the resident before those of the institution (Wilkin and Hughes, 1987). While care in residential settings is necessary for many elderly people, it is essential that we avoid, by all practical means, the syndrome of the "total" institution. Improvements of this kind may entail additional resources but they require first and foremost a re-orientation in the philosophy of institutional care.

Blackwell and his colleagues (1992) reflect this growing concern to overcome existing dichotomies between long-term institutional care and the role of carers. They advocate "the development of more attractive options for residential care" and quote Rossiter and Wicks (1982) who "suggest.. .the possibility of involving the carer as part of the caring regime in a nursing home or hospital, thus bridging the gap between care in the (nursing) home and in the community", and call for further exploration of such options (Blackwell, *et al.,*1992: 217). Moane (1993) identifies the need for ''innovative caring programmes which combine the positive features of care in the home, such as intimacy, privacy, autonomy and care by a close relative or friend, with those of residential care".

Even when they admit a heavily dependent person on a long-term or indefinite basis, therefore, institutional care providers should operate a programme to facilitate continued contact between the caring relative and the patient. This could help to address the continued need for emotional and even practical involvement between carers and the individual who is placed in an institution, and maintain some continuity for the patient who is at risk of loss of identity,

confusion and loss of self esteem. It could also improve the morale and motivation of staff by making them aware of the broader personal and social context of the patient. Institutions which also involve themselves in providing a range of community support services such as respite, day care and other services would seem to stand the best chance of receiving community support and carer involvement following placement in turn.

Following the *Care of the Aged Report* (Department of Health, 1968) county homes were to be transformed into geriatric hospitals with the emphasis on the chronically sick elderly. Residential care for the less dependent elderly was to be provided in welfare homes. These homes were to provide for the needs of many who would formerly have been admitted to county homes on social grounds. Their smaller scale (40 beds approx.), more recent design and better location reflects the fact that they were intended to be a more attractive residential option than the traditional county homes which were larger in scale and still reminiscent of their grim Victorian origins. But welfare homes may have fallen into a cleft stick, on account of retaining many of the characteristic limitations of institutional care while proving unsuitable for the changing age, medical and dependency profile of their residents (O'Shea, *et al.*,1991).

Towards the Community Hospital

Among policy makers and practitioners, more emphasis is being placed on assessment prior to admission to long-stay beds in geriatric hospitals to ensure that institutions can focus on the more dependent or ill elderly (Department of Health, 1988). This requires improvements in liaison between long-term, acute and community care personnel. It should also involve the elimination of admissions to long-term care from waiting lists, long a feature of this sector in Ireland. Alternative models of welfare accommodation for less dependent elderly people, such as sheltered housing and boarding out, are now favoured over the continued building of welfare homes. Several bodies have recommended that geriatric hospitals adopt a more flexible role in collaboration with community care providers by, for example, providing short-term respite or intermittent care and rehabilitation in addition to extended care. The concept of a community hospital has been put forward to embody this approach (Comhairle na nOspideal, 1985; National Council for the Aged, 1985b; Department of Health, 1988). Realisation of this concept has been uneven, however, and in the past few years much more attention has been focused on providing new legislation for the private nursing home sector and agreeing the level of state subvention to be paid towards such care. The *Health (Nursing Homes) Act 1990* was put into operation on 1st September 1993, and was to be fully implemented within one calendar year (Government

of Ireland, 1990). It is to be hoped that, with the implementation of this legislation, attention could again be focused on the concept of the community hospital.

By providing respite, assessment, rehabilitation, and other back-up services to the elderly in the community, geriatric hospitals and homes may become more complementary to informal carers and formal service providers in the community, and less a source of stigma or fear.

In the past, and to some extent still, waiting lists have operated for beds in geriatric hospitals. Rehabilitation wards, therefore, are increasingly seen as a necessary feature of every geriatric hospital because they can ensure that an older person is given early attention in the geriatric hospital, usually on a short-term basis (National Council for the Aged, 1985b). The period in the rehabilitation ward can be used to explore any alternatives to long-term care, including a package of care services in the community, combining informal and formal elements. Welfare accommodation in sheltered housing, boarding out, or return to home might be a possibility, if rehabilitation is provided early. In other cases institutional care would be necessary. If this is necessary it should be provided sooner rather than later. The rehabilitation ward can assist in directing the patient to the most suitable setting and provide support to the carer in the context of the transition to an institution.

Alternatively, the geriatric hospital can complement and support the carer, for example, by identifying the need for respite care, possibly in the geriatric hospital itself. Respite care in an institutional setting has become more available in recent years. In reply to a Dail question in June 1992, it was stated that in five of the eight health boards, from which information was

TABLE 3.3: Recent trends in respite bed provision in selected health boards

Health Board	1990	1991	1992
Eastern	49	76	76
Midland	80	80	80
Mid-Western	11	14	23
North Eastern	16	24	33
Southern	28	33	37
All	184	227	249

Source:Dáil Eireann, 9 June 1992

supplied, there was a total of almost *250* respite beds. Table 3.3 shows the distribution of these beds and the trend over three years (Dail Eireann, 9 June 1992).

Respite beds tend to be provided in geriatric hospitals and some of the long-stay district hospitals. In the Eastern Health Board, for example, there are respite beds in Baggot Street, Baltinglass, Bru Chaoimhin, Clonskeagh, St. Brigid's, St Clare's, St Mary's, St Vincent's (Athy), Wicklow District, James Connolly Memorial, St James's and Leopardstown Park Hospital.

While there are limitations on the benefits of respite care provided in an institutional setting, and models of community and home respite should also be explored, there are also advantages, and there is a place for such respite care in relieving carers who wish to continue to provide care at home. Among the limitations of institutional respite care are: the possible disorientation of the elderly person, particularly if confused; the danger of generating fear of indefinite institutional placement; cost factors; and its unsuitability for the least dependent. For the carer there can be problems following return home, sometimes with a difficult period of adjustment. Advantages might be that in addition to relieving the carer for a period of time long enough to have a short holiday, the centre providing respite might also be able to make an assessment of the elderly person's state of health and identify possibilities for improved support for the carer or the elderly person. Providing respite services is also a way of breaking down the stigma that attaches itself to institutional care, by transforming geriatric hospitals in the direction of the model of a community hospital, as recommended in *The Years Ahead* report. Overall, while this type of respite should be further developed, it should also be carefully deployed and evaluated so that it is used in an optimal way (Montgomery, 1992).

Alternative Forms of Long-Tern Care

Several models of alternative accommodation have been explored and developed as a means of overcoming the ill effects of institutional care. All of these have the effect of separating accommodation and other various strands of care - medical, nursing, personal social services, social contact -which might otherwise be held together in, and subject to the inherent limitations of; the institutional setting. In the community setting services can be combined more pragmatically to meet the individual's needs, with the minimum recourse to institutional care. Formal services based in the community such as home nursing and home help, meals, day care and other services can be arranged to fit in with the client's own routine, without loss of privacy and independence. Among the most important accommodation

options are sheltered housing (with wardens, alarms and some on-site facilities), boarding out, and adapted home environments.

Sheltered Housing

A study of sheltered housing (O'Connor and Ruddle, 1989) revealed 117 schemes housing 3,504 elderly people, usually located in urban (city or town) locations. The distribution of schemes by health board region is given in Table 3.4.

TABLE 3.4*:* Sheltered housing schemes in Ireland in 1988

Health Board	Schemes
Eastern	72
Midland	4
Mid-Western	
North Eastern	5
North Western	2
South Eastern	17
Southern	16
Western	1
All	117

Note: Sheltered Housing is here defined to include group schemes with either a warden or an alarm system or both.
Source:O'Connor and Ruddle, 1989

Because the residents are living in separate housing units, the formal services they receive can be complemented by informal care from a separate household, particularly in urban areas. However, sheltered housing is predominantly focused on the needs of an elderly person who lives alone, often with a reduced informal support network. The same study also showed that the dependency profile of sheltered housing residents was much better than that of a sample of elderly people informally cared for at home (O'Connor and Ruddle, 1989: 154). While such schemes are effective measures for reducing the demand for institutional placement on social grounds, and some of them provide quite high levels of support, they are limited in the role they can play in relieving the most hard-pressed carers.

They can, however, provide some level of choice about how informal and formal sources of care might come together. Sheltered housing could provide reassurance to carers who are not in a position to co-reside with the elderly person, but who live within reach and provide day-to-day support. Such carers are an important part of the system of informal care, and will continue to be important in the future. They can probably offer much more support in this context than they might in the context of institutional long-term care. Planners of sheltered housing schemes should therefore explore the openings for complementarity between informal and formal carers.

Boarding Out

Boarding out is another alternative to institutional welfare accommodation. Gilligan and Keogh (1985) made a study of schemes in existence in the mid1980s and found eight schemes operating on a county/community care area basis, with 144 people in placement in Counties Cavan, Donegal, Leitrim, Longford, Mayo, Monaghan, Offaly and Westmeath, usually in rural areas, where they continue to be successful. These varied and often quite imaginative schemes were usually, though not exclusively, caring for elderly people with difficult and deteriorating housing or social circumstances, or, less usually, a degree of dependency. Their main purpose has been to provide an alternative to institutional care for the frail elderly, though they could perform a respite (intermittent, seasonal or holiday relief) role and thus have a complementary role in relation to carers, albeit in a limited way. Under the *Health (Nursing Homes) Act 1990* boarding out is distinguished from nursing homes and subject to statutory regulation. With a firm legislative basis, the concept of boarding out should be promoted more vigorously.

Developments in Acute Hospital Care

Policy concerns in relation to acute hospital care for the elderly in the 1980s have also focused on the need to transform the type of service offered. Below we look at some important developments which have begun to affect the nature of acute care for the elderly in Ireland. Again, we will look at the issues that arise in relation to the support of informal carers.

Specialist Departments in Old Age Medicine

Probably the most important development in the acute hospital sector for the elderly in recent years is the systematic increase in the number of specialists in geriatric medicine in acute hospitals. There are now 17 departments of geriatric medicine and 21 specialist physicians based in general hospitals in

Counties Dublin, Cork, Clare, Donegal, Galway, Limerick, Mayo, Offaly, Roscommon, Sligo, Tipperary and Waterford. The strengths of this emerging discipline have been attested by experience in Ireland and in the United Kingdom, where geriatric medicine is well established. Because of their holistic approach and immediate response to elderly patients referred to them, the potential value of specialist geriatric services to carers cannot be overemphasised. Multiple pathology, atypical presentation of symptoms, rapid loss of homeostasis and polypharmacy are commonly encountered when treating the ill elderly (Coakley, 1982). Specialists in geriatric medicine offer an integrated approach to the medical care of the elderly patient by taking account of these issues.

Day Hospitals

Related to the growth of these services are day hospitals, a hybrid of the traditional out-patient clinics and in-patient hospitals. Day hospitals ideally are predicated on the development of a good relationship between formal services and informal carers. It is through these services that more elderly people can continue to be looked after in their own homes. The success of these new geriatric services will depend on the ability of the hospital to provide an integrated response to the medical and social support needs of the elderly person. This means that there must be improved levels of support for the carers who may now be caring for more medically ill people than was previously possible. However, day hospitals are not essentially respite facilities, though they provide respite as a by-product. Care should be taken to define the boundary between day hospitals and day care centres. The best way to ensure that day hospitals are not turned into expensive day centres is to provide enough inexpensive day centres with appropriate transport services and back-up.

In Ireland, day hospitals have been established in several health board regions, not necessarily with the specialist services of geriatricians, but with a range of medical, nursing, therapeutic and personal care services. In January 1990, there were 22 day hospitals nationally with between 383 and 398 beds, and an additional 75 day beds spread around other types of hospital (Table 3.5). The provision of day hospital services in different health boards is very uneven, and seems to bear no consistent relation to the size of the elderly population. In the Eastern Health Board there is also a mobile day hospital which serves small town centres outside the city.

Blackwell and his colleagues (1992) made a study of resource use, both

TABLE 3.5: Day hospital beds and day beds in other centres for the elderly by health board region in January 1990

Health Board	Day Hospitals	Day Hospital Beds/Places	Other Day beds	Total Beds/Places
Eastern	7	151	-	151
Midland	-	-	-	-
Mid-Western	4	57 to 72	-	57-72
North Eastern	-	-	-	-
North Western	8	135	50	185
South Eastern	-	-	25	25
Southern	2	30	-	30
Western	1	10	-	10
All	22	383 to 398	75	458 to 473

Source: Department of Health

formal and informal, in the care of a sample of elderly people who were using the services of a day hospital. The day hospital chosen was located on the same general hospital campus as a long-stay unit, also studied. They found that the day hospital dealt with ill elderly people whose level of dependency tended to be low, while the long-term unit on the same campus had the very highest proportion of highly dependent elderly people out of four long-stay units compared. Conversely, the day hospital sample had a similar dependency profile to a random community sample of recipients of informal home care. The day patients also relied heavily on informal care: approximately 50.5 hours per week of informal care was provided to the day hospital sample. The key day hospital inputs came from nurses, occupational therapists, physiotherapists and physicians. The patients receiving day hospital care also tended to receive more home nursing and domiciliary services such as home help than the random sample of recipients of informal home care. The authors attribute these differences between formal service provision in the community to two factors: differences in need due to the fact that more of the day hospital patients had been recently discharged from acute care, but also differences in availability of services.

One striking difference between the day hospital sample and the community sample was in the proportion of time spent on physical and instrumental care of the elderly in the highest category of dependency (category E): in the

community sample, carers of those in category E gave *65.4* per cent of their time to these tasks and the rest to supervisory care while, in the day hospital sample, only 52.8 per cent of carers' time was given to physical and instrumental tasks. Interestingly, however, the total amount of time given to informal caring was no higher among the community group for category E: an average of 84.53 hours informal care per week in the community sample compared with 85.1 hours in the day hospital sample. This seems to undermine the belief that the total amount of time given to informal care declines in proportion to the increase in formal support. Rather, the evidence seems to show that the carer gives other types of "supervisory" care once relieved of the more arduous physical and instrumental care tasks.

Psychiatry of Old Age

More recently two specialist departments of old age psychiatry have been established in Dublin. These are based, respectively, at Blanchardstown and St James's Hospital and have catchments on the north and southwest of the city. These services are crucial to the provision of timely multidisciplinary support for the elderly mentally ill and demented either at home or in a centre. Providers working in these departments are very conscious of the need for support for the carers of these patients.

By way of illustration, the North Dublin Old Age Psychiatry Service was established in January 1989 to cover Community Care Areas *6* and 7. Domiciliary assessment is standard, with provision of home-based management where possible. The service is closely integrated with other service providers in the area. Early diagnosis is encouraged and most referrals come from GPs, but also from other health professionals. The service is in the process of development and includes day care and residential care locally.

Much of the service is concerned with providing support in the community for as long as it is practical to do so. For example, carer-support groups were established as a part of the North Dublin Old Age Psychiatry Service with community psychiatric nurses acting as group leaders. Subsequently, responsibility was devolved to supportive contacts and the need for training in group leadership was identified. Initially, these were attended by carers of demented elderly people attending the day hospital service but subsequently the groups were opened to other carers of dementia sufferers. The groups meet monthly and provide support of a practical and emotional kind appropriate to needs, for example, how to cope with wandering and aggression, the trauma of discovering that a relative has dementia, family

relationships, how to get help, practical aspects of caring as well as an understanding of their relative's condition.

Other Specialist Hospital Services

The full range of medical, surgical and therapeutic interventions provided in hospital settings, on an in-patient, out-patient or day hospital basis, also play their part in the treatment and rehabilitation of elderly patients. Of particular importance to the maintenance of the independence and quality of life of older people are the benefits of procedures for the treatment of cataracts and joint replacement. Advances in technology in these areas have been dramatic and, not surprisingly, demand for such procedures has grown. Currently, the provision of these treatments is usually subject to lengthy waiting lists. In the years up to 1988, when there were large cutbacks in health expenditure, these were often implemented by reducing the number of admissions for joint replacement and cataract surgery. This was possible because they were usually "planned" as distinct from emergency admissions. Waiting lists increased further as a consequence. More recently, the Department of Health has taken some steps to reduce waiting lists, and this remains a priority under the health strategy for the 1990s.

The alleviation of dependency due to sensory or motor impairment is very important to carers of the elderly at home. Therefore, in assessing the urgency of cases and in striving to meet need, adequate account should be taken of the impact of treatment on caring relatives. Wherever waiting lists and priorities are being drawn up for these types of treatment, a full assessment of the patient's needs should take account of the need to relieve the carer.

The same principle should be applied to all types of hospital treatment. It is important to stress this because it is in the nature of hospitals that the patient is seen outside of the home and community context . It is easy to lose sight of the social context of the patient's needs. Social work services in the hospital, liaison between the hospital and community through the work of liaison nurses, and the geriatric departments themselves, have a leading role to play in bringing together the best in new medical and surgical technology, on the one side, and the best practice in support for the informal carer, on the other.

Summary and Conclusions

While demographic factors will increase the demand for institutional services, particularly long-term care, there is great reluctance among carers and elderly

people themselves to resort to institutional placement. For both humanitarian and economic reasons the use of such placement should be limited in the interests of developing suitable community alternatives. The role of institutional services should continue to be developed through the provision of respite care, and through greater co-operation with and support for informal carers, even after placement. Rehabilitation units should be available in all geriatric hospitals in order to ensure that where possible the elderly person, with the support of the carer, is enabled to continue living in the community as long as possible. The concept of the community hospital should be promoted. Sheltered housing, boarding out and other options for community living have a part to play in complementing the provision of informal care.

In the acute hospital setting, where the treatment of illness in the elderly is more important than at any time in the past, the development of geriatric medicine is vital. It is necessary that liaison between the acute unit, the community care team and carer is kept to the forefront in planning care. Specialist departments in hospitals providing treatment for the elderly should also maintain close liaison with the carer. This is not easy to achieve. The provision of day hospitals is an essential component of support for the carers of the ill and dependent in the community and should be developed further. It is encouraging to see that informal care can be combined with the work of day hospitals, without any apparent tendency of carers to opt out. As with other areas of support for carers, the effect might be to improve the quality of the carers' contribution and their own quality of life.

The examination of institutional care services, and particularly long-term care services, highlights the needs of those carers in the community who care for the most heavily dependent. We have seen that, even at the highest levels of dependency, informal care is an essential component of community care. These carers must be the focus of special attention in the formulation of policy and delivery of services in the community.

CHAPTER FOUR

Methodology

The present study was motivated by the lack of information regarding the provision of support services for carers of elderly people living at home. Its purpose was to ascertain what support services (if any) were available to carers with a view to informing policy makers, statutory service providers, relevant voluntary organisations and carers themselves.

Specifically, as noted in Chapter One, this study aimed:

1. To identify current services for informal carers of dependent elderly people in each of the 31 community care areas of the eight health boards;

2. To initiate a detailed data base of available support services for family and other informal carers of dependent elderly people living at home;

3. To identify variations in provision of services by community care area;

4. To identify and highlight gaps in service provision;

5 To outline possible initiatives in the provision of carer support;

6. To make appropriate recommendations for policy and practice.

Two avenues of exploration were considered appropriate to pursuing the questions raised in Chapters One and Two, and the aims noted above. Firstly, an examination of the services that exist for elderly people was necessary since these “indirectly” impact on the carer role, making the task of caring more or less difficult. These services are available through the statutory and

voluntary bodies who provide medical and non-medical services to elderly people. Secondly, examination of the services that exist to support and assist carers "directly" at both statutory and voluntary level was undertaken. The study was conducted in two phases to provide data for the above. Phase 1 examined indirect support services, namely those available to elderly people. Phase 2 explored direct services available to carers.

Information about indirect services was obtained primarily from a survey of directors of community care in each of the community care areas, and this was cross-referenced, or supplemented where possible, with data from documentary sources. The documentary sources were primarily reports from the Department of Health and from the National Council for the Elderly. Information about direct services for carers was obtained primarily from a survey of community-based voluntary groups which provided support services targeted specifically at carers. For both indirect and direct services, the aim was to obtain information about the availability, and accessibility, of the services to those living in the community, with particular reference to the carer.

Phase 1: Census of Indirect Support Services for Carers of Elderly People Living at Home

Indirect support services for carers are those supplied directly to the elderly person cared for. These services are generally provided by the health boards. While elderly people make specific demands on the health system they also share many of the services with the rest of the community. One of the difficulties which arose for the present study was that information on the use of services by elderly people specifically was not always available.

Health services supplied to the elderly are classified into hospital-based services, i.e., services which are based in and primarily operate from hospitals, and services which are community-based, i.e., based in the community and operating either from a community centre or via domiciliary visits. While some hospital-based services involve visits to the home by specialist secondary care service providers, the distinction is preserved for administrative and research purposes.

A further difficulty relates to the quantity of data collected. It is beyond the scope of this report to relate all of the findings of this investigation. Two areas are reported here: community-based services and services supplied directly to carers.

Respondents

The census form used in the collection of data was directed to the directors of community care for completion. Directors of community care were chosen for a number of reasons. First, information regarding services for the elderly is not available from a single source within community care areas (CCAs). Further, CCAs differ with regard to how data regarding the elderly are recorded in keeping with local needs. Since directors of CCAs are instrumental in shaping the data recording system within a CCA they are often the repository for much of the information this study sought to uncover. The researchers were of the opinion that more integrated information emanating from a central, co-ordinating source would improve the accuracy and reliability of the results. Second, directors of community care undertook to distribute the census form for completion to appropriate departments within their CCA. Since CCAs vary in their organisation the research team were of the opinion that directors of community care were better placed to decide who within their CCA was in possession of the relevant data. Finally, the research team lacked the resources to engage in the extensive field work necessary to collect much of the information at source. Consequently, the director of community care was chosen as the person most likely to possess knowledge of what services were available to the elderly and their carers, and which departments or individuals within his/her CCA provided these services.

In using directors of community care as a conduit for collecting information or for organising the selection of appropriate individuals to provide information there is an increased possibility of biasing the information collected. Specifically, directors of community care may systematically overestimate or underestimate the availability and provision of services to elderly people and their carers because health boards typically do not collect data according to sub-populations to which people belong. To address this imbalance, documentary sources are used where available.

Questionnaire for Census of Indirect Services

Data on the following community-based and home-based services were obtained in the census sent to directors of community care:

- GPs,
- PHN and other nursing services,
- Chiropodists,

- Occupational Therapists,

- Physiotherapists,
- Social Workers,
- Home Help,
- Meals on Wheels,
- Day Centres,
- Transport Services.

These community and home-based services are provided by the above primary care providers and are drawn on extensively by elderly people.

Hospital-based services include specialist secondary care service providers, and residential services. In the present study, information regarding 12 hospital-based specialist secondary care services providers was elicited from directors of community care. These specialists include:

- Audiologists,
- Dentists,
- Geriatricians,
- Opticians,
- Ophthalmologists,
- Psychiatrists,
- Psychologists,
- Speech Therapists.

These specialist secondary service providers are necessary but not essential to maintaining the elderly in the community.

The residential services for which data were obtained from the directors of community care were:

- general hospital beds,
- long-stay geriatric units,
- respite beds for the elderly,
- boarding out schemes,
- welfare homes.

Data on day hospitals and community hospitals were not obtained.

For each of the above services, information was obtained from the directors of community care on variables relevant to the availability and accessibility of the service to those living in the community. Specifically, information on five dimensions was obtained, where relevant. The first two relate to availability, the last three to accessibility. These dimensions are:

- the number of individuals or units providing the service, which could be compared with the number of people over 65 in the community care area, thus providing the ratio of service provision to elderly;
- the extent of the service provided, e.g., did it include home visits, continence advice, etc.;
- whether the service was accessed via referral and/or waiting list, and if so, the length of the waiting list;
- priorities used in providing access to the service (12 in all) with special reference to the impact of the carer;
- conditions of eligibility for the service, (11 in all) e.g., whether a medical card is needed.

A final section of the questionnaire to directors of community care sought to elicit information about organisations and groups who provided direct services to carers.

The Community Care Area* as *the Unit of Analysis

The community care area (CCA) was chosen as a unit of analysis in order to

provide a micro-level analysis of the services provided to elderly people, and to provide a more authentic picture of the spread of these services. The choice of CCAs as the unit of analysis, however, led to a number of difficulties. In some health boards services are centralised and shared with a number of CCAs. This led to over-reporting of services in some CCAs and underreporting of others. To overcome this difficulty it was necessary to utilise documentary data from health boards and the Department of Health.

Furthermore, the directors of community care were in some cases being asked to provide information about services to which they did not have direct access, although they would be aware of broad policies. For example, while they would have data on the numbers of GPs, they may not have direct knowledge of priorities used by GPs in providing services. However, as noted above, in many cases, the director of community care sent the relevant sections of the questionnaires to the appropriate personnel within the CCA. Finally, as already mentioned, detailed information about services for the elderly was not available for some services. This was particularly problematic in the case of hospital beds, where specific details of how many beds in general hospitals were occupied by elderly persons was not available. In the case of hospital beds, where the information obtained was not based on information specifically about the elderly, data are not presented in this report.

Pilot Study for Phase 1

Two areas were chosen for the pilot investigation, CCA 6 in the Eastern Health Board and Roscommon CCA in the Western Health Board. These areas were chosen because of the high proportion of elderly in the population in both areas. Further, it was hoped that any differences that might exist between urban and rural areas in terms of provision of and demand for services would be adequately captured in these areas.

A pilot census form eliciting the information described above was sent to CEOs (chief executive officers), and programme managers of community care in both CCAs. The census form was administered by interviewers to the following personnel in each of the CCAs piloted:

- Director of community care,
- Area administrator,
- Superintendent public health nurse,
- Senior social worker,

• Senior environmental officer,

· Home help organiser.

In all 15 interviews were undertaken in CCA 6 of the Eastern Health Board, and 13 in Roscommon. Analysis of these interviews indicated the need to revise, clarify and extend the piloted census form and to make it more sensitive to specific variations in the delivery and provision of services across CCAs. These suggestions were incorporated into the final version of the indirect census. The content of the indirect census form is detailed in Appendix A.

Sample and Administration of Indirect Census Form

The sample for Phase 1 of the study was 31, corresponding to 31 CCAs in eight health boards. A map of the health boards is provided in Appendix A. Census forms were sent to the directors of community care in each CCA for completion in November 1991. They completed the form themselves, or asked the relevant personnel, such as the superintendent of public health nurses, to complete the relevant section. Completed census forms were returned and coded for computer analysis prior to April 1992. The results from these analyses are presented in Chapters Five and Six.

Response Rate

The number of returned census forms in the present study was 26 corresponding to CCAs. The response rates for each section of the census form varied from 0 - 26. Throughout the analyses the Ns recorded indicate the number of CCAs which provided information. Where percentages are recorded these indicate the percentage of CCAs which provided data from the 26 CCAs which formed 100 per cent. Provision was made for non-responses including blanks, not applicables and not availables, and these are indicated in the tables by a dash. These were eliminated from the total Ns reported in the results. Thus where Ns do not total to 26, the missing Ns are attributable to various combinations of the non-response categories noted above.

Table 4.1 summarises the response rate to the indirect census form for each health board.

The low response rate from the Southern Health Board was due to specific difficulty in completing the census resulting from personnel vacancies.

TABLE 4.1: Number of CCAs and number of respondents by health board

Health Board	No. of CCAs	No. of CCAs responding
1. Eastern	10	10
2. Mid-Western	3	2
3. Midland	2	2
4. North Eastern	3	3
5. North Western	2	2
6. South Eastern	4	3
7. Southern	4	1
8. Western	3	3
TOTAL	31	26

CCA = Community Care Area

Phase 2: Survey of Direct Support Services for Carers of Elderly People

The purpose of this phase of the study was to ascertain what services are available directly to carers throughout the country and who provides those services. There is a dearth of services for carers and what services are available are largely provided by non-statutory groups and organisations, such as The Carers Association, the Soroptimists, The Society of St Vincent de Paul and others. Support services provided by these groups may be direct or indirect. Many organisations provide support to carers indirectly by offering facilities and services to elderly people, relieving the carer temporarily. Other organisations focus the provision of services directly on the carer and the carer's needs. This study examines "only" those groups who provide support directly to carers.

A principal difficulty in tracking carer services is the lack of a register of individuals who supply services. Carer services are not organised formally and therefore remain hidden from general view. The purpose of this survey was to uncover what services exist, who runs them and also to highlight the problems that carers face that are not provided for within the existing statutory services.

Identification of Carers' Groups

In order to locate an appropriate sample for the direct survey it was first necessary to compile a population of likely respondents who had information about services that existed in their area, particularly with regard to elderly people and their carers. The final section of the census of indirect services had produced a list of some services and names from directors of community care. In addition, a number of voluntary organisations and groups were identified who work in the community providing support to elderly people and who are aware of the situation of the carer. For example, these organisations include:

- The St Vincent de Paul Society,
- The Irish Country Women's Association,
- Friends of the Elderly,
- Age and Opportunity,
- Mercy Ireland,
- The Conference of Major Religious Superiors,
- The National Social Service Board,
- Diocesan Social Services,
- The Irish Wheelchair Association.

Furthermore, a few organisations exist who directly focus on support and care of the carer. For example:

- The National Carers Association,
- Soroptimists International, Ireland,
- The Alzheimer Society of Ireland,
- The North and South Dublin Stroke Clubs,
- The Catholic Social Service Conference Care of the Elderly Programme.

These organisations were asked to provide names and addresses of contact people and groups throughout the country who supplied support services

directly to the carers of elderly people. As a result of this initial trawl 267 elicitation forms were sent out to individuals and organisations nationwide to find names and addresses of likely respondents for the direct census. The elicitation form requested further names and addresses of contact people in organisations and groups who provide service and support to carers of elderly people. The response rate to the elicitation form consisted of 64 returned forms containing names and addresses of carers' groups. From this a sample of 170 possible carers' groups or respondents to the direct census was identified. Groups providing support to elderly suffering from Alzheimer's disease, or their carers, were not included as they were being studied in a separate project.

Questionnaire for Survey of Direct Services

The direct survey form elicited information from carers' groups regarding a wide variety of activities. Respondents were requested to provide a profile of their group including:

· name, address and contact person;

· an outline of the group's membership and main functions;

· information about the conduct and frequency of meetings;

• the main activities at group meetings, e.g., educational, practical, emotional, therapeutic, recreational;

· group funding and fund raising activities.

A detailed investigation of the services and activities provided by the group was included. A list of 16 services and activities was given and respondents were asked to indicate whether the service or activity was provided by them, how frequently the service was provided and the number of carers availing of the service. Respondents were also asked to list services supplied by their group that might not be included on the list and to indicate frequency of provision and number of carers availing of that service.

The effects of the carers' financial means on services provided by support groups for carers was queried.

The availability of information services and centres in the respondent's area

was elicited and the groups were asked to supply the name, address and contact person where the services were available.

Details services supplied directly to carers by statutory bodies and other voluntary groups in the respondent's locality were assessed by asking for details about the provision of a wide range of services. These included information, training, sitting, counselling, respite care, transport, and advocacy. Respondents were also asked to indicate what improvements they would make to the statutory services to make them more appropriate to the carers' needs.

Finally, the direct survey form also contained a section similar to the fmal section of the indirect census, eliciting information about groups who provided direct services to carers. This was to ensure that a significant number of carers' groups had not been missed by the initial trawl.

Details of the survey of direct services can be found in Appendix B.

Piloting of the Direct Survey Form

The pilot survey form attempted to elicit information about carer-support groups and the services they provided from a sample of 20 individuals/groups involved with carers. This group included:

· Carers;

· Social workers working with elderly people and carers;

· Members of the National Carers Association;

· Home help organisers;

• Members of Soroptimists International;

• Organisers of day centres which offer support to carers;

• Director of a nursing home offering respite and counselling to carers;

Analysis of these interviews suggested a number of clarifications and simplification to the initial form and these revisions were incorporated into the final drafting of the direct census.

Results of the Present Study

There are two chapters describing the findings of the present study. The results from the Indirect and Direct Census are presented in Chapters Five and Six.

- Chapter Five describes the findings regarding community-based services including professional and domiciliary services which support the carer at an immediate level.

- Chapter Six reports the results from the direct census.

A copy of the questionnaires used in the study can be obtained from the National Council for the Elderly.

CHAPTER FIVE

Community-Based Services Which Support Carers Indirectly

The purpose of this chapter is to describe the community-based and home care-based services that provide or have the potential to provide indirect support to the carer while targeted at the dependent person. The services that are outlined here are those that are based in the community and involve either visits by service providers to the home of the elderly person, or services visited by the elderly person. These services help to maintain the elderly person in the community, and provide relief and respite indirectly to the carer. These services include:

- the professional service provided by GPs and PHNs, who play a central role in maintaining elderly people in the community and who provide a vital support to informal caregivers in terms of practical help, relief, support and advice. In addition, services such as chiropody, occupational therapy, physiotherapy and social work services are provided which may be important in supporting elderly people and their carers;

· domiciliary support services such as home help, meals and sitting services which relieve the carer of the ongoing burden of care;

· transport and day centre services which are essential to the elderly person to maintain health and well-being, and which therefore facilitate carers by enabling them to provide better care for the elderly person.

Before proceeding with the findings regarding the above services, it should be pointed out that community-based care is affected by the size and distribution of both the elderly population and the carer population. Elderly people share with the rest of the community many services supplied by the health boards. As the profile of the population changes it can be expected that, increasingly, elderly people will make a greater claim on health board services. These

demographic factors - for example, increasing numbers of elderly people, and of the very old - have been reviewed in Chapter One. The elderly are not uniformly distributed across health boards as Table 5.1 reveals. This table charts the increase in the number of elderly people across health boards from 1986 to 1991. It is evident from Table 5.1 that the percentage of the elderly in the population has increased from 10.9 per cent in 1986 to 11.2 per cent in 1991, while the total population has dropped by 17,242 (0.487 per cent). Increases in the percentage of elderly in the population are reported for all health boards with the biggest increases occurring for the Midland Health Board (0.8 per cent). There has been no increase in number of elderly as a percentage of health board population in the North Western Health Board. The highest percentage of elderly people in both 1986 and 1991 is in the Western and North Western Health Boards where elderly people make up 14.3 per cent of the total population.

These changes in the population have important implications for the health services. As the proportion of elderly in the population increases, so health boards may expect to spend a greater portion of their income on services for the elderly.

TABLE 5.1: Elderly people as a percentage of the population by health board for 1986 and 1991

Health Board	Population in Health Board		Number of Elderly in Health Board*		Elderly as a % of Population in Health Board	
	1986	1991	1986	1991	1986	1991
1. Eastern	1,232,238	1,244,238	108,315	114,903	8.8	9.2
2. Midland	207,994	202,948	23,172	23,977	11.0	11.8
3. Mid-Western	315,435	310,511	35,240	35,907	11.1	11.6
4. North Eastern	302,035	300,265	31,853	33,356	10.6	11.1
5. North Western	212,745	208,027	30,380	29,740	14.3	14.3
6. South Eastern	384,974	383,003	42,198	43,848	10.9	11.4
7. Southern	536,894	531,533	63,981	64,206	11.9	12.1
8. Western	348,328	342,876	49,216	48,893	14.1	14.3
TOTAL	3,540,643	3,523,401	384,355	394,830	10.9	11.2

Source:Health Statistics

In the analysis that follows, each of the services mentioned above will be described. As

Chapter Two pointed out, the key questions from the carer's point of view have to do with the availability and accessibility of services. Specifically, the questions are:

1. what services are provided, which can be analysed in terms of the "ratio" of service provision to the elderly population of the area, and the nature of the different "services provided", where appropriate?

2. how accessible is the service, which can be analysed in terms of (i) whether "referrals" and "waiting lists" are involved? (ii) what are the "priorities" used in providing care, and in particular, what impact does the carer have on provision of care? (iii) are there conditions of "eligibility" e.g., possession of a medical card, for receiving the service?

These questions will not always be applicable - for example, there is rarely a waiting list for access to a GP - and will be addressed only where relevant. As indicated in Chapter Four, where there are no responses in a category this is indicated in the tables by a dash (-).

General Practitioners (GPs)

Availability: Ratios

Table *5.2* outlines the number of GPs and the ratios of GPs to elderly population for each of the health boards. Overall, there is one GP in the choice of doctor scheme to every 250 elderly people. The ratio of GPs to elderly people varies from health board to health board, although within a fairly narrow range - from 1:280 in the North Eastern Health Board to 1:228 in the Eastern Health Board.

Accessibility: Priorities

The ratios in Table 5.2 would appear to suggest that the elderly and carers should be able to access GP services easily. Additionally, access does not usually involve referral or a waiting list. No waiting list operates for this service which is available across all the CCAs which responded. However, doctors in this scheme also treat other members of the community as well as the elderly. The effect of this is that GPs have to assess the provision of services to elderly people by using a set of priorities. While the carer is of major importance in maintaining the elderly person in the community, how important is this factor to GPs in determining provision of care to the elderly?

TABLE 5.2: Number of GPs and ratios of GPs to elderly people in the population by health board (for year ending December 1990)

Health Board	No. of doctors in choice of doctor scheme*	Ratio of doctors to elderly population
1. Eastern	505	228
2. Midland	95	252
3. Mid-Western	136	264
4. North Eastern	119	280
5. North Western	102	292
6. South Eastern	179	245
7. Southern	260	247
8. Western	182	269
TOTAL	1,578	250

Source:*Health Statistics

Table 5.3 outlines the importance attached to 12 priorities used to make decisions about provision of GP services to elderly people, as reported by the directors of community care. In their view, medical criteria dominate the GPs' decision making regarding provision of care such as "urgency or acuteness of medical need" (42.3 per cent), "general state of health of elderly person" (38.4 per cent) and "level of incapacity of elderly person" (34.6 per cent). The carer was sometimes considered in making decisions about elderly. Whether the "carer of the elderly person was absent" and "if the carer was at risk" were always priorities in 11.5 per cent and 15.3 per cent of cases, and sometimes priorities for GPs in determining provision of care for the elderly person in 26.9 per cent of CCAs, according to directors of community care.

Thus, from the director of community care's perspective, the GP service, while directly accessible, is limited in availability by the need to prioritise services to elderly people. The carer is not a particular priority for GPs in making decisions about care for elderly people even though there is acknowledgement of the importance of the informal caregiver in maintaining elderly people in the community, according to directors of community care. The GP's primary focus is on the medical condition of the elderly person and not on the role the carer plays in it.

TABLE 5.3: Percentage and number for priorities used to assess the provision of

GP services to elderly people

Priorities	a	b	c	d
1) Urgency or acuteness of medical need	42.3 (11)	3.6 (1)	-	3.8 (1)
2) Age of elderly person	26.9 (7)	15.3 (4)	3.8 (1)	3.8 (1)
3) Financial situation (e.g. ability to pay for certain treatment)	11.5 (3)	11.5 (3)	19.2 (5)	3.8 (1)
4) Level of incapacity of elderly person	34.6 (9)	11.5 (3)	-	3.8 (1)
5) General state of health of elderly person	38.4 (10)	7.7 (2)	-	3.8 (1)
6) Length of time on waiting list	15.3 (4)	7.7 (2)	3.8 (1)	23.0 (6)
7) Carer of elderly person absent	11.5 (3)	28.9 (7)	-	7.7 (2)
8) Need of elderly person other than medical (e.g. social)	15.3 (4)	26.9 (7)	-	3.8 (1)
9) Other “at risk” factors	15.3 (4)	30.7 (8)	-	3.8 (1)
10) Number of beds available	15.3 (4)	7.7 (2)	3.8 (1)	15.3 (4)
11) The carer of the elderly person is at risk	15.3 (4)	26.9 (7)	-	3.8 (1)
12) Referral	11.5 (3)	7.7 (2)	-	19.2 (5)

a = always a priority in determining the provision of care
b = sometimes a priority in determining the provision of care
c = never a priority in determining the provision of care
d = not applicable
Numbers in parentheses indicate number of CCAs
Public Health Nurses (PHNs)

Availability: Ratios and Provision of Service

Table 5.4 gives the number of PHNs and the ratios of PHNs to elderlypopulation for each of the health boards. There is one whole time equivalent PHN to every 291 elderly people. These ratios appear to show greater variation than those for GPs from health board to health board, ranging from a high of 1:353 in the Southern Health Board to a low of 1:251 in the Western

Health Board. Obviously health boards vary in the provision of a GP service relative to a PHN service. Of course, PHNs also provide services to other members of the community

and thus may be unable to deliver the kind of service they would wish to the elderly and their carers.

TABLE 5.4: Number and ratio of PHNS to elderly people in the population by health board (December 1990)

Health Board	No. of WTE PHNS*	Ratio of WTE PHNs to elderly population
1. Eastern	429.3	268
2. Midland	94.4	254
3. Mid-Western	109.9	327
4. North Eastern	118.6	281
5. North Western	105.1	283
6. South Eastern	144.5	303
7. Southern	182.1	353
8. Western	174.3	251
TOTAL	1358.2	291

WTE Whole time equivalents
Source: * Health Statistics

Public health nurses supply many basic nursing and medical needs directly to elderly people in their own homes and act in a co-ordinating and mobilising role. They therefore are a vital support link for carers, and offer a variety of services which provide practical support and advice to carers. These are documented in Table 5.5.

Of particular importance to carers of elderly people are services such as continence advice and materials, help with lifting, bathing and toileting, and sitting services. Table 5.5 shows that around 20 of the CCAs provide a number of special services, mostly through the PHN, and sometimes through other nurses. Night nursing and twilight nursing tend to be provided by nurses who are not PHNs.

TABLE 5.5: Type of nursing service/aids, service provider in CCA and availability of service on medical card - percentage and number of CCAs

Service/Aids	Provider of Service in CCAs %			Availability Free on MC	Part Free on MC
Home nursing aids · (3)	PHN	76.9	(20)	65.4	11.5
Special lifting aids	PHN OT	53.9 26.9	(14) (7)	61.5 (16)	11.5 (3)
Special toilet aids	PHN OT	53.9 26.9	(14) (7)	61.5 (16)	15.4 (4)
Special beds	PHN OT	57.7 23.0	(15) (6)	53.9 (14)	15.4 (4)
Training to carer in lifting, bathing and toileting skills	PHN	76.9	(20)	69.2 (18)	3.8 (1)
Bathing and toileting 4. (1)	PHN	76.9	(20)	76.9	3.8
Continence advice	PHN CON NUR	69.1 7.7 3.8	(18) (2) (1)	80.7 (21)	-
Incontinence pads and pants	PHN CON	76.9 3.8	(20) (1)	65.4 (17)	7.7 (2)
Special Nursing Services: a) Night nursing	PHN NUR	11.5 38.4	(3) (10)	42.3 (11)	3.8 (1)
b) Day nursing	PHN NUR	53.9 11.5	(14) (3)	53.9 (14)	3.8 (1)
c)Weekend nursing	PHN NUR	61.5 15.4	(16) (4)	65.4 (17)	-
d) Twilight nursing	PHN CA NUR	15.4 7.7 46.2	(4) (2) (12)	61.5 (16)	-

Numbers in parentheses indicate number of CCAs
PHN = Public Health Nurse;
OT= Occupational Therapist;
NUR = Nurse (not PHN);
CON = Continence Adviser;
CA = Care Assistant

Accessibility: Priorities

Access to PHNs, as with the GP service, is direct, with the carer or elderly person themselves organising visits. There is no waiting list for this service in 84.6 per cent of CCAs, with 11.5 per cent reporting a waiting list for some aspect of nursing services.

These services are available free within CCAs to medical card holders. However, PHNs, like GPs, have to prioritise the provision of services. While nursing services may be free to medical card holders, the presence of a carer can have a negative effect on the nursing services delivered, with PHNs reducing the service they provide if a carer is present. In the present study 26.9 per cent of CCAs report that full nursing service is given to elderly people irrespective of the presence of the carer, and 19.2 per cent of CCAs indicate that only a partial nursing service will be given if there is a carer present.

It appears that PHNs assess the provision of nursing services to elderly people and reduce the level of service provided accordingly. This is apparent from Table 5.6, which outlines the priorities that PHNs use to make decisions. These data were obtained from the superintendent of public health nursing within each of the health boards surveyed.

Both medical and social needs of elderly people are considered in determining the provision of nursing services. Factors which are always important in determining care include “urgency or acuteness of medical need” (84.6 per cent), “level of incapacity of elderly person” (88.8 per cent) and “general state of health of the elderly person” (84.6 per cent). The presence of a carer is also important in deciding what level of care to provide. If “the carer of the elderly person is absent” (65.3 per cent), “other at risk factors” (76.9 per cent) or “the carer of the elderly person is at risk” (76.9 per cent), then level of nursing service is adjusted accordingly.

The pattern of decision making regarding provision of care by PHNs appears to rest on consideration of both medical priorities and social, familial, and physical circumstances of the elderly person. Thus, PHNs’ care would appear to extend beyond the bounds of strict medical care to include other factors pertinent to the maintenance of the elderly person in the community, including their carer.

Additional Community Based Service Providers

Data were also available regarding the provision of services for four additional professional service providers who are particularly relevant to the

TABLE 5.6: Percentage and number for priorities used to assess the provision of

public health nursing services to elderly people

Priorities	a	b	c	d
1) Urgency or acuteness of medical need	84.6 (22)	3.8 (1)	-	3.8 (1)
2) Age of elderly person	34.6 (9)	46.2 (12)	-	11.5 (3)
3) Financial situation (e.g. ability to pay for certain treatment)	7.7 (2)	11.5 (3)	53.8 (14)	19.2 (5)
4) Level of incapacity of elderly person. 4. (1)	88.8	-	3.8	-
5) General state of health of elderly person	84.6 (22)	7.7 (2)	-	-
6) Length of time on waiting list	3.8 (1)	19.2 (5)	-	65.3 (17)
7) Carer of elderly person absent	65.3 (17)	15.3 (4)	3.8 (1)	3.8 (1)
8) Need of elderly person other than medical (e.g. social)	46.2 (12)	38.4 (10)	-	3.8 (1)
9) Other “at risk” factors 4. (4)	76.9	15.3	-	-
10) Number of beds available	19.2 (5)	19.2 (5)	-	42.3 (11)
11) The carer of the elderly person is at risk	76.9 (20)	7.7 (2)	-	3.8 (1)
12) Referral	30.7 (8)	19.2 (5)	3.8 (1)	26.9 (7)

a = always a priority in determining the provision of care
b = sometimes a priority in determining the provision of care
c = never a priority in determining the provision of care
d = not applicable
Numbers in parentheses indicate number of CCAs

elderly, and who may make domiciliary visits. These include chiropodists, occupational

therapists, physiotherapists and social workers. These service providers are singled out because of the specific ongoing role they play in relation to carers of dependent elderly people. These service providers play a day-to-day role in complementing carers and maintaining independence among the elderly at home and through day centres, as part of respite care. The availability and accessibility of these services is considered below.

Availability of Service Providers

Availability of service providers was assessed by ascertaining the ratio of service provider to the elderly population. However, this information could not be supplied for all community-based professional service providers. Neither the service providers nor health boards keep records of the number of patients they see or who avail of their services in terms of age categories. Thus ratios cannot be computed for all these services. The Department of Health's census of certain professional services provides the data for Table 5.7, which gives an analysis of ratios to elderly population. Figures were not available for chiropodists or social workers.

TABLE 5.7: Number of community-based professional services and ratios to elderly population by health board (for year ending December 1990)

Health Board	No. of OTs (WTE)* population	Ratio of OTs (WTE) to elderly therapists	No. of Physio- to elderly population	Ratio of Psysio therapists
1. Eastern	106.8	1,076	40	2,873
2. Midland	9.0	2,664	21	1,142
3. Mid-Western	7.9	4,545	21	1,710
4. North Eastern	12.0	2,780	23	1,450
5. North Western	20.5	1,451	29	1,026
6. South Eastern	1.7	25,793	31	1,414
7. Southern	17.4	3,690	35	1,834
8. Western	14.5	3,372	30	1,630
TOTAL	189.8	2,080	230	1,717

WTE = Whole time equivalents

Source: * Health Statistics

Occupational therapists contribute substantially to maintaining the quality of life of the

elderly in the community. However, these are short in supply with one OT to every 2,080 elderly people. Similarly, there is one physiotherapist to every 1,717 elderly people. Table 5.7 clearly shows the variations in the distribution of OTs and physiotherapists across health boards.

This study did obtain information about the availability of chiropodists, occupational therapists, physiotherapists and social workers in each community care area. Chiropodists are reported to be available in 22 CCAs, OTs and physiotherapists in 23 CCAs, while social workers are available in 21 CCAs.

Data were sought regarding the provision of specific services by chiropodists, occupational therapists, physiotherapists and social workers who are particularly relevant to the elderly, and who may make domiciliary visits. These data are presented in Tables 5.8 - 5.11.

Table 5.8 shows that services provided by chiropodists are available free to medical card holders in the majority of CCAs which responded. The elderly person is entitled to the first three visits free on the medical card. Thereafter, payment for treatment may be required. Regular footcare is provided free on the medical card in nine CCAs, and is partly charged for in three CCAs. Special shoes and aids are free in less than half of CCAs, 12 in all, and home visits by the chiropodists are provided free in 14 CCAs. It would appear that the chiropody service operates well in supporting elderly people. However, since chiropodists do not log the number of patients they treat by age, it is difficult to establish to what extent the existing service meets the demands placed on it by the elderly population as distinct from other groups who also avail of the service. Data on waiting lists are dealt with below.

TABLE 5.8: Availability of chiropody services to elderly people - percentage and number

Availability Service	Must Pay	Free on MC	Part Free on MC	Not Available
Number of visits	-	61.5 (16)	15.3 (4)	3.8 (1)
Regular footcare	3.8 (1)	34.6 (9)	11.5 (3)	3.8 (1)
Special shoes and aids	-	46.2 (12)	3.8 (1)	3.8 (1)
Home visits	7.7 (2)	53.8 (14)	7.7 (2)	3.8 (1)

MC = Medical Card

Table 5.9 shows that most of the occupational therapy services listed are available free to

medical card holders in the majority of CCAs. Visits, equipment, aids and appliances are freely available to medical card holders in 18, 16, and 17 CCAs respectively, while adaptations to the home are freely available in 9 CCAs. Occupational therapy is important to the elderly since it frequently involves helping the older person to adjust to adaptations and changes in their quality of life. While most CCAs provide the above services, it is evident from Table 5.7 that there are only 189.8 whole time equivalent occupational therapists throughout the country, with some health board areas well-serviced and others with very few whole time equivalents occupational therapists.

TABLE 5.9: Availability of occupational therapy services to **elderly people -percentage and number**

Service	Availability		
	Free on MC	Part Free on MC	Not Available
Number of visits	69.2 (18)	-	-
Equipment · -	61.6		
Aids and appliances · -	65.3		
Adaptations to home	34.6 (9)	-	-

MC = Medical Card

TABLE 5.10: Availability of physiotherapy services to elderly people - percentage and number

Service	Availability		
	Free on MC	Part Free on MC	Not Available
Number of visits	61.5 (16)	-	-
Treatment for relief of pain/mobility	53.8 (14)	-	-
Walking aids	57.7 (15)	-	-
Wheelchairs	46.2 (12)	-	-

MC = Medical Card

Physiotherapy is a rehabilitative service and physiotherapists provide a number of

specific services which vary in their availability to medical card holders. These are summarised in Table 5.10. The services listed in Table 5.10, namely visits, treatment for the relief of pain and for mobility, walking aids and wheelchairs are available free to medical card holders in 16, 14, 15 and 12 CCAs respectively.

Social workers whose specific function is care of the elderly are few, with only six recorded across the 26 CCAs surveyed. While social workers have a mandate to prioritise the care of children, they do provide services which are sometimes availed of by elderly people. Table 5.11 shows that in the three or four CCAs where the service is available, social workers make visits, and provide counselling and assessment.

TABLE 5.11: Availability of 8ocial work services to elderly people – percentage and number

Service	Availability		Not Available
	Free on MC	Part Free on MC	
Number of visits	11.5 (3)	- (2)	7.7
Counselling	15.3 (4)	- (2)	7.7
Assessment	15.3 (5)	- (2)	7.7
Home Visits	15.3 (4)	- (2)	7.7

MC = Medical Card

It would appear from the above that the services provided by chiropodists, occupational therapists, physiotherapists and social workers are all essential (and non-overlapping), for supporting the elderly person and the carer living in the community. With the exception of social workers, these services are widely available free to medical card holders in most of the CCAs for which information is available. Whether the service is adequate to demand would ideally be answered by examining the ratio of service providers to the elderly population, which, as already discussed, is not available for most services. It

can also be addressed by data on waiting lists, which are presented in the following

section.

Accessibility: Waiting Lists

Next to GPs and PHNs, chiropodists, OTs, physiotherapists and social workers have greater demands placed on them by the elderly population than other professional service providers. These services are central to maintaining the elderly in the community. The services offered by these community-based professionals are available to elderly people through the hospital service and through home visits, and often involve waiting lists.

No data were available regarding waiting lists for the chiropody service. However, waiting lists operate in most (60 per cent or more) CCAs for OTs, and in many (46 per cent) CCAs for physiotherapists.

Waiting times to get an appointment vary for each of these services. It can take up to one year to get an appointment with an occupational therapist (1-*52* weeks). The shortest waiting period occurs for social workers (0-3 weeks). However, social workers, while available throughout the health care system, have no obligation to work with elderly people, although those based in hospitals play an important role in liaising with community services. It can take up to 16 weeks to get an appointment to see a chiropodist (2-16 weeks) and between one and four weeks to see a physiotherapist. There is clearly considerable variation in the waiting times for these services, which, as discussed above, are particularly relevant to the elderly person, and to the carer, and which provide essential services such as special aids and treatment for relief of pain. Occupational therapists, especially, are particularly under-resourced, as the data on ratios from Table 5.7, and on waiting times given above, clearly show. This may cause distress to those waiting (both carer and elderly person), and may necessitate a search for private service provision.

While waiting time may be lengthy, it should be pointed out that if a person requires emergency treatment by any of the listed health care professionals, then these patients receive priority treatment irrespective of the waiting list.

Accessibility: Decision Making and Prioritising Services

Access to chiropody service does not involve referral. No data were available on how OT and physiotherapy services are accessed by elderly people or their carers, and this issue does not apply to social workers for the reasons given above. How are decisions concerning the extent and provision of care arrived at and what weight is given to the role of the carer in arriving at such

TABLE 5.12: Percentage and number for priorities used to assess the provision of chiropody, occupational therapy,

and physiotherapy services to elderly people

Priorities	Chiropodists				Occupational Therapists				Physiotherapists			
	a	b	c	d	a	b	c	d	a	b	c	d
1) Urgency or acuteness of medical need	53.8 (14)	3.8 (1)	-	19.2 (5)	65.3 (17)	15.3 (4)	-	15.3 (4)	53.8 (14)	3.8 (1)	-	11.5 (3)
2) Age of elderly person	23.0 (6)	19.2 (5)	11.5 (3)	23.0 (6)	15.3 (4)	42.3 (11)	15.3 (4)	23.0 (6)	3.8 (1)	38.4 (10)	7.7 (2)	15.3 (3)
3) Financial situation (e.g. ability to pay for certain treatment)	15.3 (4)	19.2 (5)	11.5 (3)	30.7 (8)	3.8 (1)	19.2 (5)	34.6 (9)	269 (7)	11.5 (3)	11.5 (3)	19.2 (5)	23.0 (6)
4) Level of incapacity of elderly person	23.0 (6)	23.0 (6)	3.8 (1)	26.9 (7)	50.0 (13)	26.9 (7)	-	19.2 (5)	34.6 (9)	19.2 (5)	3.8 (1)	11.5 (3)
5) General state of health of elderly person	23.0 (6)	30.7 (8)	-	19.2 (5)	34.6 (9)	38.4 (10)	-	19.2 (5)	30.7 (8)	23.0 (6)	3.8 (1)	11.5 (3)
6) Length of time on waiting list	7.7 (2)	26.9 (7)	7.7 (2)	34.6 (9)	3.8 (1)	50.0 (13)	15.3 (4)	23.0 (6)	7.7 (2)	23.0 (6)	11.5 (3)	26.9 (7)
7) Carer of elderly person absent	7.7 (2)	11.5 (3)	7.7 (2)	46.2 (12)	15.3 (4)	42.3 (11)	7.7 (2)	26.9 (7)	11.5 (3)	9.2 (5)	77 (2)	30.7 (8)
8) Need of elderly person other than medical) (e.g. social)	3.8 (1)	15.3 (4)	7.7 (2)	42.3 (11)	3.8 (1)	42.3 (11)	15.3 (4)	26.9 (7)	7.7 (2)	26 9 (7)	77 (2)	26.9 (7)
9) Other “at risk” factors	15.3 (4)	19.2 (5)	-	34.6 (9)	34.6 (9)	38.4 (10)	-	15.3 (4)	11.5 (3)	26.9 (7)	11.5 (3)	19.2 (5)
10) Number of beds available	11.5 (3)	3.8 (1)	-	46.2 (12)	3.8 (1)	3.8 (1)	3.8 (1)	61.5 (16)	11.5 (3)	3.8 (1)	3.8 (1)	46.2 (12)
11) The carer of the elderly person is at risk	7.7 (2)	3.8 (1)	3.8 (1)	53.8 (14)	23.0 (6)	26.9 (7)	11.5 (3)	26.9 (7)	19.2 (5)	19.2 (5)	77 (2)	23.0 (6)
12) Referral	7.7 (2)	15.3 (4)	-	38.4 (10)	19.2 (5)	19.2 (5)	19.2 (5)	19.2 (5)	19.2 (5)	11 5 (3)	77 (2)	269 (7)

a = always a priority in determining the provision of care
b = sometimes a priority in determining the provision of care
c = never a priority in determining the provision of care
d = not applicable
Numbers in parentheses indicate number of CCAs

decisions? Table 5.12 summarises priorities used to determine care for community-based professional service providers which are particularly relevant to the elderly, namely,

chiropodists, occupational therapists and physiotherapists. These data were provided by directors of community care. Social workers are not included since they have no obligation to attend to the elderly in the community. Data regarding priorities for social workers is available in Table C5, Appendix C.

Decisions regarding provision of service by chiropodists rests on medical needs (53.8 per cent). For OTs and physiotherapists decisions regarding service provision revolve around medical factors such as “acuteness of medical need” (65.3 per cent and 53.8 per cent respectively).

Priorities in decision making about the provision of services are presumed to reflect the main professional concerns and preoccupations of the people who provide those services. When many services are predicated on medical decisions, service providers must give weight to those factors in deciding about extent and provision of care. However, most service providers are aware of the importance of other factors which affect the elderly patient.

What effect (if any) does the carer of the elderly person have on the provision of care? Answers from the directors of community care suggest that for none of the community-based services listed was the priority “carer of the elderly person absent” always important in determining the provision of care with a greater frequency than 15.3 per cent of CCAs. For chiropodists this was considered not applicable in 46.2 per cent of cases, and for occupational therapists and physiotherapists, in 26.9 per cent and 30.7 per cent of cases respectively. It was sometimes a factor in determining the provision of care for occupational therapy service in 42.3 per cent of CCAs, and fell to being sometimes a factor in 19.2 per cent of CCAs for physiotherapists, and to 11.5 per cent of CCAs for chiropodists.

A further question sought to ascertain the importance of impact of the carer of the elderly person being at risk on the provision of services to the elderly person. This was considered non-applicable by 53.8 per cent of directors of community care for chiropodists. However, it was considered always or sometimes a priority for occupational therapists in almost half of CCAs, and for physiotherapists in over one third of CCAs.

It appears that the role of the carer and the carer’s health in caring for the

elderly person are not perceived as important components in decisions about how elderly people should be treated with regard to the provision of certain services. This may reflect

the different relationship professionals have with elderly patients and their carers. The carer's plight is not relevant in decision making regarding the provision of certain services. This may be due to the nature of the service provided, or to the fact that many professional service providers operate in collaboration with other service providers, and thus decisions regarding provision of care are not always straightforward.

Home Help Services

Availability: Ratios, Organisation and Provision

The home help service is of critical importance in maintaining elderly people in the community. This service is supplied by statutory and voluntary bodies and has the potential to benefit the carer where it provides release from the burden of caring. How extensive is this service? Table 5.13 presents the number of recipients and the ratio of recipients to elderly population for 1990.

TABLE 5.13: Number of elderly recipients of home help and ratio of recipients to elderly population by health board (for year ending December 1990)

Health Board	No. of elderly recipients	Ratio of elderly recipients to elderly population
1. Eastern	3,765	30
2. Midland	716	33
3. Mid-Western	1,040	34
4. North Eastern	1,080	31
5. North Western	842	35
6. South Eastern	981	44
7. Southern	2,051	31
8. Western	1,599	31
TOTAL	12,074	33

*Source: Health Statistics

The majority of recipients of home help are elderly and are in health boards national ratio is one recipient of home help to every 33 elderly in the with the largest population of

elderly people. The home help service varies across health boards in terms of ratio of recipient to elderly population the population. Since greater than 80 per cent of home help recipients are elderly, these ratios can be taken to reflect the number of elderly in the population who receive home help. Table C1 in Appendix C provides the 1989 data on the ratio of home helps to elderly. Though not all elderly people require this service the ratios of recipients to elderly population indicate the penetration and spread of this service.

From the carers' point of view home help services have the potential to ease their responsibility for caring and free them to engage in other activities. However, only a small portion of the elderly population receive this service (3.1 per cent).

The present study did not obtain detailed information on the organisation and provision of the home help service. However, a compilation of Department of Health data regarding home help services by the National Council for the Elderly (NCE) in 1989 provided information on recipients of this service, how the service was organised and staffed, how it was financed and rates of pay for home helps. Data regarding the organisation of the service are relevant to the present study and these data are summarised in Table C2, in Appendix C.

The NCE's compilation of these data showed that the majority (81.1 per cent) of recipients of home help service in 1989 were elderly. Home help services are organised by home help organisers who work for the health board, or who are employed by voluntary bodies. The vast majority of home help organisers are employed full-time. Home helps may also be employed by the health boards or by voluntary bodies. Over 99 per cent of home helps are part-time, and the part-time rate for home helps ranges from £0.75 per hour to £72.50 per week.

Home helps may provide a variety of services for elderly people from domestic chores to operating a sitting service. Table *5.14* provides a summary of the sitting service that is provided by home helps. No sitting service exists in 57.7 per cent of CCAs. A sitting service is available in only 26.9 per cent of CCAs.

Also of concern to the carer, and to the elderly people who avail of the home help service, is the level of training that home helps receive. In the present study, it was found that both full-time and part-time home helps receive training in 46.2 per cent of CCAs, while 34.6 per cent of CCAs had no

training scheme in operation. The length of time spent in training varied from one to six weeks in 19.2 per cent of CCAs which responded to this question.

Given the importance to carers of a sitting service which provides some relief to them in the home, it is clear that this facility is seriously under-provided. Referring back to Table 5.5, it can be seen that nursing services outside of daytime hours are provided in many more health boards than is a home help sitting service. It would appear that this is an area where the home help service should be expanded to facilitate the temporary relief of carers from the pressures of caring.

TABLE 5.14: Provision of sitting service through home help service - percentage and number

Sitting Service	Percentage	
	Yes	No
1. Sitting service available:	26.9 (7)	57.7 (15)
2. Type of sitting service:		
Day	15.3 (4)	3.8 (1)
Night	15.3 (4)	7.7 (2)
Twilight	15.3 (4)	3.8 (1)
Weekend	11.5 (3)	3.8 (1)
3. Charge for sitting service:		
Day	3.8 (1)	3.8 (1)
Night	7.7 (2)	7.7 (2)
Twilight	3.8 (1)	3.8 (1)
Weekend	3.8 (1)	3.8 (1)

Numbers in parentheses indicate number of CCAs

Accessibility: Referral, Priorities and Eligibility

Access to the home help service is by referral (88.4 per cent), the source of referral being

from multiple combined sources for *50* per cent of CCAs and PHNs in 30.7 per cent of CCAs. There is no waiting list for the home help service in 73.1 per cent of CCAs compared to 15.3 per cent which operate a waiting list. Some CCAs charge the elderly person a fee for home help services (34.6 per cent).

TABLE 5.15: Priorities for providing home help services to elderly people - percentage and number

Priorities	a	b	c	d
1) Urgency or acuteness of medical need	53.8 (14)	23.1 (6)	-	3.8 (1)
2) Age of elderly person	19.2 (5)	50.0 (13)	11.5 (3)	7.7 (2)
3) Financial situation (e.g. ability to pay for certain treatment)	19.2 (5)	42.3 (11)	19.2 (5)	7.7 (2)
4) Level of incapacity of elderly person	69.2 (18)	11.5 (3)	-	7.7 (2)
5) General state of health of elderly person	61.5 (16)	19.2 (5)	-	7.7 (2)
6) Length of time on waiting list	11.5 (3)	15.3 (4)	7.7 (2)	50.0 (13)
7) Carer of elderly person absent	46.2 (12)	26.9 (7)	-	11.5 (3)
8) Need of elderly person other than medical (e.g. social)	26.9 (7)	46.2 (12)	3.8 (1)	11.5 (3)
9) Other “at risk” factors	34.6 (9)	46.2 (12)	-	7.7 (2)
10) The carer of the elderly person is at risk	42.3 (11)	34.6 (9)	-	11.5 (3)
11) Referral	15.3 (4)	30.7 (8)	11.5 (3)	19.2 (5)

a = always a condition in determining the provision of care
b = sometimes a condition in determining the provision of care
c = never a condition in determining the provision of care
d = not applicable
Numbers in parentheses indicate number of CCAs

Like professional and residential services, the home help service operates on scarce resources, and therefore priorities are employed in determining the

extent and provision of service. These data were supplied by home help organisers. Table 5.15 outlines how decisions regarding the provision of home help services are prioritised.

A number of factors were always priorities in deciding on provision of home help service. These include “level of incapacity of elderly person” (69.2 per cent), “general state of health of elderly person” (61.5 per cent), and “urgency or acuteness of medical need” *(53.8* per cent). The carer is also important in considering provision of home help. If the “carer of the elderly person is absent” or a “carer of the elderly person is at risk” 46.2 per cent and 42.3 per cent of CCAs adjust the level of home help they provide accordingly.

TABLE 5.16: Conditions of eligibility for home help service - percentage and number

Conditions of Eligibility	a	b	c	d
1) Must be living alone	7.7 (2)	50.0 (13)	7.7 (2)	23.0 (6)
2) Must be living in unsafe or unsanitary housing conditions	7.7 (2)	23.0 (6)	26.9 (7)	30.7 (8)
3) Must have no support from family or neighbours	-	11.5 (3)	42.3 (11)	23.0 (6)
4) Must have medical card	15.3 (4)	38.4 (10)	23.0 (6)	11.5 (3)
5) Must be incapacitated	3.8 (1)	57.7 (15)	11.5 (3)	15.3 (4)
6) Must be means tested for this service (i.e. means of elderly person only)	34.6 (9)	26.9 (7)	11.5 (3)	11.5 (3)
7) Must be means tested inclusive of carers means and elderly persons mean	23.0 (6)	26.9 (7)	11.5 (3)	23.0 (6)
8) Must be on the waiting list	3.8 (1)	7.7 (2)	38.4 (10)	38.4 (10)
9) Must be over 65 years of age	-	23.0 (6)	42.3 (11)	23.0 (6)
10) Must be able to pay for this service	-	19.2 (5)	42.3 (11)	26.9 (7)
11) Must be a home owner	-	3.8 (1)	46.2 (12)	38.4 (10)
12) Must be on disabled persons allowance	-	7.7 (2)	46.2 (12)	34.6 (9)

a = always a condition of eligibility; b = sometimes a condition of eligibility; c = never a condition of eligibility; d = not applicable.

Numbers in parentheses indicate number of COAs

The impact of the carer’s presence on the provision of home help does not always have a

positive outcome for the carer. In 50 per cent of CCAs only partial home help service is given if there is a carer present, and the service is not provided in *7.7* per cent of CCAs, if there is a carer present. Only 7.7 per cent of CCAs provide a full home help service irrespective of the carer.

Table 5.16 summarises the conditions of eligibility with regard to the home help service. A factor that is always a condition of eligibility in 34.6 per cent of CCAs is "must be means tested for this service (i.e. elderly person only)". Other factors sometimes used as conditions of eligibility, included "must be incapacitated" in 57.7 per cent of CCAs, "must be living alone" in 50 per cent of CCAs, and "must have medical card" in 38.4 per cent of CCAs.

In 50 per cent of CCAs "must be means tested inclusive of carers means and elderly persons means" was a factor determining eligibility for home help service. While many of the conditions outlined were not important in determining eligibility for home help service, it appears that the presence of a carer has a negative effect. Elderly people are better off without carers when it comes to acquiring home help services. It seems that the carers receive no support for providing services which might otherwise have to be provided by statutory services.

Meals Service

Availability: Ratios

Like the home help service, the meals service supports the efforts of carers in maintaining elderly people in the community. This service is generally provided by a mixture of voluntary and statutory bodies. According to Department of Health data compiled by the NCE (see Table C3, Appendix C), meals are supplied in a number of ways: directly to elderly people, to community centres and clubs, or to voluntary meals services subsidised by the health boards. Meals services are important for elderly people in a number of ways. Apart from their nutritional value, this service often provides opportunities for socialising and for interacting with others. From the carer's point of view the meals service offers the possibility of support and relief from continuous care.

How many elderly people receive meals services? Table 5.17 gives the number of recipients and the ratio of recipients to elderly population for each health board. A total of 11,182 individuals were in receipt of meals in 1990. Greater than 80 per cent of those who receive meals are elderly. When ratios of recipients of meals to elderly in the population are calculated, there is one recipient of meals to every 35 elderly people (i.e. *2.85* per cent of elderly people receive meals service).

TABLE 5.18: Access to meals service - percentage and number

Meals Service		Percentage
1. Access to meals service by referral:	Yes	76.9 (20)
	No	3.8 (1)
2. Referred by:	PHN	38.4 (10)
	Multiple	34.6 (9)
3. Waiting list for service:	Yes	3.8 (1)
	No	65.3 (18)
4. Amount paid by elderly person for meals service:	£1 .00-5.00	11.4 (3)
5. Amount paid:	Weekly	3.8 (1)
	Per Meal	15.3 (4)
	voluntary contribution	7.7 (2)

for elderly people. Only partial meals service is given in 42.3 per cent of CCAs if a carer is present. Full service is given in 11.5 per cent and no service is provided in 7.7 per cent of CCAs when the elderly person has a carer in the home.

Table 5.20 outlines the findings regarding conditions of eligibility. None of the factors listed were always a condition of eligibility. As is evident from Table 5.20 factors that were sometimes conditions of eligibility included “must be incapacitated” (38.4 per cent) and “must be living alone” (34.6 per cent).

TABLE 5.19: Priorities for providing meals service - percentage and number

Priorities	a	b	c	d
1) Urgency or acuteness of medical need	34.6 (9)	23.0 (6)	-	15.3 (4)
2) Age of elderly person	3.8 (1)	53.8 (14)	7.7 (2)	11.5 (3)
3) Financial situation (e.g. ability to pay for certain treatment)	7.7 (2)	30.7 (8)	23.0 (6)	15.3 (4)
4) Level of incapacity of elderly person	57.7 (15)	11.5 (3)	-	7.7 (2)
5) General state of health of elderly person	46.2 (12)	23.0 (6)	-	7.7 (2)
6) Length of time on waiting list	3.8 (1)	11.5 (3)	3.8 (1)	57.7 (15)
7) Carer of elderly person absent	50.0 (13)	7.7 (2)	3.8 (1)	15.3 (4)
8) Need of elderly person other than medical (e.g. social)	23.0 (6)	46.2 (12)	-	7.7 (2)
9) Other “at risk” factors	26.9 (7)	38.4 (10)	3.8 (1)	7.7 (2)
10) The carer of the elderly person is at risk	30.7 (8)	26.9 (7)	3.8 (1)	15.3 (4)
11) Referral	15.3 (4)	26.9 (7)	7.7 (2)	15.3 (4)

a = always a condition in determining the provision of care
b = sometimes a condition in determining the provision of care
c = never a condition in determining the provision of care
d = not applicable
Numbers in parentheses indicate number of CCAs

TABLE 5.20: Conditions of eligibility for meals service - percentage and number

Conditions of Eligibility	a	b	c	d

1) Must be living alone	-	34.6 (9)	19.2 (5)	19.2 (5)
2) Must be living in unsafe or unsanitary housing conditions	-	19.2 (5)	26.9 (7)	26.9 (7)
3) Must have no support from family or neighbours	-	7.7 (2)	38.4 (10)	26.9 (7)
4) Must have medical card	7.7 (2)	19.2 (5)	30.8 (8)	15.3 (4)
5) Must be incapacitated	-	38.4 (10)	15.3 (4)	19.2 (5)
6) Must be means tested for this service (i.e. means of elderly person only)	7.7 (2)	30.7 (8)	19.2 (5)	11.5 (3)
7) Must be means tested inclusive of carer's means and elderly person's means	3.8 (1)	26.9 (7)	15.3 (4)	23.0 (6)
8) Must be on the waiting list	-	11.5 (3)	30.7 (8)	30.7 (8)
9) Must be over 65 years of age	-	15.3 (4)	38.4 (10)	19.2 (5)
10) Must be able to pay for this service	-	11.5 (3)	38.4 (10)	23.0 (6)
11) Must be a home owner	-	-	42.3 (11)	30.8 (8)
12) Must be on disabled persons allowance	-	3.8 (1)	34.6 (9)	34.6 (9)

a = always a condition of eligibility b = sometimes a condition of eligibility
o = never a condition of eligibility d = not applicable
Numbers in parentheses indicate number of CCAs

Day Centres

Availability and Accessibility

Day centres cater for social, nutritional, medical and other needs of elderly people in the community. The day centre service operates throughout the country, with many centres funded by the health boards and others funded by

groups such as diocesan social services. All provide a range of services that benefit the carer through the range of services they offer elderly people. Their availability and accessibility is reported in Table 5.21.

There are 20 CCAs which provide day centre care catering for social and nutritional needs. Access to these day centres is by referral (80.7 per cent), the referee being PHNs (11.5 per cent), self-referral (7.7 per cent) and through multiple combined sources (57.7 per cent). No waiting list operates in 57.7 per cent of CCAs, compared to 19.2 per cent which do have a waiting list.

A second type of day centre is that funded by a health board which cater for social and medical needs. This type of day centre is available in 14 CCAs.

TABLE 5.21: Availability and accessibility of day centres funded by health boards and those funded by other sources - percentage and number

		Health board funded centres for:		Day centres not funded by health boards
		a)Social and Nutritional Needs	b)Social and Medical Needs	
1. Number of CCAs where available	76.9	53.8 (20)	57.7 (14)	(15)
2. Access by referral:	Yes	80.7 (21)	46.2 (12)	38.4 (10)
	No	-	3.8 (1)	
3. Referred by:	GP	- (2)	11.5 (2)	7.7
	PHN	11.5 (3)	11.5 (3)	3.8 (1)
	Self	7.7 (2)	-	
	Multiple	57.7 (15)	15.3 (4)	34.6 (9)
4. Waiting List:	Yes	19.2 (5)	19.2 (5)	7.7 (2)
	No	57.7 (15)	26.9 (7)	30.7 (8)

Access is by referral (46.2 per cent), referees being GPs and PHNs (11.5 per cent) and through multiple sources (15.3 per cent). A waiting list operates for access to these day centres in 19.2 per cent of CCAs, compared to 26.9 per cent of CCAs which do not

operate a waiting list.

Day centres funded by other sources are available in 15 CCAs. Access to this type of day centre is by referral (38.4 per cent). The referral is most likely from multiple combined sources (34.6 per cent), from GPs (7.7 per cent) and from PHNs (3.8 per cent). No waiting list operates for access to these day centres in 30.7 per cent of CCAs, compared to 7.7 per cent which do have a waiting list.

Some form of day centre service is available in greater than 53 per cent of CCAs. Conditions of eligibility were examined for day centre service (see Table C4, Appendix C), and were found to be not applicable in most cases. Of interest here is the fact that the carer was not considered a factor which determines the provision of service for the elderly person, unlike home help and meals services. Only 23 per cent of CCAs said that the carer was sometimes a factor determining eligibility for day centres catering for the social and nutritional needs of the elderly person.

Transport Services

Availability and Accessibility

An efficient and comprehensive transport system is necessary if elderly people are to avail of the services that are provided by the health boards These services include access to day hospitals and day centres, access to out patient departments and other hospital services, among others. As O'Mahony (1986) points out in her study of transport, one of the difficulties for many elderly people and carers is the lack of transport or lack of an adequate transport system to enable them to access services such as those noted above What transport service exists throughout the health care system and what level of transport is necessary for elderly people to be able to make effective use of health board services? Table 5.22 presents some interesting findings.

Transport is necessary for elderly people to avail of out-patient departments (38.5 per cent). However, transport for this service is provided only by 26.9 per cent of CCAs. Where transport is provided for out-patient services it is provided by statutory bodies such as the health boards (19.2 per cent) and funded by statutory bodies (19.2 per cent). Transport for out-patients is fully funded for this service in only 15.3 per cent of CCAs. A similar pattern of

TABLE 5.22: Availability of transport service for selected services - percentage and number

Service	Transport necessary to avail of services		Transport provided	
	Yes	No	Yes	No
1) Out-patients departments	38.5 (10)	-	26.9 (7)	19.2 (5)
2) Day hospitals	30.8 (8)	-	26.9 (7)	7.7 (2)
3) Day centres for social / nutritional needs	38.5 (10)	3.8 (1)	34.6 (9)	3.8 (1)
4) Day centres for social / medical needs	30.8 (8)	-	26.9 (7)	7.7 (2)
5) General practitioners service	7.7 (2)	30.8 (8)	3.8 (1)	34.6 (9)
6) Hospital services	34.6 (9)	3.8 (1)	30.7 (8)	7.7 (2)

Numbers in parentheses indicate number of CCAs

transport availability and provision emerges for day hospitals and day centres. Transport is necessary to avail of these services but provided in a relatively small number of CCAs. Where transport is available, statutory bodies are responsible for providing the funding, with voluntary bodies and private bodies both providing and funding transport on a smaller scale.

Where hospital services are concerned transport is necessary to avail of services in 34.6 per cent of CCAs and is provided in 30.7 per cent of CCAs. Transport for hospital services is provided and funded by statutory bodies in 19.2 per cent of CCAs, and is fully funded for cost in 23 per cent of CCAs.

The discrepancy that exists between the need for a service such as transport and the service provided creates problems for both carers and elderly people. Services such as those outlined above cannot be availed of which creates considerable strain on carers. The provision of transport does not meet the reported need for service.

Summary and Conclusions

The elderly population is expanding. The response to this has been a greater

emphasis on community care and on maintaining elderly people in the community. The carers are the lynch pins in such a system, volunteering their services and thereby enabling community care to work effectively. The literature indicates that rather than complementing and extending community-based service provision for elderly people, the carers often find themselves viewed as a substitute for statutory care. As the number of elderly people increases, carers will require greater levels of support, practical help, advice and information from the statutory servtce.

A number of community-based health professionals extend many practical and supporting services to carers, particularly GPs and PHNs, while additional support is provided by chiropodists, occupational therapists, physiotherapists, and social workers. GPs are available and directly accessible to elderly people and their carers. However, a cause for concern is that as seen by the director of community care, while GPs acknowledge the importance of carers in maintaining elderly people in the community, the carer is rarely a priority in decisions about provision of care for the elderly.

PHNs are also available and accessible throughout the health care system. Variation in the ratios of PHNs to elderly from health board to health board means that nursing services provided are quantitatively better in some areas than others. This service is so over-stretched that PHNs reduce the services they provide if a carer is present. Even though the carer is a priority for PHNs in determining care for the elderly person, the reality for the carer is that their presence adversely affects the practical help and support they get from PHNs.

Chiropodists, OTs and physiotherapists are available and accessible throughout the health care system. Social workers while available are not directly accessible to elderly people or their carers because their resources are focused primarily on children. Ratios for physiotherapists and for OTs in particular are cause for concern. There is great variation across health boards in the provision of OTs which means that this service is poorly provided for in some health boards. These community-based services provide a variety of specific and necessary services to elderly people which enable them to remain in the community. The presence of a carer appears to have little effect on the provision of chiropody, occupational therapy, or physiotherapy.

Domiciliary support services are available for elderly people in the form of home help and meals services. These indirectly benefit carers in many ways. However, only a small percentage of the elderly population avail of these services and therefore few carers obtain any respite from caring through these services. Factors affecting the provision of these services include assessment

of the health of the elderly person and whether the elderly person has a carer. However, if a carer is present then most health boards withdraw or offer only a partial service. These services are discretionary and therefore there is no automatic entitlement to them. Eligibility for domiciliary services must be determined before these services are provided. For the most part elderly people are means tested for these services, and here again the carer's means are taken into account when considering whether an elderly person is eligible for domiciliary support services. As with nursing services both domiciliary services examined here are withdrawn or only partially provided if there is a carer present.

Additional community-based supports include provision of day centres and transport to enable elderly people to make use of statutory services. Day centres provide many services to elderly people. They promote social contact, reduce loneliness, relieve caring relatives and provide stimulation to elderly people. In the present study day centres were available in many CCAs throughout the health system. No waiting list operates for their services though access to them is mostly by referral.

In order to be able to avail of these services elderly people often require transportation. Transport is necessary in most cases to avail of out-patients day hospitals, day centres and other hospital services. In most CCAs transport is not provided, however. This means that carers find themselves having to fill the breech, and incur additional expenses. *The Years Ahead* recommends that health boards ensure that adequate transport arrangements exist to give elderly people access to these services. It appears that the majority of health boards have still not addressed this issue.

Community-based services appear to offer little direct or indirect support to carers. While health boards acknowledge the importance of carers to maintaining elderly people in the community, the reality is that they penalise carers for doing so by withdrawing practical help and support. Carers represent a considerable cost saving to the health services if the cost of maintaining elderly people in institutional care is calculated. It is desirable that statutory bodies consider investing some of these savings in developing carer services to facilitate a transition from espoused community care to actual community care.

CHAPTER SIX

Direct Support Services For Carers

Introduction

The focus of this chapter is on profiling the direct voluntary sector services that exist for carers. To this end, a nationwide survey was undertaken to elicit names of groups which provide services for carers, and a considerable amount of fieldwork involving interviews was also carried out. It is the results of this survey and fieldwork which form the basis of findings reported in this chapter.

Groups which supply services to carers are profiled in terms of their level of involvement in providing support to carers. Separate profiles of the membership of carers' groups, meeting activities, funding and fund raising activities were also drawn up, and sources of funding for carers' groups were identified. It was hoped to highlight the lack of support that exists for carers and the difficulties that carers' groups face in this way.

A further aspect of the survey of support groups for carers was to outline in detail the actual services and activities that carer-support groups provide so as to gain some insight into the services carers require, the demand for these services, and the ability of carers' groups to cope with the demand. The effects of the carer's financial means on the provision of services by carers' groups was also examined to maintain consistency with the indirect services reported in Chapters Four and Five.

Interviews and fieldwork with carers, voluntary groups and health care specialists involved with care of the elderly were carried out since the survey and they also provide the basis for a description of ongoing activities in this area.

A profile of the services statutory bodies provide for carers was also obtained from the respondents in the survey, and the results of this are also presented in this chapter.

Profile of Carers' Groups

The process by which carers' groups were identified is outlined in Chapter Four. An extensive trawl was undertaken in order to identify possible carers' groups by using existing support groups to generate contacts. These groups were then classified according to the degree of involvement they had with carers.

Degree of Involvement with Carers and Distribution by Area

There were 29 valid responses to the direct census. Not all groups which emerged in the study provided support to carers exclusively. Groups could be distinguished in terms of their degree of involvement in providing support to carers. Some groups were involved in supporting carers in a minor way, other groups prioritised the carer and devoted much of their energies to providing services and support. Table 6.1 shows the breakdown of the 29 respondents in terms of the groups' degree of involvement in providing support service to carers.

TABLE 6.1: Degree of group involvement In providing support to carers and number of groups

Degree of Group Involvement	Number of Groups
1) Solely involved in providing support for carers of elderly.	1
2) Involved in providing support to carers of elderly as a major aspect of the group's overall activities.	15
3) Involved in providing support to carers of elderly as a minor aspect of the group's overall activities.	13
4) Not involved in any way with carers of the elderly.	75
TOTAL	104

The most numerous category of carers' group was those involved in providing support to carers of elderly as a major aspect of their overall activities (n=15). Groups which provided support for carers as a minor aspect of their overall activities accounted for 13 of the total. Only one group was solely involved in providing support for carers of elderly people. There were a total of 75

groups surveyed which indicated that they were not involved in any way with carers of elderly people. This suggests that carers' groups are relatively thin on the ground, and that where they do exist, they are more frequently involved with carers as a major concern. The majority (n=16) of groups fall into this category.

Carers' groups are not evenly distributed throughout the country. Leinster and Munster had 12 carers' groups each, while Connaught had three groups and Ulster two groups. There were no carers' groups in the Midlands. Why groups emerge in some areas and not in others is difficult to analyse. It may be the case that carers' groups emerge to redress the problem of gaps in the provision of statutory services in areas where they are most keenly felt, or it may be that carers' groups emerge as a result of the efforts of one or more dynamic individuals who respond to a perceived social need. Carers' groups do not emerge just because there are a large number of elderly in the population. If this were the case, areas such as the Midlands, Connaught and Ulster would have large numbers of carers' groups.

Membership of Carers' Groups

What is the membership of carers' groups, what is the number of carers of elderly in different groups and do the members provide help to carers of elderly? Table 6.2 summarises the responses to these questions.

The majority of carers' groups have a membership of between 11 and 30 individuals (n=16). There are five groups with membership in excess of 30, and two groups with less than 11 members. The number of carers of elderly people in each group was between one and 20 (n=12), with four groups having numbers of carers that exceed 20, and one group having no carers at all. The majority of groups which responded tended to have between one and 20 members who were involved in providing help to carers of elderly people (n=11), with five groups having greater than 20 members supporting carers, and 13 groups providing no data. The majority of members of the carers' groups in this study were not members of the National Carers Association (n=19). Of those who had members in the National Carers Association, two groups had one member and one group had 10 members who were affiliated to this association. Thus, it appears that carers' groups in general are small, with a small number of members. Few of these members are affiliated to the National Carers Association. The majority of groups have carers among their members and the majority of members provide support to carers of elderly people.

TABLE 6.2: Profile of membership in carers' groups

Item		Frequency
1. Number of members in group:	< 10	2
	11-20	8
	21-30	8
	31-50	3
	> 60	2
	Missing	6
2. Number of carers of elderly in group:	0	1
	1-10	9
	11-20	3
	21-30	1
	31-40	1
	> 100	2
	Missing	12
3.Number of members involved in providing help to carers of elderly people:	1-10	9
	11-20	2
	21-30	1
	31-40	2
	>60	2
	Missing	13
4.Are members of group members of National CarersAssociation?	Yes	4
	No	19
	Missing	6
If Yes, how many are members?	1	2
	10	1
	NA	20
	Missing	6

Meeting Activities of Carers' Groups

What happens at carers' groups meetings and how often do they meet? Table 6.3 provides a profile of meetings.

For the most part carers' groups meet regularly (n=25). By regularly, the majority of groups indicate that this means monthly (n=15), while some groups meet more frequently, weekly (n=5) or as often as the need arises (n=2). Meetings are most frequently at night between 7 p.m. and 10 p.m.

TABLE 6.3: Profile of meeting activities in carers' groups

Item		Frequency
1. Does group meet regularly?	Yes	25
	No	1
	Missing	3
If Yes, how often?	Weekly	5
	Fortnightly	1
	Monthly	15
	Every 3 months	2
	Every 6 months	1
	Annually	
	As often as need arises	2
	Other	3
2. Time of Meeting	Morning (before 12 noon)	2
	Afternoon (2-4 p.m.)	4
	Night (7-10 p.m.)	18
	Missing	5
3. Number of members on average who affend meetings	1-10	8
	11-20	13
	21-40	4
	Missing	4
4. Is there an accepted method of cont-acting carers who do not attend meetings?	Yes	15
	No	4
	Missing	8
	NA	2

(n=18). Some groups meet in the afternoon (n=4) while others meet in the morning (n=2). For most groups attendance is up to 20 members (n=21), with four groups having attendance in excess of 21 members. If carers do not attend meetings 15 groups have an accepted method of contacting them. Usually this means phoning carers or getting another carer to call around. Only four groups had no method of contacting carers who did not attend meetings. Most groups describe their group meetings as formal (n=12), while nine groups described meetings as informal, and two groups described meetings as a combination of formal and informal.

A variety of activities are undertaken by carers' groups. Table 6.4 shows that many activities are combined by groups including providing information (n=19), practical problem solving and training (n=10), emotional support

(n=13), therapeutic counselling and guidance (n=8), recreational and entertainment activities (n=7), and educational lectures on health care (n=1 1). Do different types of carers' groups engage in different activities? Table 6.4 also provides a breakdown of group activities by group's degree of involvement in providing support for carers.

Carers' groups which provide support to carers as a minor aspect of their overall activities are less likely to engage in information (n=5), practical (n=2), emotional (n=2), therapeutic (n=1), recreational/entertainment (n=2) and educational (n=3) activities that support carers. In contrast, carers' groups which provide support to carers as a major aspect of their overall function supply information (n=13), emotional support (n=10), practical and

TABLE 6.4: Main group activities broken down by group's degree of involvement in providing support to carers

Activities	Group degree of involvement in providing support to carers			
	Minor	Major	Sole	Total
Information	5	13	1	19
Practical	2	7	1	10
Emotional	2	10	1	13
Therapeutic	1	6	1	8
Recreation/Entertainment	2	5	-	7
Educational	3	7	1	11

educational support (n=7), therapeutic counselling and guidance (n=6) and recreation/entertainment (n=5). The one carers' group which was solely involved in providing support to carers engaged in all the activities listed with the exception of recreational/entertainment activities. Interestingly, irrespective of a group's degree of involvement in providing support to carers few groups provided recreation and entertainment activities for carers of elderly people. This may reflect limited resources or that these groups are more often involved in providing critical advice and support to carers in crisis. It is clear, however; that these groups are active and vibrant and that a network of close contact exists between members.

Funding and Fund Raising Activities of Carers' Groups

Who supports carers' groups and what fund raising activities do these groups engage in? Table *6.5* summarises the data in relation to these questions.

The majority of carers' groups which responded receive no funding (n=13) while some funding is received by 10 of the groups. The level of funding per annum varies from group to group. Two groups receive greater than £1,000, three groups receive between £2,000 and £4,000, one group receives £5,000 and one group receives £10,000. The latter group is identified as a day centre. The source of funding, in most cases, is from statutory bodies (n=8) with one group receiving funds from voluntary bodies, and one group receiving funds from a combination of voluntary and statutory bodies. The majority of groups engage in their own fund raising activities (n=16). These include flag days, jumble sales, sponsored walks and other sporting activities, fashion shows and many others. The quantity of funds generated through such activities is small, however. The majority of groups which responded generate between £100 and £1,000 (n=6), with three groups generating between £1,000 and £3,000, and two groups generating £10,000. These latter groups are day centres, however. Thus, it appears that carers' groups are largely not funded, and forced to rely on their own funding activities to generate moneys to cover running costs. The amount of money generated through fund raising activities is generally small and this, in turn, has implications for the range and extent of services that carers' groups can provide.

Carers' groups which are involved in providing support to carers as a minor aspect of their overall function tend to receive funding from statutory sources (n=5). However; the majority of these groups receive no funding for carers since this is not their major area of concern. Groups involved in providing support to carers as a major aspect of their overall function receive support from more numerous sources, statutory (n=3), voluntary (n=1) and a combination of statutory and voluntary sources (n=1). Again, the majority of groups in this category receive no funding and rely on their own fund raising activities to cover their costs. The group involved in providing services solely to carers, received funding from none of the sources listed. This pattern suggests that carers' groups are cash starved and are low in priority for statutory funding agencies when it comes to allocating funds. These groups function with little or no financial backing providing support services unavailable elsewhere in the health system.

TABLE 6.5: Profile of funding and fund raising activities of carers' groups

Item		Frequency
1.Does your group receive funding in order to carry out its activities?	Yes	10
	No	13
	Missing	6
If Yes, how much funding received per annum?	<£1000	2
	£2000-4000	3
	£5000	1
	£10,000	1
	Missing	7
	NA	15
If Yes, who provides funds?	Statutory	8
	Private	-
	Voluntary	1
	Stat. and Vol.	1
	NA	15
	Missing	4
2. Does group engage in fund raising activities of its own?	Yes	16
	No	S
	Missing	7
	NA	1
If Yes, amount of funds generated per annum?	£100-1,000	6
	£1 000-3,000	3
	£10,000	2
	Missing	7
	NA	11

NA = Not Applicable

Services and Activities Provided by Carers' Groups

Table 6.6 documents services provided by carers' groups. The most frequently provided service is giving information on statutory services to carers (n=17). This service is provided as often as required and a total of 150 carers availed of this service in 1990. Giving information on grants, entitlements etc. to carers is a frequently provided service by carers' groups (n=15). This service is the service most availed of by carers (228 carers in 1990).

Other information-oriented services supplied by carers' groups include giving counselling to carers (n=9), provided occasionally and availed of by 100

TABLE 6.6: Percentage and number for services provided by carers' groups, frequency of provision end number of camm availing of service

	Is service Provided		How Frequently is the Service Provided					No. of Carers	
	Yes	No	Daily	Weekly	1-3 Monthly	6-12 Monthly	as Required	Once Off	Availing of Service
a) Gives information on statutory services to carers	58.6 (17)	3.4 (1)	0.9 (2)	3.4 (1)	10.3 (3)	3.4 (1)	17.2 (5)	3.4 (1)	(150)
b) Gives information on grants, entitlements etc. to carers	51.7 (15)	3.4 (1)	6.9 (2)	3.4 (1)	13.8 (4)	-	13.8 (4)	3.4 (1)	(228)
c) Gives training on physical care of elderly people to carers	34.5 (10)	6.9 (2)	3.4 (1)	-	3.4 (1)	3.4 (1)	6.9 (2)	3.4 (1)	(197)
d) Supplies a sitting service to carers	20.7 (6)	13.8 (4)	-	10.3 (3)	-	-	3.4 (1)	-	(131)
e) Supplies a shopping service to carers	10.3 (3)	17.2 (5)	3.4 (1)	3.4 (1)	-	-	3.4 (1)		- (137)
f) Supplies help in the home where necessary (i.e. housekeeping) to carers	17.2 (5)	17.2 (5)	3.4 (1)	3.4 (1)	-	-	6.9 (2)		- (117)
g) Liaises with statutory bodies on behalf of carers	44.8 (13)	6.9 (2)	6.9 (2)	-	3.4 (1)	-	13.8 (4)	3.4 (1)	(117)
h) Gives counselling to carers	31.0 (9)	10.3 (3)	3.4 (1)	-	6.9 (2)	-	10.3 (3)	-	(100)
i) Provides legal and financial advice to carers	13.8 (4)	10.3 (3)	-	3.4 (1)	-	3.4 (1)	-	-	(35)
j) Supplies and organises respite care for carers	27.6 (8)	13.8 (4)	3.4 (1)	-	6.9 (2)	-	6.9 (2)	-	(117)
k) Organises transport for carers where necessary	31.0 (9)	13.8 (4)	3.4 (1)	-	3.4 (1)	-	10.3 (3)	-	(127)
l) Organises holidays for carers	20.7 (6)	20.7 (6)	-	-	3.4 (1)	-	6.9 (2)	3.4 (1)	(34)
m) Organises outings for carers	13.8 (4)	17.2 (5)	-	-	3.4 (1)	34 (1)	-	-	(80)
n) Lobbies TDs on behalf of carers	31.0 (9)	13.8 (4)	3.4 (1)	-	-	-	10.3 (3)	-	(117)
o) Organises lecture from health care professionals etc. for carers	37.9 (11)	6.9 (2)	-	-	3.4 (1)	13.8 (4)	3.4 (1)	3.4 (1)	(116)
p) Provides a drop-in social service	20.7 (6)	17.2 (5)	3.4 (1)	6.9 (2)	-	-	3.4 (1)	-	(124)

For each question where percentages do not total to 100 per cent this is due to missing values or the questions were not applicable.

carers in 1990, providing legal and financial advice to carers (n=4), provided occasionally and availed of by 35 carers, and organising lectures from health care professionals etc. for carers (n=1 1), provided occasionally and availed of by 116 carers. This suggests that the demand for information among carers we surveyed is high and it also pinpoints the lack of information services in the statutory sector which address the needs of carers.

A number of practical supports are also provided by carers' groups including:

- giving training on physical care of elderly people (n=10), provided occasionally but availed of by 197 carers,
- supplying a sitting service for carers (n=6), provided weekly and as required and availed of by 131 carers,
- supplying a shopping service to carers (n=3), provided as required and availed of by 137 carers,
- supplying or organising respite care for carers (n=8), provided as required and availed of by 117 carers,
- organising transport for carers (n=9), provided as required and availed of by 127 carers,
- organising holidays for carers (n=6), provided occasionally and availed of by 34 carers,
- organising outings for carers (n=4), provided as required and availed of by 80 carers, and finally,
- providing a drop-in social service for carers (n=6), provided occasionally and availed of by 124 carers.

These are services vital to maintaining carers in good health, and are critical to their well-being. Furthermore, these are services which are not provided by statutory bodies. More recently funding from the health boards and the respite grant introduced by the Department of Social Welfare in 1993 have helped towards the provision of some of these services, e.g. respite breaks and a sitting service.

Carers' groups also act as go-betweens for carers and liaise with statutory bodies on their behalf (n=13). This service is provided as is required, and is

of by 117 carers. These groups also lobby TDs on behalf of carers (n=9) and this service was provided to 117 carers.

For all the services supplied by carers' groups the number of carers availing is high suggesting that the demand for the provision of these services is great. It must be remembered that the carers who avail of the activities listed in Table 6.6 are serviced by 29 carers' groups only. The enormity of the work undertaken by such groups in meeting the needs of carers is clearly visible in this context. The most needed services for carers would appear to be advice and information, practical support in day-to-day caring activities, emotional support, and a body with strong political force to plead their case at government level and to liaise with the statutory bodies.

TABLE 6.7: Profile of information services

Item		Frequency
Is there an information service or centre in your area?		
	Yes	10
	No	4
	Missing	15
If Yes does this centre provide information regarding services to carers?		
	Yes	9
	No	-
	Missing	19
	Not Applicable	1

One of the principal needs met by carers' groups is the provision of an information service. Table 6.7 presents the data. Information services or centres were available in their area for 10 of the carers' groups and no information service existed for four groups. Of those information services and centres that existed, nine groups reported that the centres provided information regarding services to carers. Thus, it would appear that information centres do exist and provide some information for carers.

Infonnation from Interviews and Field Contact

In conducting the survey of carers' groups, contact was made with a variety

of sources who, in addition to or instead of completing a questionnaire, provided information on direct support services for carers being undertaken by voluntary groups. Groups which have particularly focused on carers, and have initiated direct support for carers, include the National Carers Association, the Soroptimists, the Alzheimer Society of Ireland, the Irish Wheelchair Association and the Catholic Social Service Conference (CROSSCARE). Initiatives sponsored by these groups include the establishment of support groups, information and advice, self-development and counselling, carer training, and respite in the form of weekend and holiday breaks. These innovations, particularly carer-support groups, are being taken up by community and general hospitals.

Perception by Carers' Groups of Services Provided by Statutory and Non-Statutory Bodies for Carers

In addition to providing a profile of their own activities, respondents in this survey were asked to provide information about services provided directly to carers by statutory and non-statutory bodies. Since carers' groups are in the business of supporting carers then the services they perceive as available are arguably those that are visible, available and have some direct impact on carers' lives. If services are provided by other bodies but are unknown to carers' groups then such services never reach their intended target (i.e. carers) through lack of information. Table 6.8 below documents carers' groups perceptions of services provided by statutory and non-statutory bodies for carers.

Throughout Table 6.8, it is evident that if services exist for carers other than those provided by carers' groups, then carers' groups are not aware of them. The most frequently endorsed available services include day care services (n=14), provided by statutory and non-statutory bodies, information and advice services (n=13) provided by non-statutory bodies, respite care for the elderly person (n=13) provided by statutory bodies, information on availability and entitlements to services for carers (n=12) provided by non-statutory and statutory bodies, and short-term respite services for weekends or short holidays for carers (n=10) provided by statutory bodies. Throughout the remaining items services are not endorsed with a greater frequency than nine groups. Laundry services (n=9) provided by non-statutory groups, home help/care attendant for carer (n=9) provided by statutory bodies and others indicate that many services critical to carers are provided by non-statutory bodies.

TABLE 6.8: Profile of services provided by statutory bodies and non-statutory bodies for carers

	Is Service available?			Who provides service			
	Yes	No	0*	Statutory	Non Statutory	Don't Know	NA
1. confidential drop-in service	13.8 (4)	27.6 (8)	58.6 (17)	-	17.2 (5)	-	82.8 (24)
2. confidential phone-in service	13.8 (4)	27.6 (8)	58.6 (17)	-	10.3 (3)	-	89.7 (26)
3. Information and advice service	44.8 (13)	3.4 (1)	51.7 (15)	13.8 (4)	31.0 (9)	-	55.2 (16)
4. Personal counselling service	24.1 (7)	17.2 (5)	58.6 (17)	3.4 (1)	17.2 (5)	3.4 (1)	78.9 (22)
5. Short-term respite service for weekend or short holiday for csrer	34.5 (10)	10.3 (3)	55.2 (16)	31.0 (9)	3.4 (1)	-	65.5 (19)
6. Holiday away from home for carer	20.7 (6)	27.6 (8)	51.7 (15)	-	20.7 (6)	-	79.3 ((23
7. Transport if necessary for carer to avail of respite or holidav	10.3 (3)	27.6 (8)	62.1 (18)	3.4 (1)	13.8 (4)	-	82.8 (24)
8. Shopping service for carer	10.3 (3)	31.0 (9)	58.6 (17)	-	6.9 (2)	-	93.1 (27)
5.Sining services for carers	20.7 (6)	20.7 (6)	58.6 (17)	-	20.7 (6)	3.4 (1)	75.9 (22)
a) Night sitting service	3.4 (1)	27.6 (8)	69.0 (20)	-	6.9 (2)	3.4 (1)	89.7 (26)
b) Day sitting service	10.3 (3)	20.7 (6)	69.0 (20)	-	13.8 (4)	3.4 (1)	82.8 (24)
c) Weekend sitting service	3.4 (1)	27.6 (8)	69.0 (20)	-	3.4 (1)	3.4 (1)	93.1 (27)
d) Twilight sitting service	6.9 (2)	27.6 (8)	65.5 (19)	3.4 (1)	3.4 (1)	3.4 (1)	89.7 (26)
10. Special nursing services for carer	17.2 (5)	13.8 (4)	69.0 (20)	24.1 (7)	-	-	75.9 (22)
11. Home help/care attendant for carer	31.0 (9)	10.3 (3)	58.6 (17)	31.0 (9)	6.9 (2)	-	62.1 (18)
12. Home improvements for carer	24.1 (7)	17.2 (5)	58.6 (17)	27.6 (8)	3.4 (1)	-	69.0 (20)
13. Financial assistance for carers	17.2 (5)	17.2 (5)	65.5 (19)	24.1 (7)	-	-	75.9 (22)
14. Legal advice for carers	17.2 (5)	13.8 (4)	69.0 (20)	6.9 (2)	10.3 (3)	3.4 (1)	79.3 (23)
15. Laundry service for carers	31.0 (9)	6.9 (2)	62.1 (18)	6.9 (2)	20.7 (6)	-	72.4 (21)
16. continence advice	27.6 (8)	10.3 (3)	62.1 (18)	31.0 (9)	3.4 (1)	-	65.5 (19)
17. Meals servlce for carers	27.6 (8)	6.9 (2)	65.5 (19)	13.8 (4)	13.8 (4)	3.4 (1)	69.0 (20)
18. Transport service for carers	13.8 (4)	13.8 (4)	72.4 (21)	3.4 (1)	10.3 (3)	-	86.2 (25)
19. Respite care for elderly person	44.8 (13)	3.4 (1)	51.7 (15)	44.8 (13)	3.4 (1)	-	51.7 (15)
20. Information centre	41.4 (12)	6.9 (2)	51.7 (15)	10.3 (3)	34.5 (10)	-	55.2 (16)
21. Travel assistance for carers	17.2 (5)	13.8 (4)	69.0 (20)	3.4 (1)	10.3 (3)	-	86.2 25)
22. Information on availability and entitlements to services for carer	41.4 (12)	3.4 (1)	55.2 (16)	13.8 (4)	31.0 (9)	-	55.2 (16)
23. Support groups for carers	44.8 (13)	3.4 (1)	51.7 (15)	-	44.8 (13)	-	55.2 (16)
24. Medical advice for carers	13.8 (4)	10.3 (3)	75.9 (22)	10.3 (3)	3.4 (1)	-	86.2 (25)
25. Day care service	48.3 (14)	-	51.7 (15)	37.9 (11)	13.8 (4)	-	48.3 (14)

26. crisis intervention care	10.3 (3)	13.8 (4)	75.9 (22)	10.3 (3)	-	3.4 (1)	86.2 (25)

* No response

Summary and Conclusions

Only 29 groups emerged from a total of 104 as being involved in providing support services directly to carers - the other groups were still primarily focused on the dependent elderly. Of these, 13 were involved in supporting carers as a minor aspect of the groups' overall function, 15 were involved in supporting carers as a major aspect of their overall function and one group was solely involved in providing support to carers. These groups tend to be concentrated in Leinster, which has 12 carers' groups and Munster, which has 12 carers' groups. Connaught has three carers' groups while Ulster has only two. The Midlands and the North Western areas have the fewest carers' groups.

Carers' groups are generally well organised. Meetings occur on a monthly basis for most groups and the average group has up to 20 members. Most of the members are carers of elderly and the majority of these are not members of the Carers Association. Meetings are generally formal and well attended. If members miss meetings there are accepted methods of contacting them. Group activities at meetings focus on providing information, giving emotional support and providing practical and educational activities for carers. There is a difference between groups with different levels of involvement with carers in terms of activities engaged in. Where carer involvement is major, groups concentrate on giving information and providing emotional support, whereas groups whose involvement with carers is minor concentrate on information provision.

Most groups receive no funding. Those that receive funding tend to gross less than £5,000 per annum and to receive their money from statutory bodies. Those not receiving funding resort to a variety of fund raising activities in order to raise money to cover running costs. The amount generated through such activities rarely exceeds £3,000 per annum. Most of the groups which receive funding from statutory bodies are involved in providing support services to carers as a minor aspect of their overall function.

A variety of services are offered to carers by carers' groups such as information on statutory services and information on entitlements. Other services include organised lectures from health care professionals, holidays for carers, legal and financial advice, counselling, supplying home help and sitting services, giving training on physical care of elderly people and liaising with statutory bodies on behalf of carers. These services tend to be provided as often as they are required. The number of carers who avail of these services is high compared to the number of groups providing services. Generally, full service is given irrespective of the carers' financial means.

When services supplied by statutory bodies were considered, a small number of services were actually available to carers. These included day care service, respite care for the elderly person and information and advice service. These were provided by the statutory services. However, of the 26 services listed (which the pilot study revealed were important services for carers) only three were supplied solely by statutory bodies, 17 were supplied by statutory bodies and also by non-statutory bodies and six were supplied solely by non-statutory agencies. It could be argued that services are available to carers which they do not avail of, or which are unknown to carers' groups. If services are invisible they can have no impact on the plight of carers and cannot provide the support or relief for which they were designed. Clearly, if such gaps in knowledge about services exists then the onus is on service providers to inform those who can benefit from such services.

From the above it appears that provision of services to carers is largely the domain of non-statutory and voluntary groups. These groups are expanding their activities all of the time, and show increasing awareness of carer needs. However, these groups are severely limited in what they can supply because they are not adequately funded. Many groups expressed the view that they could, and would, supply greater services if they had more resources. Until the statutory bodies give some support to carers' group in the form of funding, carers' needs and requirements will remain uncatered for. If statutory bodies were to support carers' groups at a national level by funding small groups to set up services throughout the country, then this would greatly enhance and improve the services provided to elderly people while substantially improving the lot of the carer.

Since the time of data collection the situation for carers and carers' groups has improved somewhat. Support groups have been set up in association with and part funded by health boards and the Department of Social Welfare's respite fund has contributed to the alleviation of carer-stress in many instances.

CHAPTER SEVEN

Key Findings, Analysis and Conclusions

The present study set out to provide an analysis of health and social services which support the carer directly or indirectly. These services were approached from the viewpoint of the carer, and were categorised as indirect services if they were oriented toward the elderly person while indirectly benefiting the carer, and direct services if they were targeted directly to the carer. In describing the existing services, key questions centred around the availability and accessibility of the services - were services which benefited carers, either directly or indirectly available, how were they provided, and were they accessible?

This chapter aims to provide an overview of support services and key findings, rather than a summary of the findings, which can be found at the end of Chapters Five and Six. The findings will first be approached from the viewpoint of the health care system as a whole, which will be followed by a more detailed analysis of community-based services, hospital and residential services, which benefit the carer indirectly, and direct services for carers.

The picture that emerges from the present study is clear, and confirms the issues discussed in Chapters One and Two. In terms of availability, there is very little provision of support services oriented directly to carers and catering specifically for their needs. Such services include information and advice, training, support groups, sitting services, relief and respite care. Most of these services are provided by voluntary bodies, albeit sometimes with funding from statutory bodies. The services which are provided or organised by statutory bodies and which are most relevant to carers, specifically home helps, meals-on-wheels and respite care, are discretionary. Home help and meals-on-wheels rely strongly on voluntary work, although financial support

is provided. It should be noted here of course that financial aid is provided to some carers in the form of a Carer's Allowance, which will be discussed in more detail in Chapter Eight. Community-based and hospital-based professional services most relevant to carers are usually overstretched. They rarely provide visits to the home or other services such as a sitting service which would be particularly helpful to carers. The provision of respite beds and hospital beds specifically for the elderly is inadequate, as is the provision of options for the elderly person upon discharge from hospital.

In terms of accessibility, the most interesting data were those on waiting lists, and on priorities in assigning the service. Here it was found that most services, whether community-based or hospital-based, required referral, and that waiting lists of up to one year were sometimes found for essential services. Priorities in assigning services were overwhelmingly medical, and where a carer was considered, it was often only to reduce or withhold the service if the carer was present. It would seem that not only are support services for carers not provided, but that indirect services to dependent elderly people may also not be provided where there is a carer available (see Chapter Five).

The absence of resources must be acknowledged as being a key factor in the provision of services, making it difficult, if not impossible, to implement many of the government's own recommendations in *The Years Ahead.* However, it is also the case that planning and distribution of resources are not done with the needs of the carer in mind.

Priorities and Decision Making Regarding Indirect Services

Carer Not a Priority in Assigning Services

At every stage in this project the single most striking feature to emerge was that when it comes to the planning and provision of community care services, the carers - through whom most of community care is provided - were not a priority, except in the public health nursing service.

The effect of the presence of a carer in relation to the provision of care to the elderly person was investigated vis-a-vis most services. Of the 17 CCAs which responded regarding the public health nursing service, the absence of a carer was always an important factor in determining the provision of services. Furthermore, for the nursing services, in 20 CCAs the carer's capacity to care was always a priority influencing the provision of service for the elderly

person. Moreover, for the majority of services this priority was not applicable. From the first part of this study, which concentrated on the statutory provision of care for the elderly person living at home, it is quite clear that the carer does not fall within the domain of many health care professionals in determining care provision. This is so despite estimates that the bulk of community care of the elderly is provided by the informal sector *(The Years Ahead,* 1988). Several studies during the past 10 years have repeatedly recognised this fact and have recommended recognition and support services for the non-professional, largely unpaid carer (Blackwell, *et al.,*1992; *The Years Ahead*, 1988; O'Connor and Ruddle, 1988).

In 1989, the National Council for the Elderly (then the National Council for the Aged) stated that "the centre of gravity of care provision must shift more in the direction of the community where three and a half times more elderly are cared for than in institutional care" (NCA, 1989). This is despite the fact that most resources are absorbed by remunerated administrative, institutional and professional service providers. These services would be of limited use without the huge burden of work assumed by carers.

Furthermore, in order to be effective, community care services have to be known about, accessed, availed of, and monitored. The carers are essential to this process, since it is the carer who contacts the GP PHN or chiropodist. They also provide or organise transport for the elderly person to and from appointments with relevant professional personnel. They meet attending professional persons and get instructions regarding medication, use of aids, etc., and also undertake necessary house improvements. This work can involve up to 150 hours a week (BIackwell, *et al.,*1992).

Looking at the demographic projections, the age of carers and the changes in family structure already referred to (Chapter One) and the situation regarding resources (Chapters Three, Five and Six) it is obvious that not only must carers be acknowledged as the key providers of home care of the elderly, but, that the basic thinking surrounding community care needs to change fundamentally to cater for this. Reference has already been made (see Chapter Two) to the importance of carer satisfaction regarding services and to the desirability of including carers at the planning stage.

It is advisable that statutory providers investigate what services carers need to enable them to care for the dependent elderly person at home. In other words, the position of the planning starting point would need to change from an administrative to a within-the-household stance. There is a need to redirect available resources to equip and facilitate carers to care in the home (see

reference to the *"In Safe Hands"* Programme, Chapter Two). Without imaginative intervention, there is a real danger that institutionalisation will become necessary for greater numbers. The current community care policy will not be able to fulfil its basic aim.

Services Reduced or Withdrawn when a Carer was Present

In some cases, services were actually reduced or withdrawn when a carer was present. In the case of home helps, if there is a carer present, in 50 per cent of CCAs only a partial home help service is given, and the service is not provided in 7.7 per cent of CCAs. In the case of meals service, in the presence of a carer, only partial service is provided in 42.3 per cent of CCAs, and no service is provided in 7.7 per cent (see Chapter Five). Although data are not available in this study, it has been suggested that early discharge from hospital is more likely when a carer is present. Such policies place considerable strains on carers.

Predominance of Medical Criteria

Health boards are in the difficult position of having to allocate scarce resources to those services which are in greatest demand within the community care areas. From the data it is clear that pressure on the system not only forces health boards to prioritise service supply, but it also forces professionals to employ certain criteria to determine the extent of care provided. It emerges too that there are differences in the criteria used by the various health professionals involved in deciding the level of services which can be provided to elderly people. This study found that the professional service providers most utilised are PHNs, GPs, chiropodists, geriatricians, physiotherapists and occupational therapists. What is not clear is whether the demand follows supply or emanates from need.

For the most part, those working within the health board system accord most weight to medical criteria in prioritising care, although this varied somewhat between services. The analysis of the data also reveals that most of the above listed service providers are aware of the importance of other factors which affect the elderly person, whether they are social, environmental or psychological. Nevertheless, in decision making medical priorities predominate.

In the case of other health services examined in this study, many of the priorities had a low rate of endorsement by service providers. With some,

medical priorities assumed importance in determining provision of care, but the vast majority of priorities were reported as not applicable. This suggests that either the priorities listed are inappropriate for decision making criteria for these services or that other priorities operate.

Availability of Service: A Health Service Under Pressure

Scarcity of Resources

Scarcity of resources in the health service is widely recognised, and is the background against which the findings and recommendations must be read. As it operates at present, there are too few health professionals to cope with too many clients/patients. Since health professionals generally, with the exception of geriatricians, do not deal exclusively with elderly people and their carers, it is difficult to assess the adequacy of the health service for elderly clients. Where delays in the delivery of services exist they are due mainly to:

· the size of the elderly population within the health board region

· the inadequate number of health professionals designated to deliver that service

In reading the data analysis of the census for indirect services (see Chapter Five), it is important to realise that the number of elderly people alone who might require any given service, greatly exceeds the number of health care professionals who could reasonably be expected to deal with them. Waiting times of up to one year for appointments are not unusual for some services (e.g., dentists, occupational therapists, opticians, ophthalmologists, psychologists and speech therapists). Other services vital to the care of elderly people in the community are not always available through the health boards at all, e.g., social workers.

Distribution of Resources

The study found considerable variation in the distribution of resources both between health boards and CCAs, and within health board and CCAs. In examining the ratios of service providers to the elderly, there were variations across health boards for GPs, PHNs, occupational therapists and physiotherapists, geriatricians, home helps and meals-on-wheels. Obviously, it was also the case that there was a much greater provision within an area of

some services, e.g., a GP service, compared with others, e.g., geriatricians. All of the services obviously have different functions and different demands are placed on them. However, the distribution of resources, both within areas and between areas, does not seem to reflect the needs of carers.

Lack of Services which Cater for Carers

Services which carers indicate a particular need for are financial assistance (this emerged particularly in field interviews in the pilot study), advice and information, personal support, assistance with the tasks of caring and respite care. These are not catered for by the health boards. Financial assistance is provided only by a Carer's Allowance, and in some cases, services are charged for. Advice and information are provided mostly by GPs and PHNs, but neither of these have the resources to provide proper carer training. Assistance with the tasks of caring is provided mainly by home helps and meals-on-wheels, which reach very few elderly people. Nursing and sitting services are very difficult to obtain outside of regular hours. And there are very few respite beds available for the elderly, and even fewer for carers. Recommendations from *The Years Ahead* regarding all of these services, e.g., that nursing and home helps be available at evenings and weekends, have rarely been implemented, although there are more continence advisers.

The findings of the survey of direct services supports the conclusion that the services which carers specifically need are not being provided adequately by statutory bodies. These services are being provided increasingly by voluntary bodies, as the study of direct services showed. Without support from statutory bodies, they cannot fill the gap left by the absence of carer-oriented services in the health care system.

Lack of Services with a Preventive Orientation

Another point, within the community care system which exists, is the predominance of the medical provision as contrasted with the dearth of occupational therapists and psychologists and the almost total absence of social workers. This deficiency highlights the lack regarding services with a preventive orientation which would address the total functioning of the older person and contribute to a higher degree of non-dependency.

Interdependency with Voluntary Organisations

In examining the funding of direct and indirect services, it was found that

there are a number of ways in which statutory and voluntary services are interdependent. Examples are provided by the home help and meals-on-wheels service, and by the funding arrangements which some of the voluntary groups have established. Again there was considerable variation in these arrangements, and the need for further development of partnerships between statutory and voluntary agencies is indicated.

Co-ordination of Services

Administrative difficulties and difficulties in provision of services are accentuated by the fact that in order to provide an appropriate care service for one elderly person, it may be necessary to deal with the community care service at different levels and in different locations. The list includes the GP the PHN, home help, meals-on-wheels, the local authority for home improvement, the Knights of Malta or ambulance services for transportation, the Society of St Vincent de Paul for financial assistance, the local social services, the local day centre organiser for social contact, and the local day hospital for medical intervention. Hence the stated preference of O'Shea, *et al.* (1991) and Blackwell, *et al.* (1992) for a case management approach to the care of the elderly in the community. The case management approach will be discussed more fully in Chapter Eight. Fragmentation in the organisation of services for groups such as the elderly is addressed in *Shaping a Healthier Future* (1994). Efforts will be made to counteract existing compartmentalisation of services in the immediate future.

Adequacy of Existing Community-Based Support Services

This section details services which support the household of the elderly person receiving care. They complement the work involved in caring within the home and serve to enhance the quality of life of the older person and the carer. Included in this category are the GP, PHN, home help, meals services, transport and day centres.

GPs and PHNs

The present study and other studies of carers indicate that these services are presently the main source of not only medical support, but also information and advice. In *The Years Ahead,* these services are seen as linchpins in the community care system, with the GP being a major source of advice and continuous medical care. The PHN is usually the central organisational figure in mobilising these resources. Like all of the services, they are overstretched,

although neither service appears to operate through a waiting list. However, PHNs in particular are limited by their case load in the amount of support they can provide to carers. In particular, night, weekend and twilight nursing services are of limited availability, although they are of considerable assistance to the carer. Specific continence advisers, although recommended in *The Years Ahead,* were found in only two CCAs.

The Home Help Service

The home help service is of critical importance in maintaining elderly people at home. It helps to ensure the safety and security of the older person and also provides a social contact. Also, it enables the carer to have a break from caring. However, it is available on an extremely limited basis. Furthermore, this study found that the absence of a carer and the poor health of the older person constituted conditions of eligibility for this service. It appears that it is seen as a substitutional service rather than a complementary one by policy makers and planners of health services. Age and financial situation are important considerations in determining the provision of home help, which exclude many who could profitably avail of it.

Meals Service

The provision of the meals service varies dramatically. It does not appear to be a priority in some health boards. This may be due to budgetary difficulties. As with the home help service, the elderly person's level of incapacity and the carer's presence or absence are taken into account when deciding on provision of the service, again indicating a substitutional approach to care in the community.

Day Centres

Day centres are vital to maintaining elderly people in the community. Although they are available across the health boards - both those which cater for social and nutritional needs and those which cater for social and medical needs - day centres have been affected by financial cut-backs and in rural areas by transport problems. Some day centres were being closed down and the service of others reduced. It Is important to note that voluntary organisations and groups are prominent in the provision, funding, maintenance and staffing of these centres. It is possible that many of these groups could expand their programmes with extra statutory funding.

Transport Services

An adequate transport service is central to ensuring quality of life for the elderly. Such a service is inclusive of public transport provision and also of sufficient health board or contracted private transport to make it possible for older people to avail of services offered. Like home help and meals services, transport services are necessary if elderly people are to be maintained in the community. From the data gathered in this study, it appears that transport provided by the health boards does not meet existing needs and this limits the efficacy of health board services.

Hospital and Residential Care

Over the past 25 years, there have been significant changes in the organisation of institutional health services, including long-term care for the elderly: the number of older people in in-patient psychiatric care at any one time has fallen; the scale of acute hospital beds has been reduced since the 1980s; throughput rates in acute and psychiatric beds have increased and out-patient care has increased. The number of long-term care beds for the elderly has increased, and long-term care is more concentrated in a distinct long-term care sector made up of geriatric hospitals, welfare homes, some district hospitals, voluntary and, increasingly, private nursing homes.

While demographic factors will increase the demand for institutional services, particularly long-term care, there is great reluctance among carers and elderly people themselves to resort to institutional placement (see Chapter Three). For both philosophical and economic reasons the use of such placement should be limited in the interests of developing suitable community alternatives. The role of institutional services should continue to be developed through the provision of respite care, and through greater co-operation with and support for informal carers, even after placement. Rehabilitation units should be available in all geriatric hospitals in order to ensure that where possible the elderly person, with the support of the carer, is enabled to continue living in the community as long as possible. The concept of the community hospital should be promoted. Sheltered housing, boarding out and other options for community living have a part to play in complementing the provision of informal care.

In the acute hospital setting, where the treatment of illness in the elderly is more important than at any time in the past, the development of geriatric medicine is vital. It is necessary that liaison between the acute unit, the community care team and carer is kept to the forefront in planning care.

Specialist departments in hospitals providing treatment for the elderly should of the ill and dependent in the community and should be developed further. It also be in close liaison with the carer. This is not easy to achieve. The provision of day hospitals is an essential component of support for the carers is encouraging to see that informal care can be combined with the work of day hospitals, without any apparent tendency of carers to opt out. As with other areas of support for carers, the effect might be to improve the quality of the carers' contribution and their own quality of life.

The importance of developing post-acute support at home, with links to hospital-based geriatric services, is underlined by recent trends in hospital throughput. The average length of stay in hospital in 1989 was 10.2 days for the 65 to 74 year age group and 14 days for the 75 plus age group. This compares with 20 days for the 65-74 age group and 27 days for the 75 plus age group in 1976. Policy regarding hospital beds, therefore, is a major concern of health care workers in the community and for carers who may not be equipped to provide nursing services.

The examination of institutional care services, and particularly long-term care services, highlights the needs of those carers in the community who care for the most heavily dependent. We have seen that, even at the highest levels of dependency, informal care is an essential component of community care. These carers must be the focus of special attention in the formulation of policy and delivery of services in the community.

Direct Services for Carers

This study found that at the time of data collection, direct services for carers were mostly provided by non-statutory bodies and voluntary groups. The only statutory service targeted directly at carers at that time was the Carer's Allowance, which is available to carers of certain recipients of long-term social welfare payments. Some of the services discussed, while targeted at the elderly person and accessed through him or her, may support the carer directly. For example GPs and PHNs do provide advice and information to carers, and home helps may provide social support.

There is a small but increasing number of voluntary carer-support groups. This study surveyed 29 such groups nationwide, concentrated in Leinster and Munster. Areas such as the Midlands and North West have few carer-support groups despite having a large percentage of older people in the population. These groups tend to have a small membership and to meet frequently. Their main activities are providing information on services and entitlements to

carers, giving emotional support, practical advice and training, and organising relief for carers. Since the completion of the study a number of support groups have been established.

Lack of funding is a serious limitation on activities by carer-support groups. Most groups report that they receive no funding from statutory bodies and meet their running costs by engaging in a variety of fund raising activities.

Carers' groups provide a variety of services to carers. Generally, the take up of services by carers is high, given the small number of groups which supply these services. Services most in demand by carers are information on services, emotional support, followed by practical services and finally political liaising and advocacy interventions (see Chapter Six). These are the services most demanded of carers' groups and most frequently provided by them. For most carers' groups the financial status of the carer is not an important issue in determining whether services will be supplied.

When carers' groups were asked to indicate which services were provided by non-statutory and voluntary groups, it was found that when it came to direct services for carers, the majority were provided by non-statutory bodies with a strong voluntary input.

If carers of elderly people are to receive adequate support for the service they provide then some statutory provision needs to be made for them. Those best equipped to help in shaping services for carers are carers themselves since they have a clear understanding of the difficulties and problems of caring and of their own needs. The statutory agencies cannot be expected to have the same insight into the problem since in providing health care their attention is much more widely focused on the global health needs of the community. As with the meals service, however, statutory agencies could contract out the provision of support services for carers to specially organised groups with a number of carers as members. By undertaking a close examination of the day-to-day reality of caring in the home, these groups would more likely focus on and practically address the needs of the carers.

Summary and Conclusions

In *Health - The Wider Dimensions*, a consultative statement on health policy which was published in 1986, statements important to our study were made. The authors state that "Primary health care will be regarded as the central component of the health care system supported by well organised and efficient

secondary and continuing care sectors" (p.29). The meaning of primary health care is clearly defined. It will "incorporate a comprehensive, integrated, multi-disciplinary provision of care for individuals, families and communities. It is not confined to medical care and curing but also encompasses prevention, health promotion, rehabilitation and a range of personal social services" (p.30).

The working party on the policy document for the elderly *The Years Ahead,* undertook to spell out what was involved in a comprehensive system of primary care. They were quite unambiguous in their recognition of the part played by carers in caring for dependent elderly people at home and in their recommendations regarding support for carers. Yet this study found that support services for carers were almost non-existent.

The findings of the study confirm the trends identified in the literature review. Carers in this country, as elsewhere, remain largely unidentified as a population. Support services for carers are largely unavailable, and if available, are made difficult to access particularly by the policy of reducing services where a carer is present. The lack of service can be seen as due to a combination of factors. In particular, lack of resources is an obvious reason for lack of availability. However, the other factors outlined in Chapter Two must also be seen to play a part, especially given the findings regarding priorities in providing access to services.

The preparatory work and the meetings set up before and during the pilot study for the direct services survey, indicate that the climate is undoubtedly changing. Statutory services especially health and social welfare are recognising the importance of carers, more carers are allowing themselves to express their frustration and anger at their growing perception of lack of support, and more non-statutory and voluntary groups are recognising and catering for the specific needs of carers.

CHAPTER EIGHT

Authors' Recommendations

The Policy of Community Care

As already said in Chapter One, the basic principle underlying community care is the desirability of enabling elderly people to remain at home at an optimum level of health and independence rather than institutionalising them. There appears to be general agreement on this. The NESC report (1987) warns that "community care cannot be presumed to exist - specific policies and interventions are required to create and sustain it". These policies must involve organised provision of services to support carers directly.

However, the present study confirms that while the level and extent of need is growing, policies and interventions are limited and inadequate. Health services are overstretched and under-resourced, and most of community care is provided by the informal sector which is predominantly unrecognised and unpaid, and which may be even further burdened where support services are reduced when a carer is present, or carer services are relied on to substitute for professional care.

To be comprehensive a community care service must acknowledge the mental and social well-being as well as the physical health of the elderly person (Blackwell, *et al.*,1992; Convery, 1987; O'Connor, 1988). Elderly people wishing to maintain a level of autonomy need social/psychological services in addition to medical support services. But the findings of this study highlight the fact that community care here still tends to focus on the physical/medical needs of the elderly and only partially on social and psychological needs.

The findings of this and other studies also show clearly that community care

has focused on the elderly person receiving care, with little provision of support for carers (Twigg, *et al.,*1990a, 1990b; O'Connor and Ruddle, 1988). This has been based to some extent on the assumption that informal care is provided by a network of family, friends and neighbours, an assumption that has not been supported by research (Blackwell, *et al.,*1992; *The Years Ahead,* 1988). Rather, caring is most often provided by one individual, usually a female relative, who receives little or no help from others. Any community care policy, to be effective, must attend to the health and support needs of the carer as well as of the elderly person, especially since resources are limited.

Community care policy must, of course, be developed in the context of demographic and social changes (Chapter One). These trends include a falling birth rate, a growing elderly population with the biggest increase in the oldest sector within this population, and, for a variety of reasons, fewer readily available carers. Broader social trends include changes in the family structure, urbanisation, migration and emigration. Restraint in public finances mean fewer resources are available, making planning and the allocation of resources all the more crucial.

The Value of Providing Support Services for Carers in the Community

The importance and value of providing effective supports in the community can be illustrated by examining the findings of the Blackwell, *et al.* (1992) study which compared the costs of caring for the elderly in institutions and in the community. It was clear from this study that there were a number of ways in which expensive hospitals and institutional resources were being used by elderly people who could be cared for at home if adequate community support was available.

That study found that a considerable number of elderly people in hospitals had low levels of dependency. The present study also noted that many elderly people in long-stay units were there for social reasons. This suggests that expensive hospital and residential resources are being taken up by elderly people who could be in the community.

On the other hand, when elderly people living in the community were studied, it was found firstly that almost one third of the sample were hospitalised at least once in the year previous to the study and this contributed a large cost factor to community care (see Chapter Three). Although most of these admissions were probably for acute care (the study did not ascertain the reasons for admission) it is possible that some of these admissions could have been avoided if adequate community care programmes were in place.

High levels of strain and of psychological stress were found among the family carers in the study (as in other studies). Although a monetary cost was not assigned to this, there was an extended cost in terms of use of health services. Specifically, it was found that 30 per cent of carers obtained high enough scores on a widely used and validated measure of psychological distress which has been repeatedly found to be associated with visits to GPs and use of prescriptions. Finally, the study found that 37 per cent of carers felt that they would no longer be able to care for the elderly person, presumably resulting in hospitalisation or institutionalisation for a large number of elderly people.

In short, this study provided a range of evidence to suggest that the use of hospital and other medical facilities could be considerably reduced if adequate community support was available.

Impact of the Carer on Provision of Services

With the exception of public health nurse and home help services, the presence of a carer and the carer's health were not considered important factors in decisions regarding the provision of services to the elderly person. While public health nurses offer advice and practical support to carers, it is also true that the degree of help offered is reduced because of the presence of a carer. In the case of home helps, very often the service is not provided because a carer is available. If carers are finding that services are not being provided because of their presence, then this has negative consequences in a number of ways. It first of all increases the burden of care with consequent implications for their own health and for their capacity to continue to care. This situation in turn probably has implications for the likelihood that the elderly person will end up being institutionalised. Thirdly, it creates an overall climate where carers may feel resentment from their former caree, thus giving rise to a negative pay-off for undertaking the role of caring in the first place. In the light of limited resources, the tendency to prioritise the provision of services on the basis of the presence or absence of a carer, while understandable, is neither justifiable nor sensible. In availing of the short-term solution, the long-term needs may put even more stress on an already overburdened health service.

In the long run, given demographic trends which will mean a diminishing supply of women in the home full-time, willing to undertake the role of caring, and a diminishing supply of religious for the voluntary sectors, an effective policy of community care will have to anticipate the possibility that the provision of support and incentives for individuals may become a requirement if they are to undertake the caring role.

Support Needs of Carers

In Chapter Two we reviewed evidence regarding the services which carers have expressed a need for. We would like to emphasise, before discussing specific needs, that the carer must be seen as both a partner in the health care of the elderly person, and as a client in his or her own right. The many factors discussed in Chapter Two have tended to obscure both of these, in that the carer is taken for granted, and often does not make demands on the system. Yet carers have intimate and detailed knowledge of the condition of the elderly person for whom they care. It is also the case that carers, particularly older carers, have medical, social, and psychological needs of their own, which arise both from the caring situation and from other factors. In Chapter Two, it was emphasised that different carers have different needs, and that the needs of carers will vary over the duration of caring. Support services must address the specific needs of the individual carer, and must be delivered appropriately to the carer. Information and advice services are obviously crucial in this process. In addition, it must be borne in mind that, as the research reviewed in Chapter Three shows, the caring role continues after institutional placement, with accompanying needs for support for the carer.

In this chapter, we make recommendations aimed at integrating the carer into the health care system as a whole. We address the specific needs of the carers and make recommendations regarding services with this in mind. All recommendations arose from data collection, documentary evidence and field interviews in the pilot study.

Financial Support

That carers receive payment for caring (non-means tested) and that they be accorded pension rights for their time in caring and proper insurance benefits.

Financial support is the need repeatedly expressed by the largest majority of carers, as research reviewed in Chapter Two found and as emerged in the pilot study. It is needed for supplies and equipment, and to obtain relief and respite. This support should be provided directly to carers to use at their own discretion.

Information, Advice and Social Support

That a well advertised information and advice centre be located in each community care area.

The need for information and advice, and indeed training, is again frequently expressed by carers. In particular, carers need to be informed about the medical condition of the elderly person, the treatment and the prognosis. They need advice about all aspects of the caring role, and information about services and entitlements. Many express a wish for training, particularly in relation to incontinence and confusion, and also in relation to lifting and other physical activities, and administration of medical treatments including drugs.

Carers are often isolated, and experience considerable strain as a result of their caring responsibilities. Social supports in the form of visits, counselling, carer-support groups and other services which affirm the carer can all ease the stress of caring.

Respite and Relief

That statutory services further grant-aid local groups to focus on carers' needs - especially to provide sitting services and short-term (half-day, day, weekend) respite.

Carers are often left isolated in the home, having sole responsibility for the elderly person. Relief to carers is provided by visitors to the home who help the carer, particularly PHNs, home helps and meals-on-wheels. There is no doubt that all of these services need to be expanded, as recognised in *The Years Ahead*, to offer twilight, night and weekend services, and also an emergency service.

Respite is provided when the elderly person is taken from the home, or when the carer leaves the elderly person in the home being cared for by someone else. Sitting services fall into the latter category, and again the home help service can be expanded to include this service. Residential respite care is badly needed for elderly persons and for carers. Day centres and day hospitals are another important source of respite.

Respite breaks funded by the Department of Social Welfare (1993, 1994) have proved immeasurably beneficial, and need to be expanded and developed throughout the country.

Variety and Choice of Support Services

Support services should be varied and flexible, and should be oriented toward the specific needs of the carer and responsive to the changing nature of the caring role.

The above supports must be seen as vital services for the carers, in the absence of which unacceptable strains are placed on the person caring. The results of the survey of voluntary groups providing direct support to carers illustrated that a wide variety of supports are relevant and helpful to carers. Help with daily activities of living such as cooking, shopping, and laundry are frequently mentioned. Recreational and entertainment options provide for social needs. Supports can be provided in different ways - respite, for example, need not always be provided in hospital beds, but may be provided by weekend breaks. Information and advice can be provided in a variety of forms. Different supports are needed over time as, for example, dependency is likely to increase, and institutionalisation becomes necessary.

Recommendations for Long-Term Planning and Policy

The Carer as a Key Element in Community Care Provision

Health boards should be restructured to include carers in planning and provision of services, to incorporate them into a definitive policy of partnership in caring.

To a significant extent, community care is dependent for its very continuance on the willingness and ability of the carer to continue to care. The findings of this research agree with the literature reviewed, that it is imperative at this juncture to acknowledge the central and essential position of the carer in caring, to see carers as a necessary resource and to strive to develop their potential by support and training. In agreement with other research studies (O'Connor and Ruddle, 1988; *The Years Ahead,* 1988), the findings of this study indicate the importance of directing thought, time and resources towards the setting up of meaningful partnerships between carers, carers' groups and professionals.

Carers should be seen as significant workers in the caring process and also as a considerable resource. Their expertise, skill and potential should be used and developed in a formal way.

Case Management and Co-ordination of Services

That a case management, carer-centred approach to service provision be adopted and promoted without delay across all health boards.

Co-ordination of services is a recurring problem identified by researchers and practitioners in the area of community care. In contrast to institutionally

based care, and as highlighted in Chapter Seven, services are located at different levels and in different locations and involve co-ordination between formal and informal care providers, with the carer as partner in caring decisions. Care is usually needed over prolonged periods of time during which the medical, social and psychological needs of the elderly person and the carer will undergo changes. The elderly person and/or the carer may also undergo hospitalisation. Given the range and complexity of the services and resources utilised, it would appear that a case management approach to community care is the most effective way to ensure effective co-ordination of services. Such an approach ensures that the complex medical, social and psychological needs of the elderly person and the carer are met by an individually tailored care package. Case management would involve a professional worker undertaking regular assessments of the elderly person and the carer, co-ordinating services based on this assessment, monitoring the outcomes of care provision and modifying the care package accordingly. Regular co-ordination between case managers on the CCA basis would then ensure that gaps in services could be identified and responded to on a coordinated basis.

Case management demands a systemic or holistic approach to the care needs of any individual older person. All professionals and administrators involved are in contact and in consultation regarding their client/patient. This ensures a more personal and effective prescription of care and obviates unnecessary overlap in time or resources. It is recommended that carers be active participants in discussions and planning. Most carers spend many hours on a daily basis providing services to dependent elderly people. They are in constant communication with the elderly person, and have an intimate knowledge of their physical, psychological and social needs. Involvement of carers in case management not only makes effective use of the carer's knowledge of the elderly person's condition, it also provides an important source of support and information for carers.

In addition to their role as informants, carers also obviously provide the vital services that enable the elderly person to continue living at home. Research shows consistently that while carers generally prefer to care for the elderly person at home, and obtain satisfaction from their caring role, this is too often undermined by the continuous stresses and strains which carers report.

Household as the Unit for Planning

That a care-giving household-based model be adopted in the planning and targeting of community care resources.

This will entail reorganisation of the present system of community care involving a fundamental change in attitude regarding the organisation and allocation of resources. In agreement with several studies referred to, the results of this research strongly suggest the advisability of undertaking a holistic approach to the needs of the older person and the carer -physical/medical, social, psychological, spiritual, environmental - and a more systemic strategy in meeting those needs. A combination of the case management method and the client-based approach is recommended. By listening to what dependent elderly people and their carers say they want, services could be shaped to meet individual caring needs. To be successful, the way forward for community care policy is to give users what they perceive they need in the way they want it, within reason, and within budgetary constraints. A proactive rather than a reactive approach could help to economise in some areas, thus releasing funds for other services. For example, it may well be in some cases that regular companionship for the older person together with relaxation therapies - e.g. reflexology - will take the place of medication, and a respite sitting service will help keep carers more healthy and so reduce the demand on the existing health service.

Allocation of Resources

That there be more definite targeting of the specific needs of the long-term dependent elderly and their carers in the community.

The data suggest that the criteria being utilised at present are inordinately influenced by hospital care considerations to the detriment of community-based care.

That the distribution of elderly people across health boards and the spatial spread of elderly people in rural areas be taken into account in budget allocation and resource management.

It is clear from the data that differences exist in the distribution of elderly people across health boards and in the spatial spread of the elderly population. The varying needs resulting from these differences have implications for policy decisions.

That resources be allocated in accordance with the criteria used in this study.

In this study the following criteria were used in order to examine the allocation of resources:

· Ratio of service providers to population of elderly within each health board;

- Waiting lists;

· Evenness of provision of services across health boards;

· Nature of services provided;

· Availability of services on medical card;

· Priorities used to assess the provision of care.

That more adequate records be kept specifically on the elderly population.

The present study indicated a lack of adequate records in CCAs and in health boards. While recognising the pressure on existing resources, this deficiency contributes to the difficulties in making decisions regarding the nature and allocation of services.

Recommendations Regarding Community-Based Support Services

Professional Service Providers

That those services which are most utilised - namely: GP, PHN, geriatrician, physiotherapy and chiropody, continue to be resourced and further resourced.

From the point of view of the carer, night nursing and twilight nursing would be of immense benefit. It may be that PHNs could be relieved of some of the present duties which might more correctly belong to social work and thus be more free to extend the actual nursing service. The introduction and/or expansion of home nursing teams with basic home nursing skills could also be effective. As with the GP in the surgery or during home visits, geriatricians are in a strong position of influence regarding the older hospitalised caree, the carer and all family members. It is recommended that sufficient resources be allocated to geriatric units to enable professional staff to maximise the opportunity presented during hospitalisation. Families could be mobilised to help with caring, where one individual carer is experiencing difficulty.

That professional services such as occupational therapy, social work and psychological services, which are at present under-resourced, be adequately funded.

The above services obviously have great potential for enhancing the quality of life of the older person and of the carer. It is recommended that an investigation be undertaken to try to find out why they are as poorly available as the data indicate. It could be argued that these services would reduce the workload on GPs, PHNs, geriatricians, hospitals, etc. Involving them in acomprehensive case management approach could well change the face of the present picture of community care. Again, reallocation of resources to these professional providers could reduce the demand on others.

That the reasons for so few social workers for the elderly be seriously examined, and that efforts be made to incorporate a realistic number of social workers into the community care system as soon as possible.

As already pointed out, social workers could ease the work burden for public health nurses and allow them more time for nursing care.

Home Help and Meals-on-Wheels

That the provision and support of community-based domiciliary services such as home help and meals service be no longer discretionary.

The discretionary nature of the home help service is pointed out in *The Years Ahead.* Because of the fact that health boards are not obliged to provide or support it, this service is naturally vulnerable at a time of budgetary constraints.

We believe that the home help service is a crucial one in supporting and maintaining the elderly person and the carer, and that more information is needed on this service.

Home helps are a vital component of community care. They provide services whose importance to the elderly person and to the carer should be more fully recognised and which should be resourced on a systematic and consistent basis across community care areas. The provision of home help at present is quite erratic. It varies considerably from health board to health board. Payment is unrealistically low and varied as is the list of recommended duties. As well as improved funding, training for home helps seems essential as well as more standardised conditions of work. The home help programme could also be extended to include a sitting service which would provide respite for carers. It should be reiterated that the presence of a carer should not be the basis for a failure to provide this service.

While the home help service is being provided, it is clear that there are severe strains on the system as it operates. If this critical service is to be maintained, it will be necessary to develop a more uniform and clear job description for home helps and to provide training and education.

At present the meals service is seen largely as a substitute for the carer. It is targeted mainly at people living alone. But its provision would contribute towards easing the burden of care especially for older carers. As a service it is important in enabling the elderly person to maintain their independence, and also towards enabling carers to continue working outside the home.

As the data indicate there is a wide variation from health board to health board in the provision of this service, and as with the home help service its discretionary nature contributes to its weakness.

Transport

That health boards be further funded to improve the provision of transport for elderly people so that they will be in a position to avail of the services provided and that a more flexible approach be adopted towards accessing available transport.

The Years Ahead recommended "that each health board ensure that adequate transport arrangements exist to give dependent elderly people access to day care, day hospitals, and out-patient departments" *(The Years Ahead,* 1988).

The findings of this study indicate the need to implement the above recommendation. Availability of transport has repeatedly been found to be essential for effective community care. The data demonstrate that needs and provision regarding a transport service vary considerably across CCAs. The inadequacy of transport provision in many community care areas, as pointed out in Chapter Seven, limits the efficacy of services provided and also creates problems for elderly people and their carers. It is uneconomical to provide services and then through lack of suitable transport make it impossible to access them. Transport policy should aim to maximise accessibility as well as choice on the part of the elderly person and their carer, and this concretely may involve the provision of direct payment for transport needs as well as a transport service. Elderly people in rural areas are particularly affected by lack of transport options. As O'Mahony (1986) demonstrates in her study, the elderly in rural areas have fewer pubfic transport services available to them although they are more in need of them because of long distances from home to service venues. This point was repeatedly made by service providers

during the pilot study undertaken in the Roscommon CCA of the Western Health Board.

Day Centres

That the recommendation of the authors of The Years Ahead,

> *"that health boards be obliged by law to provide or support day care centres for the elderly, including transport to and from such centres" (The Years Ahead, 1988),*

be implemented as soon as possible.

In her study on day centres Convery (1987) stresses "the enormous potential of day care services within the overall context of community care of elderly persons". She suggests that they be seen as part of a continuum of care options. She argues that they can be critical in maintaining elderly people in the community. She found that the development of day services was being hampered by budgetary restrictions. This finding was borne out in the present study. It appears short-sighted to economise on day centre development, thus negatively affecting older people's health and then being obliged to provide funding for medical and institutional care. From the point of view of this study the more significant benefit of day centres is that respite is provided for the carers, while their dependants are being cared for elsewhere, and that they are refreshed and revitalised through having some time for themselves.

Day centres and transport are closely linked. Without an adequate transport service, day centres cannot be accessed. Convery (1987) claims that the potential of day centres for the health of elderly people has not been realised. There is general agreement that they contribute significantly to the possibility of keeping elderly people in the community - that they are an essential element of community care. They can meet social, psychological and nutritional needs of elderly people in the community and can also economise on the time of health professionals by making it possible for them to see a number of clients in the one location. This study found that although day centres are available across the health boards many were being affected by financial cut-backs and by transport problems. Some were being closed down and the programme in others reduced.

Institutionally-Based Care

That a choice of options in institutionally-based care apart from hospitals be

made available, and that the possibility of providing more short-stay respite be examined.

A variety of options for institutionally-based care, apart from hospitals, form essential elements of community care, including day hospitals, day centres, respite care for the elderly persons and for carers, and residential care. Clearly there is tremendous variation across CCAs in the availability of these options and in the criteria used to allocate resources in these areas. It is clear that there is a need for an extension of the provision of all options. There is a need for a more flexible approach to institutional forms of care. Day hospitals and community hospitals are examples of institutional care which offer more integrated care. Caring regimes in institutions can be developed which can allow the carer to continue participating in the caring process after institutional placement. Respite care calls for special consideration. The national ratio of respite beds to the population of elderly is extremely low. As already stated in Chapter Six, carers were very willing to discuss and consider respite possibilities, during fieldwork. However, those who had no independent income foresaw difficulties for the household, in the loss of the elderly person's pension. There was also concern around transport costs to and from the respite venue and the fatigue experienced in travelling for visits.

Voluntary Services

That selected voluntary bodies be approached and requested, for example, to set up support groups for carers; to undertake training programmes in home nursing skills, to provide a counselling and advisory service and to assume a monitoring and advocacy role.

That voluntary organisations and local voluntary groups which provide support for carers be financially supported by the state.

Community care can only be effective through a partnership between formal services and the voluntary sector, with the voluntary sector being provided with consistent and adequate resources. The provision of meals service offers a clear example of a service provided on a voluntary basis and co-ordinated through the formal system. However, even this service has been unevenly provided and is not always adequate. Apart from this service, which indirectly benefits the carer, this research found that there is a small and increasing number of voluntary groups providing support directly to carers. The Soroptimists are noteworthy here. There can be little doubt that these groups will play an increasingly vital role in community care and that a continued failure to provide effective funding for voluntary groups will have

serious repercussions. Many voluntary groups have been unable to mobilise effectively largely through lack of resources.

The National Carers Association

That a realistic grant be guaranteed for a set number of years to the National Carers Association to enable it to plan, operate and co-ordinate programmes and services for carers.

That each health board appoint a carers' liaison officer to operate between carers/carers' groups and relevant statutory and voluntary groups.

Such an appointment would serve as an acknowledgement of the huge contribution made by carers to the care of the elderly. It would also help to expedite a more personalised and integrated community care service.

Summary and Conclusions

In conclusion, this study found very uneven provision of support services for carers of elderly people living at home. While the documentary research, the fieldwork and the data presented leave no doubt as to the magnitude of the task facing this country to provide an acceptable level of care for the older population, it would appear unwarranted to pre-empt or underestimate our capacity to grapple with the challenge of care with practical courage and imagination, given our tradition and record in caring, and the many current exemplifications of care and self-giving in our people.

Co-operation between all parties involved, the older generation, carers, non-statutory and voluntary groups, and the statutory services, together with good sense and energy in interpreting the signs of the times would make possible a satisfactory and acceptable level of care for dependent elderly people living at home - but only if suitable and adequate support services are provided for carers. This study unequivocally demonstrates that support services are few and far between, therefore, further delay in remedying the situation cannot be countenanced. Policy documents such as *The Years Ahead* (1988), the PESP report (Department of the Taoiseach, 1991), the studies on carers by O'Connor, *et al.* (1988) and Blackwell, *et al.* (1992) together with this study, all agree that services have to be provided. Studies have indicated what carers need and want. Since so few services exist, any of the above recommendations could be chosen as a starting point. Co-operation between statutory agencies, non-statutory and voluntary organisations, and local groups could expedite matters, and make the best possible use of existing resources.

APPENDIX A

Content of the Indirect Census Form

The final version of the indirect census forrn was divided into four sections each dealing with specific services. These are outlined below.

Section A: Medical, Paramedical and Other Vital Professional Service Providers to Elderly People in the Community Care Area

This section of the census dealt with the provision of professional services to elderly people by the following professional personnel:

- Audiologists
- Chiropodists
- Public health nurses and other nursing services
- Dentists
- Geriatricians
- General practitioners
- Occupational therapists
- Opticians
- Ophthalmologists
- Physiotherapists

- Psychiatrists
- Psychologists
- Social workers
- Speech therapists

For each profession the following information was elicited:

- The number of individuals providing a service
- Route of access for elderly person to service provider, e.g., through referral and if so by whom
- Demand on service as evident through the use of waiting list for service, the length of time taken to get an appointment and the number of elderly who availed of the service

A number of professional services which are drawn on extensively by elderly people were examined in greater detail, including chiropodists, public health nurses and other nursing services, geriatricians, general practitioners and physiotherapists. These services were regarded as core services and are dealt with separately in the analyses. Degree of availability to medical card holders of specific services provided by these professionals was examined and is outlined below:

- For chiropodists, availability of regular footcare, special shoes and aids, and home visits
- For public health nurses and other nursing specialists, availability of visits, special aids, continence advice and care, and sitting services
- For occupational therapists, availability of visits, equipment to help with everyday life, aids and appliances, and adaptation to the home
- For physiotherapists, availability of visits, treatment for relief of pain/mobility, walking aids, and wheelchairs
- For social workers, availability of visits, counselling assessment and home visits

Twelve priorities for determining the provision of care emerged during the pilot stage. In order to examine how decisions about the provision of care to

elderly are made, each of the 14 professional services were required to indicate whether priorities listed were always, sometimes or never priorities in determining care.

Section B: Provision of Institutional and Residential Care for the Elderly

Elderly people place a considerable demand on the health service in terms of residential and institutional care.

This section of the indirect census focused on eliciting the extent of provision of residential care for medical assessment, short-term and long-term respite, and acute hospital places for the elderly in the community care area.

The following four institutions were investigated:

· Health board hospitals

· Public voluntary hospitals

· Pay hospitals

· Mobile hospitals

A profile of each of these institutions was elicited containing information regarding:

· The number of institutions per CCA

· The number of beds available

· The number of beds available for elderly care

· The number of beds occupied by elderly people

· The number of respite, extended care, day care and crisis intervention beds

Availability of services to medical card holders within each of the four institutions listed was measured with regard to the following services:

· Length of stay

· Tests and assessment

- Out-patient treatment
- Short-term stay
- Extended stay
- Respite care
- Day care
- Crisis intervention

The use of the 12 priorities identified in Section A for determining the provision of care within each of the four institutions listed was also assessed, in order to provide some insight into decision making regarding residential care at the CCA level.

The number of beds available to elderly per CCA and the number of elderly who availed of these beds were examined with regard to the following types of beds:

- Short-term respite beds
- Crisis intervention beds
- Long-term extended care beds

Some of these data are available at health board level.

The following institutions also provide services to elderly people and were examined:

- Day centres funded by the health board catering for social nutritional needs
- Day centres funded by the health board catering for social and medical needs
- Day centres funded by other sources (e.g., diocesan social services)
- Welfare homes
- Boarding out schemes

The following information was required for each of the above institutions:

· Number of institutions in the CCA

· Number of elderly people who availed of the service

· Route of access to service for elderly person, e.g., by referral, and if so by whom

· Waiting list for service

Each of the services outlined in this section was examined in the light of nine conditions of eligibility for institutional and residential care.

While the Department of Health compiles data regarding many of these services at health board level, this study attempted to provide a more detailed assessment of services at a local level by focusing on the CCA.

Section C: Home Improvement Schemes, Home Help Service, Meals Service and Transport Service

Four services were explored in this section and the information gathered under each section is outlined below. These services are vital to maintaining elderly people in the community and are drawn on extensively by elderly people.

1. Home Improvement Schemes

Four home improvement schemes operate which elderly people can avail of:

· The Home Improvement Grant for Disabled Persons

· Remedial Works Scheme

· Essential Repairs Grant Scheme

· Special Housing Aid to the Elderly

The following information was elicited for each of the above schemes:

· Number of people employed to carry out work on the homes of elderly people

· Total budget allocation for improvements

- Maximum and minimum grants available
- Number of elderly in receipt of improvements
- Frequency and type of improvements made
- Number of repairs carried out by local authorities versus those carried out by other contractors
- Number of repairs fully covered for cost versus those partially covered for cost
- The effects of the presence of a carer on the extent of improvements that will be undertaken
- Use of conditions of eligibility in determining provision of grant aid

2. Home Help Service

The following profile was required of the home help service:

- Number of full-time and part-time home helps
- Budget allocation for home help service
- Number of home help co-ordinators in the CCA
- Number of elderly in receipt of home help service
- Number of hours work per day and per week by full-time and part-time home helps
- Number of hours of full-time and part-time home help paid for by health boards and by elderly person
- Hourly rate of pay for full-time and part-time home helps
- Route of access to home help service
- Provision and cost of sitting service
- Use of priorities in determining provision of home help service
- Conditions of eligibility for home help service

3. Meals Service

The following is a profile of the information detailing the meals service:

- Number of people employed by the health board to provide meals to elderly people
- Number of meals supplied to elderly people, to voluntary meals service, to community centres and clubs
- Number of elderly people who receive meals each month
- Number of voluntary bodies subsidised by the health boards to supply a meals service
- Route of access to meals service and waiting list for service
- Amount paid by elderly person for meals service
- Use of priorities in determining the provision of a meals service
- Conditions of eligibility for the meals service

4. Transport Services

The following is a profile of the information sought in this section of the indirect census:

- Number of people employed in the CCA to enable elderly people to travel to and from hospitals, etc.
- Number of people who avail of this service
- Number of ambulances, buses and taxis supplied by both health boards and other contractors to provide transport to elderly people
- Number of groups contracted by the health board to provide travel services to elderly people
- Necessity and provision of transport to avail of selected services
- Provision and funding of transport by statutory, voluntary or private bodies
- Extent of funding of transport service

· Effects of the presence of a carer on the provision of transport service

· Availability of travel assistance, maximum and minimum amounts paid toward travel costs

Much of the information sought in Section C is available at health board level through the Department of Health Statistics. However, in order to fulfil the purpose outlined at the beginning of Chapter Four a more concise level of analysis was necessary.

Section D: Directory of Services for Carers

This section of the census was concerned with eliciting the names and addresses of services and service providers that give support directly to carers in the community. The information sought here included:

· Names and addresses of carer-support groups in the CCA

· Availability of a Community Resource Directory

· Names and addresses of organisations providing any of the following services to carers of elderly people:

Confidential drop-in service

Confidential phone-in service

Information on shopping service

Information on sitting services

Information and advice service

Personal counselling service

Short-term respite care to enable carer to take a break

Holidays away from home for the carer

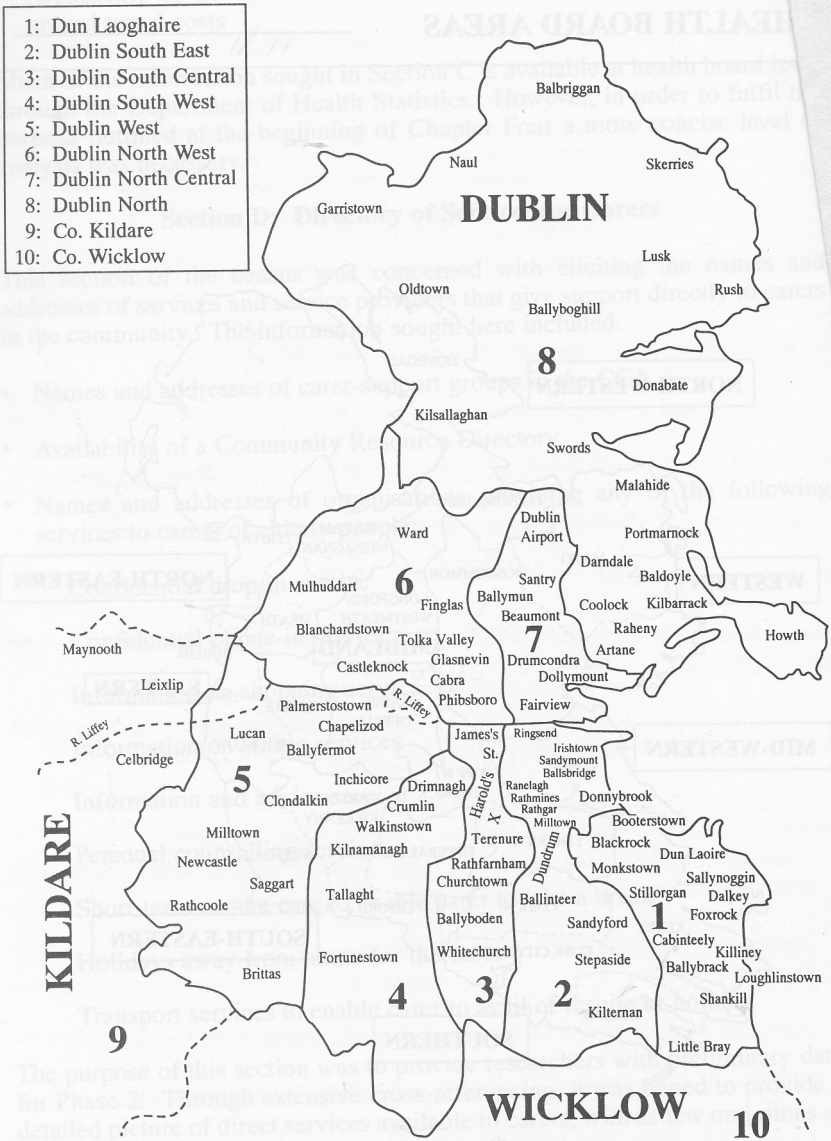
Transport services to enable carer to avail of respite or holiday

The purpose of this section was to provide researchers with preliminary data for Phase 2. Through extensive cross-referencing, it was hoped to provide a detailed picture of direct services available to carers, with as few omissions as possible.

COMMUNITY CARE AREAS ----------

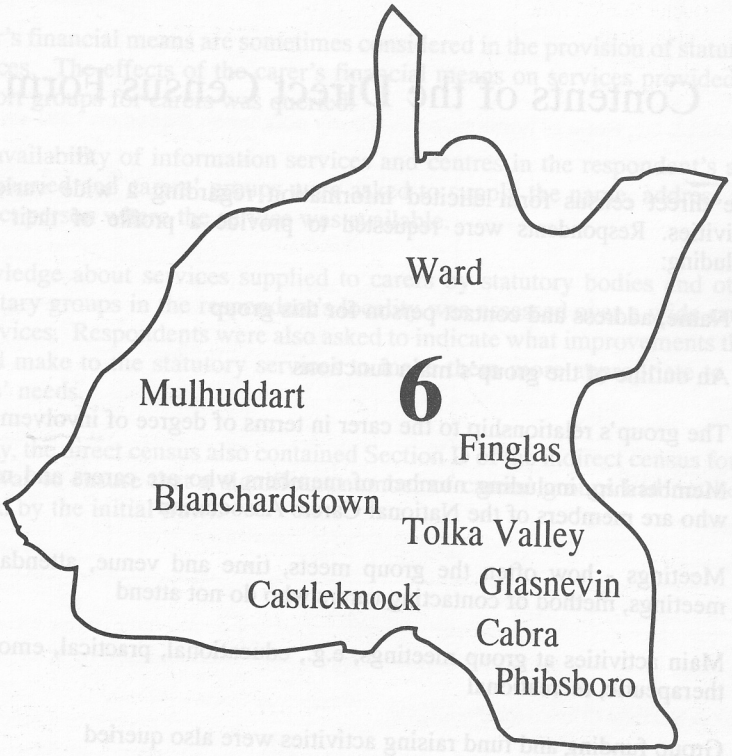
HEALTH BOARD AREAS _____

COMMUNITY CARE AREAS



COMMUNITY CARE AREA 6

Dublin North West



APPENDIX B

Contents of the Direct Census Form

The direct census form elicited information regarding a wide variety of activities. Respondents were requested to provide a profile of their group including:

- Name, address and contact person for this group
- An outline of the group's main functions
- The group's relationship to the carer in terms of degree of involvement
- Membership, including number of members who are carers and number who are members of the National Carers Association
- Meetings - how often the group meets, time and venue, attendance at meetings, method of contacting carers who do not attend
- Main activities at group meetings, e.g., educational, practical, emotional, therapeutic, recreational
- Group funding and fund raising activities were also queried

A detailed investigation of the services and activities provided by the group was included. A list of 16 services and activities was given and respondents were asked to indicate whether the service or activity was provided by them, how frequently the service was provided and the number of carers availing of the services. The sample of the services listed is given below:

- Supplies a shopping service to carers

· Provides legal and financial assistance to carers

· Organises holidays for carers

· Supplies a sitting service to carers

Respondents were also asked to list services supplied by their group not included on the list and to indicate frequency of provision and number of carers availing of that service.

Carer's financial means are sometimes considered in the provision of statutory services. The effects of the carer's financial means on services provided by support groups for carers was queried.

The availability of information services and centres in the respondent's area was queried and carers' groups were asked to supply the name, address and contact person where the service was available.

Knowledge about services supplied to carers by statutory bodies and other voluntary groups in the respondent's locality was assessed over a wide range of services. Respondents were also asked to indicate what improvements they would make to the statutory services to make them more appropriate to the carers' needs.

Finally, the direct census also contained Section D of the indirect census form. This was to ensure that a significant number of carers' groups had not been missed by the initial trawl.

APPENDIX C

TABLE C1: Ratio of home helps to elderly population (based on 1989 data)

Health Board	No. of *home helps	Ratio of home helps to elderly population
1. Eastern	3,305	34
2. Midland	461	51
3. Mid-Western	912	39
4. North Eastern	1,065	31
5. North Western	542	55
6. South Eastern	524	82
7. Southern	1,420	46
8. Western	852	58
TOTAL	9,081	37

* includes those employed by the health boards and those employed by voluntary bodies, part-time and full-time.

Source: National Council for the Elderly

TABLE C2: Profile of home help service by health board in 1989

Home Help Service	Eastern	Midland	Mid-Western	North Eastern	North Western	South Eastern	Southern	Western	Total
1. Number of recipients by category:									
a) The elderly	3,617	427	945	992	845	785	1,863	1,420	10,894
b) Families under stress	525	62	51	49	29	59	66	112	953
c) Physically handicapped	548	182	60	65	62	11	69	93	1,090
d) Others	150	-	123	57	44	28	77	15	494
e) Total	4,840	671	1,179	1,163	980	883	2,075	1,640	13,431
2. Number of home help organisers:									
a) employed by the health board									
Full-time	0	3	4	0	5	3	4	3	26
Part-time	0	0	1	0	1	3	0	0	5
Total	0	3	5	0	6	6	4	3	31
b) employed by voluntary bodies									
Full-time	39	0	1	0	0	0	0	0	40
Part-time	30	0	3	0	0	0	0	0	33
Total	69	0	4	0	0	0	0	0	73
c) Total home help organisers	69	3	9	0	6	6	4	3	104
3. Number of home helps:									
a) employed by the health board									
Full-time	-	14	0	10	19	5	0	59	107
Part-time	287	447	476	1,041	332	519	1,414	793	5,309
Total	287	461	476	1,051	351	524	1,414	852	5,416
b) employed by voluntary bodies									
Full-time	-	0	0	0	0	0	3	0	3
Part-time	3,018	0	436	14	191	0	3	0	3,662
Total	3,018	0	436	14	191	0	6	0	3,665
c) Total home helps	3,505	461	912	1,065	542	524	1,420	852	9,081
4. Number of voluntary agencies in receipt of grants to carry out home help service	36	0	3	4	49	4	6	0	102
5. Finance - cost of service									
a) provided directly by the health board	£226,464	£387,467	£489,000	£242,744	£899,932	£441,521	£933,049	£942,076	£4,562,253
b) provided by voluntary bodies (i.e.. level of grants paid to such bodies)	£2,263,000	-	£418,245	£14,726	£92,582	£1,000	£15,668	-	£2,805,221
c) Total	£2,489,464	£387,467	£907,245	£257,470	£992,514	£442,521	£948,717	£942,076	£7,367,474
6. Rates of pay									
a) Full-time home help organisers	£75 pw	£112.15 pw -£13,937 pa	£8,800 - £12,840 pa	- -	£11,105 - £13,816 pa	£247.60 pw - £14,653 pa	£211.95 pw - £12,295 pa	£10,731 - £13,338 pa	£75 pw - £14,653 pa
b) Part-time home help organisers	£75 pw	-	£65 pw - £762.50 pm	-	£5,552.50 pa	-	-	-	£65 pw - £762.50 pm
c) Full-time home helps	£1.50 - £2.00 ph	£149.98 - £164.34 pw	-	-	£3.75 ph	-	£146.48 - £164.34 pw	-	£1.50 ph £164.34 pw
d) Part-time home helps	£1.50 - £2.00 ph	£5.00- £72..50 pw	£1.50 - £2.16 ph	£1.20 - £1.25 ph	£2.23 ph	£1.00 - £2.50 ph	£0.75 ph	£0.80 ph	£0.75 ph - £72.50 pw

Source: National Council for the Elderly

TABLE C3: Meals service by health board for year ending December31, 1989

Meals Service	Eastern	Midland	Mid-Western	North Eastern	North Western	South Eastern	Southern	Western	Total
1.Number of recipients by category:	5,500	435	14	407	537	1,277	1,215	623	10,008
a) The elderly									
b) Families under stress	-	14	-	5	-	104	6	17	146
c) Physically handicapped	-	27	3	14	8	146	36	5	239
d)Others	-	19	5	-	4	65	73	12	178
e) Total	5,500	495	22	426	549	1,592	1,330	657	10,571
2.Number of voluntary agencies which receive grants to provide a meals service	120	24	1	9	46	24	43	24	291
3. Finance - cost of service									
a) provided directly by the health board	£364,000	£7,395	-	-	£17,400	£47,613	-	£11,655	£448,063
b) grants given to voluntary bodies to carry out the service	£546,000	£56,812	£13,500	£12,700	£69,076	£44,100	£179,640	£65,046	£986,874
c) Total	£910,000	£64,207	£13,500	£12,700	£86,476	£91,713	£179,640	£76,701	£1,434,937

Source: National Council for the Elderly

TABLE C4: Conditions of eligibilify for day centre services - percentage and number

Conditions of eligibility	Day Centres for Social and Nutritional Needs				Day Centres for Social and Medical Needs				Day Centres not Funded by the Health Boards			
	a	b	c	d	a	b	c	d	a	b	c	
1) Must be living alone	-	19.2 (5)	42.3 (11)	23.0 (6)	- (3)	11.5 (5)	19.2 (10)	38.4 (1)	- (2)	3.8 (10)	7.7	3
2) Must be living in unsafe or unsanitary housing conditions	-	26.9 (7)	26.9 (7)	26.9 (7)	- (3)	11.5 (5)	19.2 (10)	38.4 (1)	- (2)	3.8 (10)	7.7	3
3) Must have no support from family or neighbours	-	26.9 (7)	26.9 (7)	26.9 (7)	-	7.7 (2)	19.2 (5)	38.4 (10)	-	-	7.7 (2)	3 (
4) Must be medically at risk	3.8 (1)	19.2 (5)	34.6 (9)	23.0 (6)	3.8 (1)	15.3 (4)	7.7 (2)	38.4 (10)	-	-	7.7 (2)	3 (
5) Must be incapacitated	-	19.2 (5)	38.4 (10)	23.0 (6)	-	19.2 (5)	7.7 (2)	38.4 (10)	-	-	7.7 (2)	3 (
6) Must be means tested for this service	3.8 (1)	11.5 (3)	34.6 (9)	26.9 (7)	3.8 (1)	15.3 (4)	11.5 (3)	38.4 (10)	-	-	77 (2)	3 (
7) Must be referred	38.4 (10)	11.5 (3)	15.3 (4)	19.2 (5)	23.0 (6)	7.7 (2)	3.8 (1)	34.6 (9)	-	-	7.7 (2)	3 (
8) Carer of the elderly person must be at risk	-	23.0 (6)	23.0 (6)	30.7 (8)	-	15.3 (4)	15.3 (4)	38.4 (10)	-	-	11 5 (3)	3 (

a = always a condition of eligibility
b = sometimes a Condition of eligibility
C = never a Condition of eligibility
d = not applicable
Numbers in parentheses indicate number of CCAs

TABLE C5: percentage and number for priorities used to assess the provision of services to elderly people

Priorities	Audiologists				Dentists				Opticians			
	a	b	c	d	a	b	c	d	a	b	c	d
1) Urgency or acuteness of medical need	19.2 (5)	7.7 (2)	3.8 (1)	42.2 (11)	46.2 (12)	-	-	19.2 (5)	34.6 (9)	-	-	23.0 (6)
2) Age of elderly person	15.3 (4)	7.7 (2)	7.7 (2)	46.2 (12)	15.3 (4)	15.3 (4)	11.5 (3)	23.0 (6)	15.3 (4)	7.7 (2)	-	34.6 (9)
3) Financial situation (e.g., ability to pay for certain treatment)	11.5 (3)	11.5 (3)	3.8 (1)	50.0 (13)	11.5 (3)	7.7 (2)	7.7 (2)	34.6 (9)	11.5 (3)	3.8 (1)	11.5 (3)	30.7 (8)
4) Level of incapacity of elderly person	23.0 (6)	15.3 (4)	7.7 (2)	34.6 (9)	26.9 (7)	15.3 (4)	-	23.0 (6)	11.5 (3)	3.8 (1)	11.5 (3)	30.7 (8)
5) General state of health of elderly person	15.3 (4)	19.2 (5)	3.8 (1)	38.4 (10)	23.0 (6)	19.2 (5)	-	23.0 (6)	11.5 (3)	11.5 (3)	3.8 (1)	26.9 (7)
6) Length of time on waiting list	11.5 (3)	23.0 (6)	3.8 (1)	38.4 (10)	11.5 (3)	11.5 (3)	11.5 (3)	30.7 (8)	7.7 (2)	11.5 (3)	3.8 (1)	34.6 (9)
7) Carer of elderly person absent	11.5 (3)	11.5 (3)	7.7 (2)	38.4 (10)	3.8 (1)	7.7 (2)	7.7 (2)	42.3 (11)	7.7 (2)	7.7 (2)	-	38.4 (10)
8) Need of elderly person other than medical(e.g., social)	7.7 (2)	23.0 (6)	-	42.3 (11)	3.8 (1)	11.5 (3)	7.7 (2)	38.4 (10)	7.7 (2)	11.5 (3)	-	38.4 (10)
9) Other “at risk” factors	7.7 (2)	23.0 (6)	-	42.3 (11)	7.7 (2)	15.3 (4)	-	42.3 (11)	3.8 (1)	11.5 (3)	-	42.3 (11)
10) Number of beds available	11.5 (3)	3.8 (1)	-	65.3 (17)	-	3.8 (1)	-	53.8 (14)	3.8 (1)	-	-	53.8 (14)
11) The carer of the elderly person is at risk	7.7 (2)	11.5 (3)	-	57.7 (15)	3.6 (1)	3.8 (1)	7.7 (2)	46.2 (12)	-	7.7 (2)	3.8 (1)	46.2 (12)
12) Referral	11.5 (3)	-	(3.8) (1)	50.0 (13)	-	11.5 (3)	-	46.2 (12)	15.3 (4)	-	-	34.6 (9)

a = always a priority in determining the provision of care
b = sometimes a priority in determining the provision of care
C = never a priority in determining the provision of care
d = not applicable

Numbers in brackets indicate number of CCAs

TABLE C5: Contd…

Priorities	Ophthalmologists				Psychiatrists				Psycologists			
	a	b	c	d	a	b	c	d	a	b	c	d
1) Urgency or acuteness of medical need	38.4 (10)	3.8 (1)	3.8 (1)	23.0 (6)	34.6 (9)	7.7 (2)	- -	26.9 (7)	7.7 (2)	-	-	69.2 (18)
2) Age of elderly person	11.5 (3)	16.3 (4)	11.5 (3)	30.7 (8)	3.8 (1)	15.3 (4)	19.2 (5)	30.7 (8)	-	11.5 (3)	3.8 (1)	57.7 (15)
3) Financial situation (e.g., ability to pay for Certain treatment)	7.7 (2)	3.8 (1)	19.2 (5)	38.4 (10)	-	11.5 (3)	15.3 (4)	42.3 (11)	3.8 (1)	-	3.8 (1)	69.2 (18)
4) Level of incapacity of elderly person	15.3 (4)	11.5 (3)	15.3 (4)	26.9 (7)	11.5 (3)	19.2 (5)	-	38.4 (10)	7.7 (2)	7.7 (2)	-	61.5 (16)
5) General state of health of elderly person	11.5 (3)	19.2 (5)	15.3 (4)	23.0 (6)	3.8 (1)	30.7 (8)	3.8 (1)	30.7 (8)	3.8 (1)	7.7 (2)	-	65.3 (17)
6) Length of time on waiting list	15.3 (4)	19.2 (5)	7.7 (2)	289 (7)	77 (2)	115 (3)	38 (1)	46.2 (12)	3.8 (1)	7.7 (2_	-	65.3 (17)
7) Carer of elderly person absent	3.8 (1)	11.5 (3)	3.8 (1)	50.0 (13)	7.7 (2)	26.9 (7)	-	3.8 (1)	3.8 (1)	7.7 (2)	-	65.3 (17)
8) Need of elderly person other than medical (e.g. social)	3.8 (1)	19.2 (5)	3.8 (1)	42.3 (11)	3.8 (1)	230 (6)	77 (2)	30.7 (8)	3.8 (1)	7.7 (2)	3.8 (1)	57.7 (15)
9) Other “at risk” factors	7.7 (2))	19.2 (5)	3.8 (1)	38.4 (10)	7.7 (2)	23.0 (6)	3.8 (1)	30.7 (8)	7.7 (2)	7.7 (2)	3.8 (1)	57.7 (15)
10) Number of beds available	7.7 (2)	7.7 (2)	-	53.8 (14)	11.5 (3)	19.2 (5)	3.8 (1)	34.6 (9)	3.8 (1)	-	-	73.1 (19)
11) The Carer of the elderly person is at risk	7.7 (2)	3.8 (1)	3.8 (1)	53.8 (14)	-	34.6 (9)	-	34.6 (9)	3.8 (1)	11.5 (3)	-	61.5 (16)
12) Referral	15.3 (4)	7.7 (2)	3.8 (1)	34.6 (9)	19.2 (5)	15.3 (4)	3.8 (1)	26.9 (7)	-	-	-	69.2 (18)

a = always a priority in determining the provision of Care
b = sometimes a priority in determining the provision of Care
C = never a priority in determining the provision of Care
d = not applicable

Numbers in brackets indicate number of CCAs

TABLE C5: Contd...

Priorities	Social Workers				Speech Therapists			
	a	b	c	d	a	b	c	d
1) Urgency or acuteness of medical need	11.5 (3)	3.8 (1).	-	76.9 (20)	42.3 (11)	3.8 (1)	-	30.7 (8)
2) Age of elderly person	3.8 (1)	11.5 (3)	11.5 (3)	61.5 (16)	11.5 (3)	30.7 (8)	7.7 (2)	26.9 (7)
3) Financial Situation (e.g., ability to pay for Certain treatment)	-	7.7 (2)	15.3 (4)	65.3 (17	7.7 (2)	-	19.2 (5)	50.0 (13)
4) Level of incapacity of elderly person	11.5 (3)	7.7 (2)	3.8 (1)	65.3 (17)	11.5 (3)	11.5 (3)	26.9 (7)	26.9 (7)
5) General state of health of elderly person	7.7 (2)	15.3 (4)	-	65.3 (17)	15.3 (4)	34.6 (9)	-	26.9 (7)
6) Length of time on waiting list	-	11.5 (3)	3.8 (1)	73.1 (19)	11.5 (3)	15.3 (4)	7.7 (2)	42.3 (11)
7) Carer of elderly person absent	7.7 (2)	11.5 (3)	7.7 (2)	61.5 (16)	7.7 (2)	15.3 (4)	11.5 (3)	42.3 (11)
8) Need of elderly person other than medical (e.g., Social)	7.7 (2)	15.3 (4)	7.7 (2)	57.7 (15)	15.3 (4)	19.2 (5)	7.7 (2)	34.6 (9)
9) Other ‘at risk” factors	7.7 (2)	11.5 (3)	7.7 (2)	61.5 (16)	7.7 (2)	23.0 (6)	-	42.3 (11)
10) Number of beds available	7.7 (2)	11.5 (3)	-	69.2 (18)	7.7 (2)	3.8 (1)	-	65.3 (17)
11) The carer of the elderly person is at risk	11.5 (3)	11.5 (3)	3.8 (1)	61.5 (16)	7.7 (2)	7.7 (2)	3.8 (1)	57.7 (15)
12) Referral	7.7 (2)	3.8 (1)	3.8 (1)	69.2 (18)	23.0 (6)	7.7 (2)	3.8 (1)	38.4 (10)

a = always a priority in determining the provision of care
b = Sometimes a priority in determining the provision of care
C = never a priority in determining the provision of care
d = not applicable

Numbers in brackets indicate number of CCAs

Bibliography

Abel, E.K., 1989. "Family Care of the Frail Elderly: Framing an Agenda for Change", *Women '5 Studies Quarterly,* 1 and 2.

Action for Carers, 1988. *A Guide to Multi-Disciplinary Support at Local Level,* London: King's Fund Centre.

Arbet; S., Gilbert, N. and Evandrou, M., 1988. "Gender, household composition and receipt of domiciliary services by the elderly disabled", *Journal of Social Policy,* 17, 2.

Aronson, J., 1990. "Women's Perspectives on Informal Care of the Elderly: Public Ideology and Personal Experience of Giving and Receiving Care", *Ageing and Society,* 10, 61-84.

Barer, B.M. and Johnson, C.L., 1990. 'A Critique of the Caregiving Literature", *The Gerontologist,* 30, 26-29.

Bayley, M., 1973. *Mental Handicap and Community Care,* London: Routledge.

Blackwell, 3., O'Shea, E., Moane, G. and Murray, P., 1992. *Care Provision and Cost Measurement. Dependent Elderly People at Home and in Geriatric Hospitals,* Dublin: Economic and Social Research Institute, General Research Series, Paper 157.

Boyd, S.L. and Treas, 3., 1989. "Family Care of the Frail Elderly: A New Look at Women in the Middle", *Women's Studies Quarterly,* 1 and 2, 66-74.

Brody, E.M., 1981. "Women in the Middle and Family Help to Older People", *The Gerontologist,* 21, 471-479.

Butler; R.N., 1975. *why Survive? Being Old in America,* N.Y: Harper Collophon Books.

Cameron, E., Badger; F. and Evers, H., 1989. *Community Care Project Working Papers,* No.19. Health Services' Research Centre, Birmingham: University of Birmingham, Edgbaston.

Campbell, A., Mitchell, S. and Earwicker, 3., 1981. *The Elderly at Home in Hammersmith and Fulham: Report of Research Projecting the Needs of the Elderly,* London: Borough of Hammersmith and Fulham.

Cantor, M.H., 1979. “Neighbours and Friends: an overlooked resource in the informal support system”, *Research on Ageing,* 1, 434-63.

Central Statistics Office, 1969. *Census of Population 1960 Volume VL Housing and Households,* Dublin: Stationery Office.

Central Statistics Office, 1991. *Census ‘86 Volume III, Household Composition,* Dublin: Stationery Office.

Central Statistics Office, 1993. *Census ‘91 Summary Population Report -First Series,* Dublin: Stationery Office.

Centre for Policy on Ageing, 1990. *Community Life: A Code of Practice for Community Care,* London: Centre for Policy on Ageing.

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

Challis, D., Chessum, R., Chesterman, 3., Luckett, R. and Woods, B., 1988. “Community Care for the Frail Elderly: An Urban Experiment”, *British Journal of Social Work,* 18, Supplement, 13-32.

Clifford, D., 1990. *The Social Costs and Rewards of Caring. Avebury Studies of Care in the Community,* Aldershot: Gower House.

Coakley, D., 1982. *Establishing a Geriatric Service,* London and Canberra: Croom Helm.

Comhairle na nOspideal, 1985. *Long-Term Institutional Care - The Medical Aspects - A Discussion Document.* Dublin: Comhairle na nOspideal.

Convery, 3., 1987. *Choices in Community Care: Day Centres for the Elderly in the Eastern Health Board,* Dublin: National Council for the Aged.

Crowley, 5., 1990. “Firms Help Workers Who Help at Home”, AARP *Bulletin,* Vol.31, Washington, April 16.

Daatland, S.O., 1990. “What are Families for? On Family Solidarity and Preference for Help”. *Ageing and Society,* 10, *1-15.*

Dail Eireann, 1991. *Dail Debates,* October 1991, p.338, Dublin: Stationery Office.

Dail Eireann, 1992. *Dail Debates,* 9th June 1992, p. 1873-4, Dublin: Stationery Office.

Daniels, R.S., Baumhover, L.A. and Clark-Daniels, C.L., 1989. "Physicians -Mandatory Reporting of Elder-Abuse", *The Gerontologist,* 29, 321-327.

Department of Health, 1968. *The Care of the Aged: Report of an Interdepartmental Committee,* Dublin: Stationery Office.

Department of Health, *Health the wider Dimensions,* 1986. A Consultative Statement on Health Policy, pp.29-30, Dublin: Department of Health.

Department of Health, 1988. *Long-Stay Geriatric Statistic,* Dublin: Stationery Office.

Department of Health, 1989. *Health Statistics,* Dublin: Stationery Office.

Department of Health, 1990. *Survey of Long-Stay Units,* Dublin: Stationery Office.

Department of Health, 1990. *Health Statistics,* Dublin: Stationery Office.

Department of Health, 1991. *Health Statistics,* Dublin: Stationery Office.

Department of Health, 1992. *Health Statistics,* Dublin: Stationery Office.

Department of the Taoiseach, 1991. *Programme for Economic and Social Progress,* Dublin: Stationary Office, *pp.25-26.*

Donovan, R., 1989. "We Care for the Most Important People in Your Life. Home Care Workers in New York City", *Women's Studies Quarterly,* 1 and 2, *56-65.*

Evers, H., Badger, F., Cameron, E. and Atkin, K., 1988. *Community Care Project,* Working Papers No.28. Health Services' Research Centre, University of Birmingham, Birmingham: Edgbaston.

Giarchi, G.G., 1988. *The Community Care of "Stay at Home" Very Elderly Persons in Three EEC Areas.* E.S.R.C. British Library Document Supply Centre.

Gilligan, R., 1985. *Home from Home: Report on Boarding Out Schemes for Older People in Ireland,* Dublin: National Council for the Aged.

Goffman, E., 1968. *Asylums: Essays on the Social Situation of Mental Patients and Other Inmates,* Middlesex: Pelican.

Goodman, C.C. and Pynoos, 3., 1988. "Telephone Networks Connect Caregiving Families of Alzheimer's Victims", *The Gerontologist,* 28, 602-605.

Government of Ireland, 1990. *Health (Nursing Homes) Act, 1990,* Dublin: Stationery Office.

Griffiths, R., 1988. *Community Care: A Report to the Secretary of State for Social Services. Agenda for Action.* London: H.M.S.O.

Hedley, R. and Norman, A., 1983. *Home Help: Key Issues in Service Provision,* London: C.P.A. Report 1.

Hey, R.P. and Carlson, E., 1991. "Granny Dumping" New Pain for U.S. Elders. AARP *Bulletin,* Vol.32. No.8. Washington D.C., September.

Hughes, B. and Wilkin, D., 1987. "Physical Care and Quality of Life in Residential Homes", *Ageing and Society,* 7, 4, 399-426.

Ingersoll-Dayton, B., Chapman, N. and Neal, M., 1990. "A Programme for Caregivers in the Workplace". *The Gerontologist,* 30, 126-130.

Johansson, L., 1991. "Informal Care of Dependent Elderly at Home - Some Swedish Experiences". *Ageing and Society,* 11, *41-58.*

Kane, N.M., 1989. "The Homecare Crisis of the Nineties". *The Gerontologist,* 29, 24-31.

Kastenbaum, R.J., 1986. *Death, Society and Human Experience.* Columbus, Ohio 43216: Charles E. Merrill Publishing Company.

Kennedy, E, 1989. *Family, Economy and Government in Ireland.* Dublin: ESRI General Research Services.

King's Fund Carers' Unit, 1989. *Doctors, Carers and General Practice,* King's Fund Carers' Unit, King's Fund Centre, London: Tavistock.

Kohner; N., 1988. *Caring at Home.* London: King's Fund Centre.

Kosberg, J.I., 1988. "Preventing Elder Abuse: Identification of High-Risk Factors Prior to Placement Decisions". *The Gerontologist,* 28, 43-50.

Lambert, D.J., Dellman4enkins, M. and Fruit, D., 1990. "Planning for Contact Between the Generations: An Effective Approach". *The Gerontologist,* 30, 553-556.

Lang, A.M. and Brody, E.M., 1983. "Characteristics of Middle-Aged Daughters and Help to Their Elderly Mothers". *Journal of Marriage and the Family,* 193-202, February.

Larragy, J.F., 1993. “Formal Service Provision and the Care of the Elderly at Home in Ireland” in *Journal of Cross-Cultural Gerontology*, Vol.8, No.4, October 1993, 361-379. KIuwer: Netherlands.

Levin, E., Sinclaix; I.A.C and Gorbach, P., 1989. *Families, Services and Confusion in Old Age*, Aldershot: Gower.

Lewis, J. and Meredith, B., 1988. *Daughters Who Care*, London and New York: Routledge.

Malcolm, A.H., 1984. “Some Elderly Choose Suicide over Lonely”, *Dependent Lives.* The New York Times, September 24.

Melcher, J., 1988. “Keeping Our Elderly Out of Institutions and Putting Them Back in Their Homes”. *American Psychologist*, 643-647, August.

Midre, G. and Synak, B., 1989. “Between Family and State: Ageing in Poland and Norway”. *Ageing and Society*, 9, 241-259.

Moane, G., 1993. “Dependency and Caring Needs Among the Elderly”. *The Irish Journal of Psychology*, 14, 1, 189-203.

Montgomery, R.J.V and Borgatta, *E.E*, 1989. “The Effects of Alternative Support Strategies on Family Caregiving”. *The Gerontologist* , 29, 457 464.

Montgomery, R.J.V, 1992. “Examining Respite: Its Promise and Limits”, in *In Home Care for Older People*, edited by M.G. Ory and A.P. Drucker; London and California: Sage.

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

Nash, J.M., 1992. “When Love is Exhausted. The Abandonment of an Elderly Alzheimer’s Patient Highlights the Pressures on Those Who Care the Most”. *Time Magazine*, Vol.139, No.14, p.38, April 6.

National Council for the Aged, 1985b. *Institutional Care of the Elderly in Ireland*, Dublin: National Council for the Aged.

National Council for the Aged, 1989. *Report on its Second Term of Office. June 1984 - May 1989*, Dublin: National Council for the Aged, p.112.

National Economic and Social Council, 1987. *Community Care Services: An Overview* (by Sheila O’Connor), Dublin: National Economic and Social Council.

Nolan, B., 1991. *The Utilisation and Financing of Health Services in Ireland,* Dublin: ESRI General Research Paper, No.155.

Noonan, M., 1983. *Who Cares About the Carers?* Dublin: Council for the Status of Women.

Novak, M. and Guest, C., 1992. "A Comparison of the Impact of Institutionalization on Spouse and Non-Spouse Carers", *Journal of Applied Gerontology,* 11, 4, Dec 1992, 379-394.

O'Connor; J., Smyth E. and Whelan, B., 1988a. *Caring for the Elderly. Part 1: A Study of Carers at Home and in the Community,* Dublin: National Council for the Aged.

O'Connor, J. and Ruddle, H., 1988b. *Caring for the Elderly. Part II: The Caring Process: A Study of Carers in the Home,* Dublin: National Council for the Aged.

O'Connor; J., Ruddle, H. and O'Gallagher, M., 1989. *Sheltered Housing in Ireland: Its Role and Contribution in the Care of the Elderly,* Dublin:
National Council for the Aged.

Ogawa, N., 1989. "Population Ageing and its Impact upon Health Resource Requirements at Government and Familial Levels in Japan", *Ageing and Society,* 9, 383-405.

O'Mahony, A., 1986. *The Elderly in the Community: Transport and Access to Services,* Dublin: National Council for the Aged.

O'Shea, E., Donnison, D. and Larragy, J., 1991. *The Role and Future Development of Nursing Homes in Ireland,* Dublin: National Council for the Elderly.

Parker, G., 1990. *with Due Care and Attention - A Review of Research on Informal Care* (new edition), London: Family Policy Studies Centre.

Pedrick-Cornell, C. and Gelles, R., 1982. "Elder Abuse: The Status of Current Knowledge", *Family Relations,* 31, 457-465.

Phillipson, C., 1990. *Delivering Community Care Services for Older People: Problems and Prospects for the 1990s,* Working Paper No.3. Centre for Social Gerontology: University of Keele.

Pillemer, K.A. and Finkelhor, D., 1988. "The Prevalence of Elder Abuse: A Random Sample Survey", *The Gerontologist,* 28, 51-57.

Pitkeathley, 3., 1989. *It's My Duty, Isn't It? The Plight of Carers in Our Society, London: Souvenir Press.*

Pollitt, P., Anderson, I. and O'Connor, D.W., 1991. "For Better or for Worse: The Experience of Caring for an Elderly Dementing Spouse", *Ageing and Society,* 11, 1991, 443-469.

Reconstruction and Improvement of County Homes, 1951. Department of Health, Dublin: Stationery Office.

Richardson, A., Unell, 3. and Aston, B., 1989. *A New Deal for Carers,* London: King's Fund Centre.

Rossiter and Wicks, 1982. *Crisis or Challenge? Family Care, Elderly People and Social Policy,* London: Study Commission on the Family.

Salvage, A.V, 1986. Attitudes of the Over 75s to Health and Social Services: Final Report. Research Team for the Care of the Elderly, Cardiff: University of Wales College of Medicine.

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

Swiss Reinsurance Co. (UK) Ltd., 1990. *Más Tinn Nó Más Slán Muid,* Dublin: Swiss Reinsurance Co. (UK) Ltd.

Tester, 5., 1989. Caring by Day: *A Study of Day Care Services for Older People,* London: Centre for Policy on Ageing.

The Care of the Aged, Report of an Inter-Departmental Committee, 1968. Dublin: Stationery Office.

The Carer, The Journal of the Carers National Association. 29 Chilworth Mews, London W2 3RG.

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

Thornton, P., 1988. "Creating a Break", Social Policy Research Unit, University of York, *Age Concern.* Institute of Gerontology. Research Paper No.3.

Thorslund, M., Norstrom, T. and Wernberg, K., 1991. "The Utilisation of Home Help in Sweden: A Multivariate Analysis", *The Gerontologist,* 31, 116-119.

Twigg, J., Atkin, K. and Perring, C., 1990a. *Evaluating Support to Informal Carers.* Part 1, Final Report, York: D.H.S.S.

Twigg, J., Atkin, K. and Perring, C., 1990b. *Carers and Services: A Review of Research,* London: H.M.S.O.

Wallace, S.P., 1990. "The No-Care Zone: Availability, Accessibility and Acceptability in Community-Based Long Term Care", *The Gerontologist,* 30, 254-261.

Wenger, G.C., 1990. "Elderly Carers: The Need for Appropriate Intervention", *Ageing and Society,* 10, 197-202

West, P., 1984a. "The Family, The Welfare State and Community Care: Political Rhetoric and Public Attitudes", *Journal of Social Policy,* 13, 4, 417-446.

West, P., Illsley, R. and Kelman, H., 1984b. "Public Preferences for the Care of Dependency Groups", *Social Science and Medicine,* 18, 4, 287-295.

Wicks, M., 1989. "Where does the Government think a woman's place is?" London: *The Independent,* 27.1.

Wilkin, D. and Hughes, B., 1987. Residential Care of Elderly People: The Consumers View, *Ageing and Society,* 7, No.2, June, 175-202.

Wilson, J., 1988. *Caring Together. Guidelines for Carers' Self-Help and Support Groups,* London: King's Fund Centre.

Zarit, S.H. and Whitlatch C.J., 1993. "The Effects of Placement in Nursing Homes on Family Caregivers: Short and Long Term Consequences", *Irish Journal of Psychiatry,* 14, 1, 25-37.