

# Family Care of Elderly People: Australian Perspectives

**Author:**

Kinnear, David; Graycar, Adam

**Publication details:**

Working Paper No. 23  
Reports and Proceedings  
858232553 (ISBN)

**Publication Date:**

1982

**DOI:**

<https://doi.org/10.26190/unsworks/955>

**License:**

<https://creativecommons.org/licenses/by-nc-nd/3.0/au/>

Link to license to see what you are allowed to do with this resource.

Downloaded from <http://hdl.handle.net/1959.4/45269> in <https://unsworks.unsw.edu.au> on 2024-04-20

---

# SWRC Reports and Proceedings

No 23

May 1982

---

## FAMILY CARE OF ELDERLY PEOPLE Australian Perspectives

David Kinnear  
and  
Adam Graycar



Social Welfare Research Centre  
THE UNIVERSITY OF NEW SOUTH WALES

SWRC REPORTS AND PROCEEDINGS

No.23 MAY 1982

Reprinted, March 1983

FAMILY CARE OF ELDERLY PEOPLE

Australian Perspectives

by

David Kinnear

and

Adam Graycar

ISSN 0159 9607

ISBN 85823 255 3

Social Welfare Research Centre  
The University of New South Wales  
P.O. Box 1, Kensington, N.S.W. 2033, Australia

## CONTENTS

### Preface

I	INTRODUCTION	1
	- Dependency	8
	- The Study	11
II	COMMUNITY CARE AND ITS SUPPORT	17
	- Home Nursing Subsidy Act 1956	18
	- Domiciliary Nursing Care Benefit (1973)	22
	- Current Situation	23
III	SURVEY RESULTS	29
	- Dependents and Carers	29
	- Outside Sources of Assistance	34
	- Caring Experiences	39
	- Employment of Carers	43
	- Housing	46
	- Income and Expenditure	46
	- Services Knowledge and Usage	48
IV	CONCLUSIONS AND IMPLICATIONS FOR SOCIAL POLICY	53
	- Day Care	58
	- Respite Care	59
	- Grannysitters/Home Visiting Services	59
	BIBLIOGRAPHY	61

## TABLES

Population Dynamics 1981 → 2001	2
Chronic Conditions per 1,000 Population	3
Average Number of Nurses Employed by Domiciliary Nursing Organisations 1956 to 1981	21
Commonwealth Funding for Institutional and Non-Institutional Services 1975/76 - 1980/81	24
Change in Commonwealth Funding for Institutional and Non-Institutional Services 1980/81 - 1981/82	26
Age of Elderly Person	29
Current Health Problems of Dependent Relative	29
Ability of Dependent Elderly Relative to Perform Daily Living Tasks	31
Composition of Households	32
Carers' Siblings	34
Willingness of Other Relatives to Care	34
Difficulty in Asking for Help	35
Duration of Caring Situation	37
Reasons Why Family Care is Provided	37
Reasons Why Dependent Elderly Relative Began Living with Carer	38
Difficulties Experienced with Caring	39
Changes in Carers' Lifestyle Since Caring Began	42
Health of Carer	44
Length of Time Since Carer's Last Holiday	44
Sources of Income By Persons in Receipt	46
Sources of Household Income	47
Knowledge and Use of Services by Carers	49
Percentage Never Heard of Services	50
Suggestions for Services to Make Family Care Easier	51

## PREFACE

Roughly three per cent of households in Australia contain an elderly person who is a relative of the household head. This family form occurs for a variety of reasons, but the most important of these is the chronic health status of the elderly person. Most elderly people begin living with relatives because of illness and attendant activity limitations for which continuous support and care is necessary and available through family support. This study investigated the costs and difficulties of family care for both the carer and the family and showed that the caring situation was usually established because the elderly relatives either could not look after themselves or needed supervision and care. Data were collected in Sydney and Hobart from a sample of 75 residents and this enabled the study to reflect some perspectives that extended beyond the boundary of one state on the issue of family care. The study found almost 93 per cent of the elderly relatives were aged 75 years and over, with the majority of those being aged 80-89 years. Thus the majority of elderly fell into the category 'old' old and consequently were most likely to be suffering from chronic health problems. This had great negative impact on most social aspects of the carers' life.

The research found that the carers :

- had less time for recreation and leisure activities (79%);
- (in paid employment) suffered a deterioration in work performance (84%);
- had less time to complete housework and allied chores (52%);
- suffered from a deterioration in the relationship with their spouse (56%);
- were less able to relax and sleep at night (60%);
- were apprehensive about their growing older (51%);

Furthermore, the carers'

- relationships with brothers and sisters deteriorated rapidly (90%)
- general emotional state declined (50%)

In short, the pattern that emerged was a marked deterioration in many important areas of the carers' lifestyle.

The study also found that over 95 per cent of the carers were women which demonstrates that family care is, in reality, care by women. Care by women is so firmly entrenched in the family role structure that over 50 per cent of the carers surveyed had given up jobs in order to provide care.

Although family care often invokes a belief that care is shared within the family, our research has shown this is not so. Neither spouses nor children contributed significantly to care for the elderly relative. While many husbands were supportive of their wife's caring role, they felt it was her duty and provided little assistance. This situation also extended to the caring function of relatives. Although over half of the carers had other relatives, only 49 per cent of relatives gave assistance and of these almost 59 per cent were sisters of carers. Thus the traditional caring role assigned to women permeates the whole of the extended family.

An important finding was that over 80 per cent of those caring rejected the possibility of the option of nursing home care and felt that the family should care in the first instance. Some 65 per cent of the carers recognised that nursing home care may be necessary but only when the family had well and truly exhausted its caring capacity. The other 35 per cent flatly refused to consider the idea of nursing home care. Thus our research shows that families have not abrogated their responsibility for care of the elderly and do not seek to displace their elderly to situations of institutional care. Finally, there was much conflict and tension generated amongst immediate family members and within the extended family network. Family care, instead of welding the family together tends to cause rifts and disruptions that ultimately increase the burden of care.

A major implication of the study is that public policy should aim at enhancing and bolstering family care and not regard the family as an institution capable of sustaining its well-being and that of dependent elderly relatives under the onerous burden of care.

This study would not have been possible were it not for the generous donations of time from the seventy-five people whose lives revolve around providing care for a dependent elderly relative. The samples would not have been obtained without the assistance of the administrators of the Bankstown Area Health Centre, the Fox Clinic (Bankstown Council) and the Sydney Home Nursing Service; and without the active support of the home nurses who delivered our letters and gave generously of their time in discussing details of the study when it was in its formative stage. Linda Adamson, formerly a Research Assistant in the Social Welfare Research Centre, worked with the authors in the early stages of the project including the development of the

questionnaire. Linda also assisted with some of the Sydney interviews. For assistance with the Tasmanian sample and for arrangements in Hobart we are grateful to Jan Fisher of the Tasmanian Department of Health. Claire Stevenson of the NSW Carers Association gave us encouragement, as did a large number of people in health and welfare circles. It is to all of the above, and to Joan Phillips who typed the manuscript, that we extend our thanks - for without them there would be no report.



## I INTRODUCTION

The "graying" of Australia's population has been a regular topic of discussion in government, demographic, health, and social service circles in recent years. It has been noted carefully because shifts in population structure, particularly increases in the so called "dependent" populations have serious implications for resource allocation in areas of income support and service provision. Because of varying assumptions about fertility, mortality and immigration, any set of population projections will have many qualifications, and predictive accuracy cannot be expected. However one calculates the projections, Australia's current elderly population (those aged 65 and over) which at present comprises 9.6 per cent of the total population, will rise to between 13 and 14 per cent of the population in fifty years time. This proportion prevails in at least a dozen European countries today (German Democratic Republic, Austria, Sweden, Federal Republic of Germany, France, Belgium, United Kingdom, Norway, Denmark, Switzerland, Czechoslovakia, Hungary) and thus it is not appropriate to say it is necessarily calamitous for Australia to head towards these proportions. Furthermore the progression to these proportions will be fairly steady over the next 50 years, which provides an opportunity for sensitive planning. (For a discussion of recent demographic controversies see Graycar, 1981, p.286-288).

There is, however, an important point to make that concerns not the number of elderly people as a proportion of the whole population, but rather the age distribution within the population aged 65 and more. In 1901, for those aged 65 and over the ratio of those aged 65-74 to those aged 75 and over was 75 : 25; by 1976 it had changed to 64 : 36. Over the same period life expectancy for males had increased marginally - at age 65 it increased from 11 to 13 years; at 70 from 9 to 10 years; at 75 from 7 to 8 years; at 80 from 5 to 6 years. On the other hand the increase for females has been much greater - at age 65 from 12 to 17 years; at 70 from 10 to 14 years; at 75 from 7 to 10 years; at 80 from 5 to 8 years. (These data have been developed by Rowland, 1981a, p.6). The significance of these data is that the dependencies of ageing, which are chronic and cumulative rather than transitional, build up and have the greatest impact as disability combines with age. As people get older living arrangements often become more precarious and this has implications for the elderly people themselves, for the formal service provision system, and for the families of the elderly people.

At a demographic conference in Canberra in September 1981 Professor Borrie presented a series of population projections (W.D. Borrie, 1981). Extrapolating from these projections the following can be noted for four sets of circumstances. All four projections assume that the Nett Reproduction Rate will recover to 1 by 1987 and will remain constant thereafter to 2001. In addition Scenario 1 assumes no migration and mortality down by 1.5 per cent; Scenario 2 assumes no migration and constant mortality; Scenario 3, annual migration of 80,000 and mortality down by 1.5 per cent; Scenario 4, annual migration of 150,000 and mortality down by 1.5 per cent.

Table 1.1

	Scenario 1	Scenario 2	Scenario 3	Scenario 4
Numbers aged 65+ will rise by	800,000	600,000	900,000	1,013,000
Numbers aged 75+ will rise by	500,000	400,000	575,000	625,000
Australia's population will rise by	18%	15%	31%	42%
Population aged 65+ will rise by	57%	42%	64%	70%
Population aged 75+ will rise by	105%	75%	113%	120%
Those aged 75+ in 1981 constituted (percent of aged persons)	36%	36%	36%	36%
Those aged 75+ in 2001 will constitute (percent of aged persons)	47%	44%	47%	47%

Population Dynamics 1981 → 2001

Source : Calculated from Borrie, 1981.

These data indicate that whatever likely assumptions are made, the over 75 population will increase rapidly. Australian dependency ratios, however, are actually declining. In 1901, for every 100 people aged 15-64 (labour force age) there were 64.5 either under 15 or over 65. By 2001 it is projected that this number will fall to 50.7 (see Graycar & Kinnear, 1981, p.96). On the surface this does not indicate a serious situation. With further analysis a different picture emerges. In 1901 those 64.5 people comprised

57.9 under 15 and 6.6 over 65; that is 8.7 children for every elderly person. By 2001 the 50.7 will comprise 35 under 15 and 15.7 over 65, that is 2.2 children for each elderly person. At the demographic conference just cited, Dr. Sidney Sax claimed that public income and service support costs were approximately three to four times as high for elderly persons as they were for children (Sax & Staines, 1981, p.6).

As life expectancy at higher ages increases and as people live longer, there is an accompanying increase in the incidence and extent of chronic and degenerative diseases. Rates of chronic illness in all industrial societies are very high, and Australia is no exception. The Australian Bureau of Statistics released a survey of chronic conditions in July 1980 (ABS Cat. No. 4314.0). The data presented did not disaggregate by age beyond age 65. Consequently there are no separate data on chronicity for those aged 75 and over. Not surprisingly, as Table 1.2 shows, chronic conditions increase in incidence with age. It can be assumed that the incidence for those aged 75 and over is higher than that shown in the table.

Table 1.2  
Chronic Conditions per 1,000 Population

Age	Number of People Experiencing Chronic Conditions per 1,000 Population	Number of Chronic Conditions Experienced per 1,000 Population
under 15	239.2	318.8
15 - 44	416.3	657.0
45 - 64	659.4	1347.7
65+	776.3	1791.3

Source: ABS Australian Health Survey 1977-78 Chronic Conditions  
Cat. No. 4314.0

Not all chronic conditions are themselves limiting and not all create social problems. The ABS survey classified any person aged 65 or more who was confined to bed, confined to home, or needed help in getting out of the house, as somebody who would have an activity limitation. For every 100 people over the age of 65 in Australia, 13 were regarded as having an activity limitation - 15 out of every 100 females and 11 out of every 100 males. Activity limitations mean that people with chronic conditions need some form of social and medical support. It is not known how many people with activity limitations live in institutional care, how many live alone, or how many live with relatives.

Data developed by D.T. Rowland show that in 1979 approximately one half of those aged 65 and more lived with their spouse, approximately one quarter lived alone, 16 per cent lived with other family members or other persons, and 7.6 per cent lived in an institution (Rowland, 1980, p8). The differences between the sexes are striking: 401,400 or 70.3 per cent of elderly males lived with their spouse but only 280,700 or 35.6 per cent of elderly females lived with their spouse; 84,500 or 14.8 per cent of elderly males lived alone, while 269,700 or 34.2 per cent of elderly females lived alone; 33,100 or 5.8 per cent of elderly males lived in an institution while 70,185 or 8.9 per cent of elderly females lived in an institution.

It is of great importance to try to understand the network of services, statutory and non-statutory, formal and informal, which can be developed and blended together to improve the quality of life of the elderly person, whether suffering from a chronic illness or not, whether living alone, with spouse, with other family, or in institutional settings, and also those which might provide support for the families of elderly people.

Many elderly people live with their adult children. This occurs more often than not after many years of the elderly person and her adult children having maintained separate households. While it is often argued that families have been abdicating their caring responsibilities and expecting the state to play the major support role, the evidence does not support this contention. What evidence there is suggests that the families are not at all abdicating their responsibility, but rather they are under enormous pressure because their capacity to deal with and provide adequate care for elderly dependent relatives is diminishing. This relates primarily to economic circumstances which govern income, household size, and most of all,

that precious resource, time - in particular time available to the caretaker to play an economic and social support role. There is often an intense personal situation when households re-form after many years of separation. The arrival of a dependent elderly person (with limitations which make it impossible for her/him to continue to live alone) is disruptive to the household, and data presented below accords with overseas studies which show that relationships and activities in the household deteriorate. Rather than binding the family together, entry into a care relationship can often put great stress on the family, and thus to argue blandly that the family is the best care agent is only to tell part of the story. For families to play an effective caring role, it is essential that they be provided with adequate support. Before examining arguments about support, family structure and dependency, it is necessary to provide a little more data on the dimension of the family care situation as it relates to elderly people.

Working with Matrix Tape 25 of the 1976 Census Dr. Rowland has developed data on multi-generation households in the Sydney urban area (Rowland, 1981b). In Sydney in 1976 10.6 per cent of women aged 60 and over, and 4.4 per cent of men aged 60 and over were an ancestor of the household head or of his or her spouse. This proportion increased with age. For men aged 60-64, 1.9 per cent were ancestors, for those aged 65-74, 4.2 per cent were ancestors and for those aged 74+ it was 9.5 per cent. For women in corresponding age groups ancestors comprised 6 per cent, 9.7 per cent and 16.2 per cent. These figures apply only to Sydney, but if one were to assume that the same proportions prevailed throughout the country there would be at least 160,000 households which contain an ancestor. Many of these would be people with activity limitations. Most would require some support in a care situation. Although 160,000 does not appear to be a great number it must be remembered that this is approximately 3 per cent of all households in Australia. Although Australia is reputed to have the highest rate of institutional care, 55 per cent more elderly people live with adult children than in nursing homes or other institutions. (This is a minimum figure, and falls far short of the estimate made by a NSW Government official and reported in The Sydney Morning Herald on 9/3/82 that "eight times as many old people are cared for in private homes as are in nursing homes or other institutions").

It is the contention of this paper that aged people in the future will probably look more towards the formal system of care and less to their families. This does not suggest any lack of willingness on the part of families to care for elderly people. Rather, by examining data on population projections, chronic illness, and living arrangements, and placing these against data presented below which indicates capacity shortfalls and the structure of dependency, future scenarios will have an increasingly dependent proportion of the elderly population, an increasingly tense family situation within an increasingly difficult family economic environment. Adaptation will occur in some cases, but if an element of dignity and humane concern is to be expressed on behalf of elderly people and carers, a range of policy options and support systems must be planned now. Many families want to look after their elderly relatives but they are not equipped to do so nor do they have the social support they need. What has come through overwhelmingly in our survey is that most families are reluctant to commit their elderly relatives to the care of a nursing home, despite the extreme difficulties that prevail in most caring situations.

The study was undertaken to identify an existing situation and provide data and analyses for future planning. Current debates stress the importance of community care, but resources seldom match rhetoric. The emphasis on community care comes at a time when there is an emerging ideology of non-acceptance of public responsibility in providing services except to the poorest elderly who remain alone and without informal supports (Cantor, 1981). Increasingly the lynch-pin of community care is care by the family.

The amount of family care has been severely understated in recent times, and has given rise to a mythology of negligible family support and an isolated, expunged elderly population that is devoid of family contact (Horowitz, 1978, p.1). Numerous studies over the last decade have largely dispelled this myth although there is some residual truth in it. Increasingly family policies are being aired again in an attempt to bolster the ideology of the family as the most appropriate caring unit. At the same time, however, advocates of family care gloss over the changing pattern of family structure and the change in women's attitudes to family and work. Due to lower birth rates, families today are much smaller. With an average of two children per family the total number of female children is diminishing. Fewer female children throws doubt on the ability of families to provide care as in the recent past. In addition increased female labour force participation

(especially of married women) creates some concern that those generally entrusted with the caring role will not be home to fulfil that role.

Labour force participation rates for women have increased in the past decade from 39 per cent to 45 per cent. While rates for unmarried women are higher than for married women, the fastest growing set of employment opportunities for married women are in the part-time sector, in areas other than manufacturing. This means that with only partial absences from the home family care may still be possible, especially as research by Brody and Cantor has revealed that many women are not abandoning their familial responsibility but rather they either abandon work or attempt to juggle competing roles of wife, mother, worker and carer (Brody, 1980; Cantor, 1981). In fact what is occurring is that women are now assuming greater burdens of caring since working, and are not shedding their loads.

When they were working, elderly people had some means of claiming a modest share of society's gains. In old age their relative powerlessness is increased because they are sidelined from the mainstream of social activity. Even more so old age becomes a battle for resources and in the process of the allocation of resources the elderly are extremely limited in their bargaining position (Fanshel, 1981). Not only is this apparent in areas of income support, but also in service support. The rapid growth in institutional investment led to cost escalations and ultimate questioning on both economic and humanitarian grounds of the appropriateness of institutional care. Relatively powerless to influence events elderly people are likely to be squeezed. The slowing of economic growth and scarcity of resources has introduced a new agenda of the aged having to fight to secure allocations of resources. Increased competition, says Hudson (1978, p.43), has arisen because of the "growing absolute and relative cost burdens for meeting the needs of the older population, increasing debate over the actual distribution and intensity of older persons needs, and sharpening competition for limited discretionary social-welfare dollars are likely to erode traditional sources of support for the ageing while yielding new competitive and cost-based pressures". The question is who will be forced to have less? It is in this context that debates about the relative roles of statutory care, voluntary sector care, and informal patterns of care come to the fore. These debates make sense only in the light of a clear understanding of the notion of

dependency and the social structuring of patterns of dependency in our society.

### Dependency

It is necessary, in this context, to understand the concept "dependency", its social construction, and why the concept is so intensely under scrutiny. (The following comments are in summary form only\*).

Despite attacks by the more conservative sections of our society, state provision for those in dependent situations is generally regarded as legitimate. The term dependency assumes different meaning to people according to their specific disciplines. Whatever the discipline, one of the most common assumptions made is that dependency is bad and ought to be reduced. Just how this is to be achieved depends very much on the type of dependency referred to, its origins and its consequences. All people are dependent for considerable periods of their lives, most notably when very young, and if frail when elderly. It is recognised that during the stages of the life cycle, people fluctuate between states of dependence and independence. Although such recognition exists, apparent to the observer is the indeterminable conflict that exists between situations of dependence and independence and the acceptance of society of what situations constitute "tolerable" reliance of individuals on the "generosity" of the state. Normative relationships of dependency are evident within the existing social framework, namely children on families for nurturing and protection, youth for education, and workers for training prior to engaging in work. These forms of dependence are acceptable because it is recognised that these times only represent phases of reliance prior to being engaged in the productive system.

In this context, states of dependency have predominantly been defined in psychological terms, concerning fluctuations between the extremes of dependence and independence. Most writings have exemplified the bio-psychological aspects of dependency and, until recently, little attention has been given to evidence that suggests a social construction of dependency also occurs.

---

\* A detailed analysis of the concept "dependency" by David Kinnear is in preparation and will be published shortly by the Social Welfare Research Centre. It was not deemed appropriate to include all of the complex and detailed arguments here. When published, the monograph on dependency will service as a companion volume to this report.



More recent theorising has widened the meaning of dependency to include exclusion from economically productive endeavours whereby complex industrial society has structured varying states of dependency in accordance with its requirements for self-perpetuation. The influential theoritician, Richard Titmuss, outlined two types of dependency, the first being what he called the natural dependencies of childhood, child bearing periods and extreme old age. Full dependencies are usually caused by physical and psychological ill-health or incapacity. The second type of dependency was that which he considered arose from culturally or socially determined forces; that is, man-made dependencies (Titmuss, 1963, p.42). More recently others have termed it the social structuring of dependency (Townsend, 1981; Walker, 1980). Included are unemployment, education, compulsory retirement, occupational injury and unpaid work.

In recent times, there has been a greater focus in public debate on examining the ways in which social policies create and foster dependency. The more recent analyses have concentrated on understanding dependency in relation to one particular group, the elderly. Walker contends that the work of the elderly is systematically devalued by bureaucratic structures who use such terms as "efficiency" and "productivity" to confirm that the elderly are no longer able to contribute effectively to capitalist modes of production (Walker, 1980, p.72). In a further examination of the causes of dependency among the elderly Walker (1981) has identified four types of dependency:

First there is a life-cycle dependency which relates to the exclusion from productive and paid work. This could be examined in terms of retirement policies and demographics;

Second there is physical and mental dependency which relates to physical, social and psychological incapacity. There are arguments about the extent to which an impairment or disability may be a handicap but overall, dependency is a social relationship, the exact form and degree of which rests on interaction with at least one other person, but sometimes also with physical objects;

Third there is political dependency which is a curtailment or restriction of freedom on the part of the individual to determine his or her own course of action. This is based on unequal power relations between one person and another;

Fourth there is financial and economic dependency, which involves reliance wholly or partly on the state for financial support (over 80% of the aged in Australia list social security benefits as their main source of income).

The institutional responses to dependency have exacerbated its presence and consequence. The strategies developed from policies in an attempt to reduce dependency and promote self-determination, self-help, self-care and self-direction (Graycar & Kinnear, 1981, p.51) have in reality been attempts to promote greater independence on the part of the elderly. Several studies have demonstrated that permanent physical and psychological dependence is increasingly the end result, as a consequence of engaging in a heavy commitment to long-term care facilities (Townsend, 1981; Walker, 1981) while the provision of state income and social service transfers is a consequence of the social construction of dependency.

Those in states of dependency and receiving public support are having the legitimacy of that support questioned. Prevailing economic conditions have led to a resurgence of attacks on the welfare state, labelling it a wasteful consumer of resources in areas that do little to stimulate economic growth. Many believe that, as a result of these attacks, government expenditures have been reduced. However, cutbacks in expenditure are selective with the greatest reduction occurring in social consumption expenditure (O'Connor, 1973; Navarro, 1982).

Both Gough (1979) and Cass (1981b) argue that curtailment of welfare expenditure may involve an attendant move to reprivatise parts of the welfare state, specifically for "...expenditure to switch from direct state provision of services to public subsidisation and purchase of privately-produced services" (Gough, 1979, p.141). A direct consequence of this may be that the state will look to other institutions to provide services, with the limits on social services growth forcing the responsibility for care of the dependent (e.g. the elderly) back on to those traditionally entrusted with it.

Its crucial effect will undoubtedly force the jettisoning of social welfare policies that call for increased expenditure. Rather there will occur a growth of new policies deriving from new ideological and political positions that seek to provide welfare through purchase of services in the private sector, through increased reliance on the voluntary sector and through the encouragement of family care.

In his analysis of Matrix Tape 25 of the 1976 Census, Rowland examined individual incomes and living arrangements of elderly people in Sydney. He identified five living arrangements - living with spouse; living alone; ancestor of household head; other family living arrangements; living with non-family member - and prepared a table classifying living arrangements by income, by age group and by sex (Rowland, 1981b, p.25). Using three income groupings (1976 dollars) \$3000 or less, \$3000-\$6000, over \$6000 he found that in every case those classified as ancestors were the largest group of those earning \$3000 or less, and in every case were the smallest group of those earning \$6000 or more. This applied to both males and females and shows conclusively that the poorest elderly people live with their children. Given income patterns in families, it is likely that their children will also be at the lower end of the income spectrum and so the mantle of disadvantage which envelopes many elderly people may extend to their families. In the survey data reported below, there are interesting comments on 'making do'. What this highlights, however, is the economic aspect of the dependency pattern, which is quite a separate thing from physical disability.

### The Study

Although family care is frequently cited on humanitarian and economic grounds as the most appropriate form of care for the frail elderly, changing demographic and social trends indicate that it can no longer be expected or assumed that families are both willing and able to care on an extended basis. While caring for an elderly relative can be a positive experience there are also many stresses and costs related to the caring role. The day-to-day responsibilities of care usually fall on one person - generally a spouse, a daughter, or a daughter-in-law. The stresses and costs appear to be primarily associated with what is often the isolated nature of the role, the financial penalties, and the effects of caregiving on the mental and physical health of the responsible family member. Some families caring for an elderly relative reach a crisis point where there no longer exists any

alternative to institutionalising their relative. Usually the decision is made as a last resort after the family has exhausted both coping abilities and resources.

To examine these issues, a study was undertaken to determine the (non-monetary) costs - physical, social, and economic, to the family and the state, of family care of dependent elderly relatives and to examine the needs of the caring family in relation to the provision of formal services. By way of a structured interview with the principal carer, information was gathered about most aspects of the caring situation. The questions asked of the sample included: the reasons leading to the decision to care, how that decision affected other family members, who is involved in caring in the home, the suitability of housing arrangements, the need for special adjustment or equipment within the home, the financial situation of the family, the day-to-day stress of caring, the availability and effectiveness of services in the area, and the private costs of caring (social and psychological).

Some of the themes and issues in the study included examination of:

- the financial situation of caring families; the income-earning role of the primary carer; what aged parent-related expenditure is incurred by the family; the financial stage at which the family undertakes to care for an elderly person?
- the role of caring; does primary care fall on one household member, usually the woman; what are the costs (physical, social and psychological) of caring?
- what mix of financial and social services does the state provide to families caring for elderly persons; do these services meet the needs of caring families? What are the housing, health and service needs of caring families and the elderly? What caring expectations are placed on women by family/society and are these expectations held by women themselves?
- what is the nature and function of the dependency of both the elderly relative and the caring family?
- what is the role of the family and of the state in light of changing demographic and social trends?

It was decided that any attempt at a random survey would be futile. While this could limit the degree of generalization that might flow from this study, the in-depth nature of the interview yielded qualitative data on many of the issues and difficulties experienced in the caring situation. Similarities between our findings and a recent British study (Nissel and Bonnerjea, 1982) illustrate that the situation described by our sample could well apply to many families in similar situations. The overall intent was to make a tentative assessment of problems and needs of families caring for elderly relatives in anticipation of the development of appropriate policies.

The sample was found in two locations. One location was a local government area in the outer suburbs of Sydney, an area with a proportion of elderly people matching the state average, and an area with a relatively stable residential pattern, but with significant family reformation. The second location was in the Hobart metropolitan area in Tasmania. This was chosen to remove any possible Sydney bias, and while falling considerably short of anything which could be called national, it was intended to provide understanding from a different urban configuration and of the effect of policies of two state governments.

Samples in both locations were obtained from local home nursing organisations. Negotiations with the nursing bodies led to nurses making the first contacts for us. On their regular rounds they delivered a letter from the researchers to their patients' families seeking their permission to be included in the study. This desire to limit unnecessary intrusion into the busy lives of carers obviously biased the sample in two ways. First only those who had the time and inclination to be interviewed were included (but rarely does any study include those without time or inclination!), and second the population sampled was one already receiving one specific type of service - home nursing. This ensured that there was a person being cared for who had an activity limitation, but it also excluded families which were not fortunate enough either by virtue of physical isolation or other reasons to receive the nursing service. (Cost cutting in NSW for example has led to a freeze on acceptance of new patients). It was put to us that by interviewing in situations in which the service was being received we were getting the "lucky ones" and missing the cases of greater need. If this is so, the situation, as the data below will show, is terrifying.

A detailed, structured interview taking from one to two hours was conducted, not with the elderly person being cared for, but with the carer. In nearly all cases the elderly person was not present. In those very few cases where the elderly person was present, the situation became quite tense. Although the carers were under great time pressures they were very keen to share their experiences and their helpful cooperation is highly valued. In all, 75 interviews were conducted, roughly equal numbers in both Sydney and Hobart. The data have been presented together except where significant differences between the two groups was found. The Sydney interviews were conducted in November 1981, and the Hobart ones in March 1982.

A further set of interviews was conducted in Sydney with a small number of families who had cared for elderly relatives, but were no longer able to provide care. The objectives were: to investigate the extent to which the causes of dissolution arise from the incapacity of families to continue caring; to discover the factors which force the family not to continue rendering support; to investigate the extent to which the decision to seek institutionalisation arose from the lack of formal support systems to assist and complement the functions performed by the family; and to ascertain whether families feel that care in their own home is the most responsible and satisfying way of caring for an elderly relative. The results of this second set of interviews will not be reported in this monograph but will form the basis of a subsequent report.

In the main study what came through overwhelmingly was the extreme difficulty under which most carers operate, and their extreme reluctance to consider institutional care for their relative. This would point to the appropriateness of extending support services but, surprisingly, while all received home nursing, the vast majority were largely unaware of other services which were available. The results which are reported in detail below, paint a picture of a sample of elderly people with a wide range of chronic illnesses and disabilities who have been cared for, mostly for over one year, and in 36 per cent of cases for over six years. A significant number of the elderly people who had moved into their child's house were unwilling to have made the move, and were unhappy about doing so. In many households most relationships and activities had suffered as a result of reconstituting the household, and in many households this led to strong resentment.

The carers by and large felt themselves fairly isolated. Few had anybody to provide any periodic relief when it was required. Many of those receiving home nursing often felt it was more of a hinderance than help. Those who had husbands and children found them generally supportive, but very often the support was only verbal and did not translate into action. Many of the carers themselves had health problems but even if they fell ill they had no option but to continue offering care. Most had not had a holiday for years and there was much resentment of their consequent loss of independence. Many experienced great anxiety, generated by the belief that they could not leave their elderly relative for any length of time for fear it would be construed as neglecting their family responsibilities. Some felt a tremendous emotional drain on themselves and this was exacerbated by the lack of help from people other than their own family. In addition their current responsibilities ensured that any plans they had made for the future were no longer operative. The situation adds up to the fairly complex one of considerable sacrifice being made in the absence of what might be regarded as a broad range of community support services.

This study is an attempt to investigate the process of family care and its impact on the principal carer within the family. Accordingly it sets out to examine the non-monetary costs of family care in an endeavour to suggest ways in which social supports could be allocated to families to enhance rather than substitute for family care. In effect, such supports would attempt to alleviate the burden and emotional strains of caring.

## 11 COMMUNITY CARE AND ITS SUPPORT

Historically, care structures in Australia have had a strong institutional orientation. This has applied not only to elderly people, but also to most dependent populations. For the elderly the hospital was the main formal care structure. While the numbers of elderly requiring formal care remained low the hospital system seemed capable of meeting demands from all groups. As the overall population of Australia increased, and in particular that of the elderly, the demand for hospital care began to outstrip capacity to provide care. Thus there was an overload on hospitals created largely by the presence of numerous old people who were patients, not because they were acutely ill, but simply because there was no other alternative. There arose an economic necessity to ensure that hospitals did not provide care that lay outside their prime functional basis for existence. Reinforcing this economic necessity was an ideological shift towards a belief of "care in the community" in preference to institutional care.

What emerged from this shift in emphasis of care was the establishment of an alternative care system through the aegis of nursing homes. Essentially to provide care for the chronically ill elderly, who could no longer be cared for at home, they provided the means by which hospitals (both general and mental) were able to relieve themselves of non-acute patients. Without the introduction of nursing homes, old people would probably have become an almost impossible resource consumer in the public hospitals system. The 'purging' of inappropriate patients from public hospitals and mental institutions was justified on humanitarian grounds in that care in the community was regarded as a far more beneficial and humane system of care. Over the last few decades we have witnessed a sustained growth in such care together with other complementary forms; these being - hostel accommodation, retirement villages and aged and disabled housing. Today the historical venture of promoting 'community care' seems to have turned full circle as increasingly governments talk about the need to establish systems of 'community care' on the grounds that the concept and reality of 'community care' of yesteryear was merely an extension of institutional care; something very akin to that provided by the hospitals systems at that time. There is ample evidence from various research on nursing home accommodation that validates this belief (Bayley, 1973; Townsend, 1981).



What transpired, essentially, was the failure of an approach to care, premised on the notion that care in the community was the ideal solution. There is now mounting evidence to suggest that the ideology of care is now 'care by the community' which does not necessarily mean provision of care by various statutory organisations, but rather greater reliance upon the informal and voluntary sectors of care, especially the family and self-help groups. This latest endeavour for a new form of community care comes during a period of economic downturn and an ensuring commitment by conservative governments in western nations to curtail public expenditures, especially social expenditures. This prevailing ideology of welfare is one of more responsibility for support to be assumed by the informal and voluntary sectors of care. Frequently one is assailed by comments and reports in the media that decry the lack of responsibility on the part of families to care for their elderly relatives and the need for society to return to an era when families recognised and assumed this responsibility, an ideology that Cass labels an attempt to invoke the traditional dependencies of the family (Cass, 1981a). While there appears to be government recourse to this action, there is mounting evidence, especially in Britain, that social supports and supplements to community care networks are being eroded. In Australia, it appears that the pressures being sustained by local service organisations impel them in relation to the elderly to restrict coverage of their services to those elderly who have no familial or social support networks (NCOSS, 1981).

On the part of government there appears to be a lack of commitment to fostering the growth of community care. Rather, its approach seeks to thrust greater responsibility of care upon informal care systems and emphasise service support to the 'truly' needy; these being the elderly without social supports. Evidence pointing to this approach can be obtained from an historical and contemporary analysis of government attempts to bolster two care networks; the Home Nursing Services by way of the Home Nursing Subsidy Act 1956 and family care through the Domiciliary Nursing Care Benefit.

#### Home Nursing Subsidy Act 1956

For over 50 years Home Nursing in Australia had been delivered by voluntary organisations surviving on subscriptions, donations and fees for service. Organisations dispensing home nursing to the poor and needy largely fell under the rubric of District and Bush Nursing services. Their services which ranged from general care and sponging, to daily or weekly

visits, enabled many patients to be discharged from hospital care to their home, and prevented many elderly from entering hospital. No restrictions were placed on those eligible for the service though, by reason of prevalent chronic illness, the aged formed the greatest number receiving assistance.

In 1956 the Federal government proposed the adoption of legislation that sought to increase the range of home nursing service throughout Australia. The Home Nursing Subsidy Act (1956) authorised financial assistance to approved organisations already dispensing home nursing services in the form of a subsidy equal to the grants of the various state governments. As an inducement for the creation of new organisations, a subsidy equal to half of that granted to existing organisations was approved. The subsidy was only to be paid with respect to additional staff engaged over the current number as at 1st January 1957. Subsidies were not available to statutory organisations but were payable to the various church-based nursing services.

There were both ideological and economic reasons for government intervening into a hitherto voluntary sector network of care. The then Minister for Health, Dr. Cameron carefully imputed the ideological reason to be that 'care in the community' was more humane and effective than hospital care (CPD (H of R), 10-10-56, p.1306-8). However, as many members of the Federal Opposition argued, the espousal of 'care in the community' rested more on economic precepts heavily reinforced by ideological reasoning than on the grounds of just and equitable care. The Bill was criticised by some Opposition members who suggested that because government expenditure to these services would be quite slight, such moves were more economic in intent than humane. In fact, the Bill was seen by many of the Opposition to be a means of circumventing the crisis that had arisen over the shortage of hospital beds.

There is some justification for this reasoning, as the Minister for Health at the time outlined in the first parliamentary reading of the Bill that an accommodation crisis existed within Australian hospitals, a crisis that necessitated the discharge of surgical cases earlier than previously in order to free beds. The Home Nursing Services facilitated early discharges and these services were viewed as a means of providing care during recovery from illness or hospitalisation. The Minister went on to justify the expansion of home nursing services through government support on the grounds that community care was less costly than hospital care (CPD (H of R), 10-10-56, p.1307). According to 1956 figures, the 150 nurses then employed nationally

were saving 900 hospital beds which represented huge cost savings when hospital costs and nursing costs were compared. A hospital bed cost three pounds per day while home nursing cost only seven shillings per day. It was calculated that this represented a saving of almost one million pounds a year. As one hospital administrator, G. Casey, summed it up: home nursing ought to be encouraged for the reason that "bed is bad for... the elderly ... Another is that hospital beds are needed for people who are ill, rather than old. The third is that it costs the community too much to maintain them with trained hospital staff at their beck and call" (Casey quoted by Chaney in CPD (H of R), 10-10-56, p.1627). In his monumental history of Australian social security T.H. Kewley began a paragraph "The expenditure on hospitals would, no doubt, be slightly greater but for the Commonwealth Home Nursing Subsidy Scheme..." (Kewley, 1965, p.359). While the Government was concerned to develop a more comprehensive system of care in the community, its incursion into the area of community care was not aimed at replacing voluntary caring networks with statutory caring organisations. Instead its philosophy insured that its activities would not do anything to discourage voluntary effort in the community, simply because such moves would be 'contrary to the interests of society' (CPD (H of R) 10-10-56, p.1626). The debates supporting the Bill expressed, again and again an ideological sentiment that essentially welcomed care in the community but only to the extent that the assistance given did not undermine or replace the existing forms of care provided by the community.

Also permeating the debates from both sides of the House were laments that the family had neglected its caring responsibility and its neglect was just a tragic reflection of the materialism that is eroding the basis of our social structure (CPD (H of R), 18-10-56, p.1639). It was the Government's resolve therefore not to encourage families to abrogate responsibilities but to call upon and encourage the notion of citizenship whereby people understood and attended to the needs of others. The role of government, then, was perceived as one which gave substance to the continuance of voluntary services by means of cash and encouragement of community involvement. This sentiment is neatly encapsulated by K. Wilson who described the Bill as a partnership between government and the people; a partnership in which the Government will act to help those who are carrying out humanitarian activities of caring for the sick and the elderly to expand their activities (CPD (H of R), 18-10-56, p.1659).

Over the last 25 years the Commonwealth Government has maintained its subsidy to home nursing services. Combined with subsidies from State Governments, funding allocations have seen the number of home nursing organisations grow from 61 in 1966 to 194 in 1979 (Commonwealth Dept. Health Annual Reports). Subsequently the number of nurses employed has increased from 210 in 1956 to 1927 in 1980. In 1956 there was one home nurse for each 43,000 people in Australia. By 1980 this had come down to one for each 7,584 people. The main growth was between 1956 and 1971. Since then less growth has been experienced. Table 2.1 reveals that between 1971 and 1980 the number of nurses has risen from one per 14,157 to one per 7,584 of the population.

TABLE 2.1

AVERAGE NUMBER OF NURSES EMPLOYED BY  
DOMICILIARY NURSING ORGANISATIONS  
1956 TO 1981

	1956-1971	1973	1974	1975	1976	1977	1978	1979	1980
No. of nurses	210 901	1091	1233	1449	1653	1746	1778	1857	1927

Source: Commonwealth Department of Health,  
Annual Reports, 1975-76 to 1979-80

The recent decline in the rate of growth is attributable to the decision of the Commonwealth Government in 1976 to impose a freeze on nursing staff establishments in organisations funded under the Home Nursing Subsidy Act (1956). As a consequence nursing services were prevented from expanding at a time when there was unprecedented demand for care (McKenzie, 1981, p.66). In 1980, the Minister for Health, Mr. MacKellar announced in Parliament that the restrictions imposed on the number of subsidised positions were to be lifted in the 1981-82 financial year (CPD (H of R) 29-4-81, p.1719). This coincides with another dramatic rise in demand for services, that will probably see the services' capacity to cope being eroded further. The services are presently in a severe funding crisis (see NCOSS 1981).

### Domiciliary Nursing Care Benefit (1973)

Further encouragement for community care came from the introduction of the Domiciliary Nursing Care Benefit in 1973. The benefit was designed to provide financial assistance to people caring for chronically ill elderly persons. The benefit was described in a Ministerial statement as a "further initiative emanating from the Federal Government's continuing policy of providing planned assistance in areas of greatest need" (CPD (H of R) 29-8-72, p.833). The move indicated that there were social advantages in retaining elderly people in their home environment. The needs of this group are only partly associated with nursing and medical care, and the bulk of needs are able to be met by the family, friends and relatives. Although convinced that there had been an 'erosion of the extended family and attendant responsibilities', the Government, explained the Acting Minister for Health Dr. Forbes, has almost implacable faith in the belief that there do exist families who remain firmly loyal to a sense of "family totality" and who thus make and are willing to make considerable sacrifices to ensure that community care becomes reality (CPD (H of R) 29-8-72, p.835). As a means of encouraging family care, the Government on behalf of the community, granted some financial assistance to families who were in care arrangements. Initially this assistance stood \$14 per week. It rose, in 1980, to \$21 per week.

While the Government may describe the introduction of the benefit as the expression of community gratefulness to families providing care, and also a recognition of the need for public responsibility at the Commonwealth level, its introduction should not be construed as an intrusion by statutory organisations. Rather, it should be seen as an extension of the Commonwealth Government's desire to encourage more care by the community and particularly in relation to this benefit, the family.

The financial assistance offered was to a person who provided care for an elderly person 65 years and over who was in need of continuous nursing care and was in receipt of such care. As was the case with the financial assistance to home nursing services, the introduction of a benefit seems to have ensued from other than humanitarian grounds. It is more likely that its introduction rested on a combination of economic and ideological foundations. Spiralling costs of hospital care led to the encouragement of family care whose costs are more 'hidden', and thus enabled the opportunity

for considerable savings to result through the release of hospital beds now occupied by chronically ill elderly. Not only would savings result from a decrease in extensive care services but reducing the long-term care hospital population would lessen the urgency to provide more expensive hospitals. In addition, the high costs of nursing home care were just becoming evident, a factor compounded by the practice of hospitals of dispensing of unwanted long-term care patients to nursing homes (CPD (H of R) 29-8.72, pp.833-839). Family care, therefore, was mooted to be a more humane method of caring especially when compared to the apparent abuse of institutional care, an awareness of which was just emerging from the evidence of recent research on long-term care facilities. The Health Minister described the Governments' intention thus:

"We decided to provide assistance in respect to domiciliary care because not only do we think that the humanity of the situation is so critical but also because it will help in relation to overcoming the overall problems of nursing homes and ultimately hospitals". (CPD (Senate), 27-10-72, p.2135)

#### Current Situation

At present, home nursing organisations are undergoing a crisis of inadequate funding to meet the growing demand for their services. The current bias in Federal funding is still towards institutional care, to the extent that 10 times more financial assistance is given to institutional care than home support care. A survey of 239 home support services by the New South Wales Council of Social Service found that "the steadily rising demand, reduced real resources rapidly rising costs, and the lack of adequate planning coordination and administration arrangements, all combine to increase pressure on a foundering system of services" (NCOSS, 1981, p.15).

Over the last six years the bias of funding has been toward institutional care, as shown by Table 2.2 (p.24). Funding to institutional care has increased by 99 per cent over that period while funding of non-institutional care has risen by 94 per cent. If the figure for the Domiciliary Nursing Care Benefit (due to increase in its rate in 1980) is excluded the growth of funding for non-institutional care drops sharply to 66 per cent. This trend has continued as the New South Wales Council for Social Service has shown. Their report estimated that over the period 1980-81 to 1981-82 funding to the institutional care sector will increase by 36 per cent while for the non-

TABLE 2.2

COMMONWEALTH FUNDING FOR INSTITUTIONAL AND NON-INSTITUTIONAL SERVICES  
1975/76 - 1980/81

<u>INSTITUTIONAL</u>	1975-76	1976-77	1977-78 \$'000	1978-79	1979-80	1980-81	% Change
Nursing Home Benefits	141,446	162,748	185,241	200,058	227,406	277,832	+ 96.4
Nursing Home Assistance	51,904	70,081	68,612	68,485	85,016	103,827	+ 100
Aged & Disabled Persons Homes and Hostels	22,170	42,387	42,116	52,726	51,144	45,771	+ 106.5
Personal Care Subsidy	9,493	11,072	12,564	13,315	14,468	19,645	+ 106.9
	225,013	286,288	308,533	334,584	378,034	447,075	+ 98.7
<u>NON-INSTITUTIONAL</u>							
Domiciliary Nursing Care Benefit	7,697	8,089	7,929	8,333	9,762	17,485 <sup>(a)</sup>	+127.2
Home Nursing Subsidy	7,200	9,360	10,700	11,205	12,273	13,500	+ 87.7
Home Care Services (incl. Senior Citizens Centres)	9,877	11,558	13,805	14,458	14,680	16,879	+ 70.9
Delivered Meals	11,799	11,911	12,208	12,280	12,491	13,621	+101.3
	26,573	30,918	34,642	36,276	39,206	51,485	(b)+193.7 (c)+ 66.1

(a) Inflated figure due to increase in rate of benefit from \$28 to \$42 per fortnight from September 1980.

(b) Calculated using inflated 1980-81 DNCB figure.

(c) Calculated using an adjusted 1980-81 DNCB figure.

SOURCE: Department of Social Security Annual Reports, 1975-76 to 1980-81.  
Commonwealth Department of Health, Annual Reports, 1975-76 to 1979-80.

institutional sector will increase by 15 per cent (Table 2.3, p.26). Further calculations on their past estimate show that the Commonwealth is spending in the order of 20-45 times as much per person in an institution than on those outside them (NCOSS, 1981, Appendix 1). It can be concluded that although the rhetoric for community care is strong, government expenditure patterns indicate a different funding base. More emphasis and reliance is being placed on invoking family care where savings are possible because costs become hidden in this sector.

Similar to the 1956 experiences, the experience of contemporary services is that the majority of clients are elderly people. Australia is experiencing a slow ageing of the population but a steadily increasing growth in the number of 'old' old. It is this latter growth that presents difficulties for community services. Elderly people aged 75 years and over are most likely to be suffering from the cumulative effects of the ageing process and thus do suffer from chronic illness. It is this population that has effectively placed home nursing services in a position whereby they face shortfalls of staff to respond to the growing demand. Lack of funds to expand services has forced organisations to institute severe curtailments to their services. According to the New South Wales Council of Social Service survey many Sydney home nursing services are 'spreading the jam more thinly'; visits are made less often and for shorter periods of time. One particular service, the Sydney Home Nursing Service, was forced to close its books in 1981 because expended resources prevented further expansion.

The cumulative pressures of rising demand and funding shortfalls are forcing many services to establish new eligibility criteria that will reduce the demand placed on them. The Sydney Home Nursing Service has recently stated that additional funds are being sought from the New South Wales State Treasury in order to match Federal Government Grants, in order to permit an expansion of services. If this is not possible, funding is such that priorities in relation to "present resources will have to be established". Unless the situation changes, not all new patients will be accepted (McKenzie, 1981, p.66).

This organisation, like many others offering home support services, is being forced to limit its services to the 'truly needy' which in the case of the elderly are those without community supports; a more specific interpretation is that elderly without a spouse or a family are accorded the highest priority.



TABLE 2.3

CHANGE IN COMMONWEALTH FUNDING FOR INSTITUTIONAL  
AND NON-INSTITUTIONAL SERVICES 1980/81 - 81/82

<u>INSTITUTIONAL</u>	1981/82 \$M	1980/81 \$M	Change \$M	%
Nursing Home Benefits	387.0	277.8	+109.2	+39.3
Nursing Home Assistance	155.2	103.8	+ 51.4	+49.5
Nursing Care for Veterans	43.6	39.2	+ 4.4	+11.2
Aged and Disabled Persons Homes and Hostels	58.0	45.8	+ 12.2	+26.6
Personal Care Subsidy	21.6	19.6	+ 2.0	+10.2
	665.4	486.2	+ 179.2	+36.8

(Plus: hospital inpatients  
components of health programme  
grants and veterans programmes)

NON - INSTITUTIONAL

Domiciliary Nursing Care Benefit	20.6	17.5	+ 3.1	+37.7
Home Nursing Subsidy	16.0	13.5	+ 2.5	+18.5
Home Care Services (incl. Senior Citizens Centres)	24.4	21.5	+ 2.9	+13.4
Paramedical Services (not NSW)	1.0	1.0	-	
Delivered Meals	4.1	3.6	+ 0.5	+13.8
	66.1	57.1	+ 9.0	+15.7

Source: NCOSS, 1981, Appendix 1.

The concern of the Federal Government has been to support and supplement, albeit in a meagre fashion, the informal sectors of care. It has not, contrary to popular belief, sought to replace informal organisations providing care with statutory organisations. The responsibility undertaken to encourage and enhance care by the community is embraced in an ideology that views community care as a less costly and more humane way of caring for dependent populations. What we have witnessed since the enactment of legislation governing financial assistance to home support services is more of a commitment to care by the community and not as much to care in the community. This is highlighted by the crisis that has overtaken these community-based organisations in the last five years. Increasingly, the growing demand for such services has pushed beyond the limit the ability of organisations to satisfy that demand. Shortages of resources have led to a rationalisation of services and reduced their coverage to those groups without adequate social and familial supports.

This brings us to the crux of the care issue, and that involves the relationship between statutory, voluntary sector, and informal patterns of care. Obviously there is no single answer as to which is "best". As policy interventions may result in the extension or diminution of much-needed support and as the interventions often work from assumptions about the relationship between family members and their dependent relatives, and assumptions about care patterns, it is instructive to examine the data in the following section. The information was gathered to illustrate aspects of the care relationship.

Dependents and Carers

The overwhelming majority (92%) of the dependent relatives in the study were aged 75 or more. The modal group was in the 85-89 age group. In accord with population patterns, the majority of dependent relatives were women.

TABLE 3.1  
AGE OF ELDERLY PERSON

Age	N	Per cent
60 - 64	1	1.3
65 - 69	1	1.3
70 - 74	4	5.3
75 - 79	10	13.3
80 - 84	18	24.0
85 - 89	28	37.4
90 - 94	4	5.4
95 - 99	7	9.3
100 -104	2	2.7
Total	75	100

Over two thirds of our sample fell into the category 'old' old, and consequently were the ones most likely to suffer from chronic and degenerative illness and the more debilitating aspects of ageing.

TABLE 3.2  
CURRENT HEALTH PROBLEMS OF DEPENDENT RELATIVE

Health	Responses*	Per cent of Respondents
arthritis, rheumatism	44	58.6
stroke, paralysis	23	30.6
heart problems	31	41.3
blindness, failing sight	28	37.3
nervous conditions	19	25.3
hearing problems	15	20
fractures	14	18.6
problems with breathing, asthma, bronchitis	13	17.3
other	4	5.3

\* Multiple Responses

Chronicity and attendant activity limitations mean that those afflicted require social and medical support, and our sample contained many people with conditions which require continuous support and care. The mobility limitations identified in Table 3.3 (page 31) indicate that many of the dependent elderly were either chair-bound or limited to movement over short distances. The ability of dependent relatives to perform a range of daily living tasks shows the extent to which help is needed to do most things. Of 1125 different responses to questions about varying abilities to perform daily living tasks, more than three quarters of the responses indicated that dependent elderly people in the sample were unable to perform certain tasks alone (see Table 3.3).

Families are at the forefront of offering support in respect of these mobility limitations. This immobility required a significant amount of care and allocation of time from the carer. Most elderly could not be left alone for long periods of time, and the carers were limited to a quick errand to the corner shop, if that. Due to their physical state, outings if they were possible, were limited and of a short duration. Many of the elderly people were, either from lack of interest to move, or nervousness, disinclined to venture from the security of the home. Consequently this tended to make the carers housebound except for short essential outings. Even then they could not block out their role as there was a constant worry about whether the elderly relative had in the meantime fallen or sustained an injury or suffered some other accident. Thus there seems to be no temporary reprieve from the caring role available to carers even when physically separate from the person for whom they care. Nor does it seem appropriate to consider options for community support that involve the movement of the dependent elderly to the service. Rather it may be of greater importance to provide services that go to the person.

There are problems when one considers household size. Including the dependent relative, one half of the households contained either two or three people. That caused problems in terms of lack of back-up support, or alternative carers during periods of difficulty. On the other hand 30% of the families had children under 17, and as will be shown below, presence of an elderly dependent relative often was associated with deterioration of relationships.

TABLE 3.3

ABILITY OF DEPENDENT ELDERLY RELATIVE  
TO PERFORM DAILY LIVING TASKS

Tasks	No difficulty	%	With difficulty	%	Must have help	%	Total
Use the telephone, including looking up numbers and dialling	13	17.3	10	13.3	52	69.4	75
Shop for groceries and other things	5	6.7	9	12.0	61	81.3	75
Get to places outside of walking distance	2	2.7	9	12.0	64	85.3	75
Prepare his/her own meals	4	5.3	8	10.7	63	84.0	75
Do light housework (such as dusting, dishes, making bed)	9	12.0	8	10.7	58	77.3	75
Take his/her own medication	15	20.0	13	17.3	47	62.7	75
Handle his/her own money (that is, paying bills, managing pension money)	26	34.7	7	9.3	42	56.0	75
Feed him/herself	34	45.3	21	28	20	26.7	75
Dress and undress him/herself	24	32	20	26.7	31	41.3	75
Care for his/her own appearance (combing hair, shaving)	25	33.3	17	22.7	33	44.0	75
Get about his/her house	25	33.3	21	28	29	38.7	75
Get up and down stairs	10	13.3	17	22.7	48	64.0	75
Bathe or shower him/herself	11	14.7	10	13.3	54	72.0	75
Get to bathroom on time (bladder and bowel control)	26	24.7	12	16	37	49.3	75
Cut his/her toenails	7	9.3	6	8	62	82.7	75

TABLE 3.4  
COMPOSITION OF HOUSEHOLDS

Household Composition	N	Per cent
Carer/Dependent Relative	19	25.3
Carer/Dependent Relative/ Children	3	4.0
Carer/Dependent Relative/Adults	13	17.3
Carer/Dependent Relative/Adults/ Children	4	5.4
Couple/Dependent Relative	18	24.0
Couple/Dependent Relative/ Children	13	17.3
Couple/Dependent Relative/Adults	2	2.7
Couple/Dependent Relative/Adults Children	3	4.0
Total	75	100

The notion of family care invokes an image of care shared among each family member. Research above (p. 6) has shown that family care in reality often is reduced to care by women with varying degrees of support given by other family members. Our study lends support to the notion that family care equates with care by women - usually one woman.

It may be reasonable to assume that the carers had other relatives upon whom they could call to relieve them periodically from the caring role. However, this was not the case. Those immediately in the home (children/husband) seldom contributed significantly to the care of the elderly person. While 29 per cent of spouses and 75 per cent of children were supportive of the care given, neither group actually provided care of any significance. The carers interviewed stated overwhelmingly that both spouses and children provided some assistance (76 per cent and 70 per cent respectively). When they were asked to elaborate on the assistance given, it turned out that both groups did little more than occasional bursts of night care and house-cleaning.

The orientation of children (of the carer, i.e. grandchildren of the dependent person) to the elderly person was mostly one of tolerance and acceptance, and hardly ever one where they actively participated in providing care. With regard to husbands (of carers), they were positive in accepting that the family

should care, except their definition of 'family care' was one which envisaged this being an extension of their wife's role already within the family structure. Several reasons account for this. In some instances care by males was prevented because the elderly person was female and any attempt to bathe or dress the aged person was regarded as an impropriety; in other cases because the males were working; while others did not perceive care to be one of their tasks as reflected by one comment that 'you can't ask a bloke to chuck in his job'. Many carers' comments when speaking of their husbands' assistance, are epitomised by the following "... husband raises no objections, is very supportive and extremely helpful" and while each carer tended to state that the male did offer support and showed concern, the impression the interviewer was often left with after the carer had described her tasks and daily routine, is that it is almost a perfunctory gesture or concern on the part of the husband. It must be stated that there were a very small number of husbands who appeared to be providing an equal share of the care, a situation made easier in some cases, because they were retired.

Instead of welding a nuclear family together, a caring situation often generates tension and conflict and this in turn makes the burden of care more onerous. Carers' children are often uneasy about dependent grandparents and in some cases this manifests itself in disrespect and resentment. Because of changes that have overtaken the households husbands (of carers) sometimes feel angry towards the elderly person. The carer/mother/wife, trying to fulfil a number of competing roles is often caught in the middle, both as a super worker and family mediator, e.g.

"... the kids get resentful and I'm the one in the middle, I try to divide my time up between everyone"

another said

"Time is not your own, rushing from children to father - continual demands the whole time - and trying to keep the children out of the way of their grandfather".

Seventy eight per cent had themselves come from large families and had brothers and/or sisters living either in Sydney or Hobart.

TABLE 3.5  
CARERS' SIBLINGS

Relationship	N	Per cent
Sister	11	14.6
Brother	10	13.4
Sisters/Brothers	37	49.4
None	16	21.3
Brother-in-law	1	1.3
Total	75	100

It is often assumed that assistance and support will be forthcoming from other relatives. Although over half of the carers in our study had other relatives (sister/brother or both) not all relatives were supportive, and those giving assistance gave minimal support. Only 48 per cent of relatives gave support and of these almost 59 per cent were sisters of carers. The traditional care-giving role of women extends mostly to other women not directly involved in providing care. The care provided by relatives was predominantly that of occasional visiting to see the elderly person or to take them on a short holiday.

The lack of tangible support from relatives is not only attributable to their living elsewhere (in some cases in a rural area or interstate), but also figuring prominently is a simple preference to leave the routine of caring to the one person, a position of isolation that is reflected by a comment from a number of carers that "if it was left up to others in my family, mum would be put in a nursing home". Table 3.6 shows that 86 per cent of carers felt that no one else would be prepared to provide full time care.

TABLE 3.6  
WILLINGNESS OF OTHER RELATIVES TO CARE

Any other person	N	Per cent
Yes	6	10.2
Maybe	2	3.4
No	51	86.4
Total	59	100



Any suggestion that "family care" means care through an integrated family network is not supported by our evidence. "Family care" most often means that one particular family member is "selected out" to care because their circumstances lend themselves more conveniently to caring. The burden of care therefore falls unevenly within the family. While some tensions within the nuclear family are evident, tensions are often heightened with the resentments which come when carers believe their siblings are not doing their share. This is exacerbated when the carer is unmarried and the siblings are married. Several respondents felt that their unmarried status allowed them to be placed under greater pressure, e.g.

"... I feel my brothers and sisters have taken advantage of my single state, and do not realise what caring for mum means to me"

#### Outside Sources of Assistance

The existence of sources of care outside the immediate family were very poor. Almost three quarters of the carers did not receive any help from people outside the family. The remainder received help in the form of neighbourly visits and infrequent inquiries of concern about the present state of care. The reasons for this are many and varied. Many carers were reluctant to seek outside help for fear that it reflected some inability on their part to care. Others were unsure of who to ask since they felt that friends and neighbours should not be burdened unnecessarily with their problems. Almost one third said they found it difficult to ask for help, 17 per cent did not know who to ask while a very small number (8%) asked for help but were refused. Almost half felt they could manage it in their own way and did not want any help.

TABLE 3.7  
DIFFICULTY IN ASKING FOR HELP

Reasons for Difficulty	N	Per cent
Difficult to ask for help	20	26.7
Don't know who to ask	13	17.3
Asked but refused	6	8.0
Don't want help	36	48.0
Total	75	100

The evidence from the study does raise some questions concerning the position of voluntary assistance and mutual support groups within the community to assist families who care. Some families were reluctant to consider using voluntary services because they relied on untrained staff who may not be capable of giving appropriate care. Others were upset by intrusions into their privacy. Thus the argument that families have a depth of untapped resources in the community to call upon cannot be sustained.

It came through clearly that there was a differential impact of care according to socio-economic status. The impact of caring on the life of the carer was evidenced by loss of independence, by becoming housebound, by a general shrinking of the social relationships available to each carer, and by care being an almost continuous situation. The majority of carers were responsible for the bulk of caring because they could not afford to purchase services in the private market. At least two carers had attempted to use private nursing services but eventually were forced to cancel the service because they were too costly. Since most respondents' families were of lower socio-economic status, it can be assumed that they lacked the financial resources to purchase services in the private market.

A similar situation did not apply to families from higher socio-economic levels. In the case of 4 per cent of high income families where a private nurse was hired, the carers found that they now had greater freedom and independence. They were more able to arrange for holiday periods, to go out when they wanted and generally to have time available to engage in social relationships, beyond the immediacy of the family home. So the impact of care is very much governed by the financial, social and familial resources available to individual families.

Many carers worked within what were initially unrealistic appraisals of care requirements and often had erroneously assumed that the caring situation would not last for any considerable period of time because of the physical and mental condition of their elderly relative. Of those caring, almost 93 per cent had been caring for one year or more while 36 per cent had sustained their care in excess of six years.

TABLE 3.8  
DURATION OF CARING SITUATION

Years	N	Per cent
Under 1 year	6	8.0
1-2 years	17	22.7
3-4 years	17	22.7
5-6 years	8	10.6
6 years and over	27	36.0
Total	75	100

In 63 per cent of cases family reformation occurred as a result of the elderly person moving in with an adult son or daughter. In other cases a daughter moved back with her mother after the death of her (the daughter's) spouse, or after a divorce. In other cases the mother and daughter had never lived apart.

Demographic change, most notable in decreased family size and higher rates of marriage, has lessened the likelihood of women adopting a traditional "spinster role", one feature of which was to take care of elderly parents. This, together with the increasing labour force participation rates of all women, and in particular older women, highlights the situation of care being provided by women whose time and energy is heavily committed elsewhere. It seems likely that if family care continues, more and more women will be asked to scale down other areas of concern in order to provide care. This is not to suggest of course that there is any great unwillingness on the part of carers to provide care. When asked why family care was being provided, the following responses were given :

TABLE 3.9  
REASONS WHY FAMILY CARE IS PROVIDED

Reasons for Care	Responses*	Per cent of Respondents
Loves parent	38	50.6
Family has responsibility	42	56
Want to repay past help	13	17.3
Hates idea of nursing home	20	26.6
No-one else will accept care	13	17.3

\*Multiple Responses.

When asked why the move actually took place, the following responses were given :

TABLE 3.10  
REASONS WHY DEPENDENT ELDERLY BEGAN LIVING WITH CARER

Reasons	Responses*	Per cent of Respondents
Couldn't look after themselves	33	44
Needed supervision/care	31	41.3
Husband dies and no longer capable of living alone	9	12
Always lived with mum	8	10.6
Major illness precipitated move	8	10.6
No-one else willing to care	4	5.3

\*Multiple Responses

The caring situation was usually established as a result of elderly people having cause to move. The majority of those who moved (80 per cent) were willing to have done so. Twenty per cent, however, were unwilling to have moved and consequently were resentful of the situation. Many elderly had spent some time in hospital prior to moving. The caring situation arose because the elderly person suffered some severe physical or mental impairment which required hospitalisation, or suffered (badly) the death of a spouse, both of which were situations that compelled the families, either on their own volition or in a small number of cases, on advice from outside sources (doctors, social workers) to feel that their relative was unable to cope alone. Under these circumstances the family felt it was necessary for the elderly person to move in with them. This is reflected in the reasons families gave on why family care was preferred. (Table 3.10)

In deciding about whether a move ought to have taken place three quarters of the households claimed they had no option but to take the course of action they did. What came through overwhelmingly was the rejection of any form of institutional care as a feasible alternative.

Carers whose dependent elderly relative had lived with them for a long time were able to distinguish between the period where no care was given and the period where care began. However as the elderly person grew older, caring

functions probably were performed although they may not have been recognised as being such. These carers were able to decide that caring began at a certain point which usually coincided with a sudden decline in physical health requiring from them a stronger care commitment.

### Caring Experiences

As time went on the care provided became more extensive. Although families were initially not opposed to the elderly person moving in, the decline in health and greater dependency did cause stress and tension between different members of the families. It was not uncommon for comments like

"They didn't mind at first ... they sometimes feel now that it isn't right, ... that I should be with them ... but how can I do that if I have to look after my uncle ..."

Many carers reported feelings about being caught in the middle, of trying to give attention to the elderly while feeling that they were neglecting their family.

The provision of extensive care meant that carers experienced many difficulties. These difficulties as revealed in Table 3.11 show that 'neglect of family commitments' and 'loss of independence' were significant outcomes of extensive care.

TABLE 3.11  
DIFFICULTIES EXPERIENCED WITH CARING

Difficulties Experienced	Responses*	Per cent of Respondents
Neglecting family commitments	21	28.0
Loss of independence	27	36.0
Poor health causing problems	11	14.6
Shopping curtailed	4	5.3
Outings limited	11	14.6
Privacy decreased	10	13.3
Caring made more burdensome	12	16.0
None	4	5.3

\* Multiple Responses

Despite the problems associated with care, the carers as reported above overwhelmingly rejected nursing home care. Almost 80 per cent did not recognise that alternative living arrangements may have been possible when the question of care first arose. When faced with what conceivably may have been an alternative to home care, most families really never perceived themselves as having any real option. To them, there was a clear duty or obligation to care, whether it was because it presented an opportunity "to repay my mother for her past help" or because "families ought to look after their parents". This sense of duty or obligation was also reflected in their reluctance to consider the hypothetically posed question that there may come a time when nursing home care was the most practical, sensible and workable solution.

Almost two-thirds (65%) responded to this question by admitting some possibility of nursing home care existed but only when the elderly relative became so physically dependent that the care required was beyond their means especially if the elderly person became confused, incontinent and generally unaware of their surroundings. However they rarely felt that their relative would last to this stage. The other 35 per cent were adamant that "as long as I am alive, my mother will never be placed in a nursing home". For quite strong reasons, they never really entertained the idea of nursing home care. Put simply, it was their role and duty to look after parents who cannot maintain themselves.

The reasons for their rejection of institutionalised long term care are multifarious and reflect cultural, political, social and personal values. Many were wary of the standard of care provided by nursing homes, and often were persuaded by criticism in the media that nursing home care was the last desperate resort for any family. A few, however, had experienced the care provided by an individual nursing home and had quickly terminated the relationship. On the whole, the attitude to nursing home care emanated from a mixture of guilt, cultural expectations and family responsibility toward the elderly.

This provides evidence that families are not, as many pundits believe, dumping elderly relatives into various forms of formal care and eschewing a caring role. The families in our sample certainly are not surrendering this caring role to the state or state supported mechanism. (A note of caution must be expressed here for our sample dealt only with elderly people in a

domestic situation and did not reach elderly people alone in institutions. However the strength of support among our sample provides evidence that a significant number of families play a strong caring role). Providing care, however, takes its toll.

Generally the elderly relatives had undergone physical and mental deterioration since the family had first commenced to care. Over 60 per cent of the elderly had suffered further impairment to their ability to make judgements about life and for almost 70 per cent the state of emotional health had worsened. Complementary to this decline was a decrease in the ability of the elderly to perform daily living tasks. As Table 3.3 (above p.31) shows, for almost all of the daily tasks, they required assistance. Only in the areas of eating, money handling, caring for appearance, movement about the house, and bladder and bowel control was there any real degree of independence.

That caring is an onerous burden is clearly shown by the fact that of the 1057 different responses in Table 3.12, just one per cent of responses suggested any improvement.

While the elderly suffer from chronic conditions it has taken time for interested parties to recognise that the carers may also be starting to exhibit effects of ageing. More so now, the literature on ageing is replete with examples of research studies which show convincingly that the role of carer is made more difficult because of the imposition of their own deteriorating health.

In our study the carers mostly fell into the 50-60 age group and exhibited some distinct patterns of ageing. There was evidence of the beginnings of arthritis, bad backs, high blood pressure and heart problems which all contributed to making caring more difficult especially in the area of lifting and turning of immobilised elderly relatives. The most striking feature concerning the health of the carers was that when they themselves became ill, they (apart from those who were able to call upon the help of a husband or relative) were forced to continue.

The decline in functional ability of the elderly had profound effects on the lives of the carers and on other family members. Looking at Table 3.12 (p. 42), the areas where most effect was felt were on recreational and

TABLE 3.12

CHANGES IN CARERS' LIFESTYLE SINCE CARING BEGAN

Changes in Lifestyle	Improved		No Change		Deteriorated		Total
	N	%	N	%	N	%	
Time available for recreation and leisure activities	0		15	21.3	59	78.7	75
Family's financial situation	3	4.0	56	74.7	16	21.3	75
Performance at work	0		1	16.1	5	83.3	6
Plans for seeking employment	0		54	72.0	21	28.0	75
Ability to complete housework and chores	0		36	48.0	39	52.0	75
Health and physical stamina	0		35	46.7	40	53.3	75
Relationship with spouse	1	5.6	7	38.9	10	55.6	18
Relationship with children	0		14	70.0	6	30.0	20
Relationship with brothers/sisters	0		4	10.5	34	89.5	38
Relationship with elderly relative	1	1.3	51	68.0	23	30.7	75
Feelings toward elderly relative	3	4.0	49	65.3	23	30.7	75
Relationship with friends	0		38	50.7	37	49.3	75
Plans for the future	0		48	64.0	27	36.0	75
General emotional state	2	2.7	38	50.7	35	46.7	75
Feelings of self-worth	0		46	61.3	29	39.7	75
Ability to relax and sleep through the night	1	1.3	29	38.7	45	60.0	75
Feelings about growing older	0		37	49.3	38	50.7	75



leisure activities (79%), work performance (83%), relationship with siblings (90%), relationship with spouse (56%) and sleeping patterns (60%). Other areas were less affected and still other aspects had not changed. The cumulative effects of debilitation became evident particularly in regard to the ability of carers to go out. For almost 51 per cent, going out was impossible while about half of those who stated that they could leave the elderly person alone were only able to remain absent for about two hours. This limited absences to essentials such as shopping. Making holiday arrangements became a very complicated procedure and often was impossible to attempt. Over 60 per cent of the carers had been unable to take a holiday for more than two years. The difficulties arose not only in try to find someone to provide substitute care but to find someone who they could trust to give the care and attention the families desired. Even if someone was fortunate enough to have a holiday, it never freed them from anxiety and of how the aged relative was coping.

Thus, the changes to the majority of the carers' lives meant that the demands of care intruded into other areas of freedom they once enjoyed. Routine household tasks took longer, relationships with sisters, brothers and family became strained, outside activities especially recreational ones, were severely curtailed, and visits to and by friends less frequent. Feelings about themselves as people became more negative, often causing further disharmony between the carer and the elderly person. Many tended to exhibit negative feelings about growing old, and some were so overcome that they declared never could they permit their children to care for them in a similar way, a feeling strongly put in the following comment - "At eighty I'm going over the Gap. I wouldn't live to put my kids through this". Generally, the overall feeling was that of loss of independence, of having become tied down and without the freedom to engage spontaneously in activities to satisfy their wants and needs.

While health of carers varied among the sample, those in ill-health were denied that restorative tonic, the holiday away.

TABLE 3.13  
HEALTH OF CARER

Condition	N	Per Cent
Excellent	9	12.0
Good	26	34.7
Fair	25	34.7
Poor	14	18.6
Total	75	100

TABLE 3.14  
LENGTH OF TIME SINCE CARER'S LAST HOLIDAY

Time in Years	N	Per Cent
Under 1 year	21	28.0
1 - 2 years	10	13.3
Over 2 years	44	58.7
Total	75	100

### Employment of Carers

Employment in our society is not associated with subsistence but rather with providing income that is sufficient to pursue some or many of the activities which are part of modern industrial society. Except in extremely rare circumstances, income from employment exceeds income obtainable from government social security benefits. Employment furthermore enhances self concept, and exclusion from employment has a profound effect on diminishing one's feelings of self-worth.

The women in our study often found that they could not manage all of the competing expectations on them and in fact almost half of them had stopped paid employment in order to care for their elderly relatives. It was a position that many carers found intolerable and they deeply regretted the loss of employment. One person who gave up work commented "...a job I loved, I could really get my teeth into it". Not only were the women cut off from participating in the labour market, but also reduced from being someone who generated an income to someone whose independence - emotional and financial - was reduced to dependence upon another, a position that was bitterly resented,

prompting one carer to state ' "I have not been a woman but a paid servant for the last five years". Some indicated that they were keen to return to work if the opportunity presented itself, but realistically appraised their chances of doing so as fairly impossible after considering their age, sex and previous employment history. This is a bitter pill in the light of increasing labour force participation rates and general opportunities, after having raised a family, of re-entering the labour force and thereby engaging in rewarding and satisfying activity as well as achieving a degree of economic independence.

Of those who had not been employed at the time caring began, one-third had given up work to have a family or when they first got married. One husband commented - "I married to keep you, not you to keep me". This is not an atypical comment and from such situations, it is obvious that the role of carer was not a new one to most of the women but merely an extension of a pattern firmly established through their marriage. The major effects of giving up employment were not evaluated in terms of the effect on the family but the impact on the carer. Being out of the labour force seemed to be a signal to other family members that the carer's needs were not important, and were always to come last as "everyone demands your time".

There is obviously a high opportunity cost foregone in the caring situation. Only a brief comment on the financial costs of foregone income is made here. Further discussion takes place in the concluding chapter.

Over half of those caring gave up employment in order to provide full time care. This not only entailed social and emotional costs but also financial costs of foregone income. Those that ceased working fell broadly into the occupational categories of clerical workers, assemblers, process workers; metal, electrical; and stenographers and typists. The average weekly earnings for these occupations ranged from \$186 for process workers to \$273 for clerical workers (1981).

After considering the deductions that the average worker faces in these occupations, the foregone income may have been substantial. Some monetary compensation is derived from the \$42 per fortnight Domiciliary Nursing Care Benefit but its adequacy in terms of compensation relative to a wage, falls vastly short. It appears that families who care are relatively more impoverished than those who do not.

## Housing

Housing did not seem to present any great difficulty to many families. Most (81%) owned their own homes. However, some families did experience difficulties in relation to the physical layout of their houses - access to toilets and showers. As most families were owner/occupiers they were able to make minor changes to their homes. Usually this was through the additions of bath and toilet rails, wheelchair ramps, raised toilet seats and non-slip bath mats. A few families had added, at great cost, an additional room for their relative. A small number had purchased relatively expensive communication systems for use in night emergencies. One change that some families suggested might be helpful was access to cheap means of adding an extra room for the elderly person. Separate living space would guarantee some degree of independence to both the aged person and the caring family. Those carers who already had this arrangement unanimously felt that it eased the 'burden' of care for them and, by creating more time for family interaction, less conflict for the family.

## Income and Expenditure

Wages or salaries were the major source of income in just over one-third of the households (37.3%). In many of these households income was supplemented by the elderly relative's pension and/or the Domiciliary Nursing Care Benefit. In the remaining two-thirds of households there was no employment income, but rather government pensions or benefits, or some form of retirement pension. In a significant number of cases there was more than one pension/benefit coming into the household, that of the carer and that of the elderly relative.

TABLE 3.15  
SOURCES OF INCOME BY PERSONS IN RECEIPT

	<u>PERSONS</u>				
	Carer	Elderly Person	Person 1 Husband	Person 2 Son	Person 3 Daughter
Wages and salary	4	-	26	2	1
Age pension	23	66	2	-	-
Widow's pension	4	-	-	-	-
War disability pension	-	1	3	-	-
Service pension	3	-	3	-	-
Superannuation, retirement pension	2	2	5	-	-
Invalid pension	5	1	2	-	-
War widow's pension	1	2	-	-	-
DNCB	61	-	-	-	-
Family allowances	2	-	-	-	-
Dividends, interest, etc.	2	-	1	-	-
Unemployment benefit	-	-	1	-	-
Supporting persons benefit	2	-	-	-	-

However, with the age pension somewhat below 25 per cent of average weekly earnings the total received would still be less than normal employment income. For those living on pensions and benefits, financial problems were a central feature of life. In these circumstances both carer and relative tended to contribute equally to the meagre family income. Where there was employment income, there were few financial problems, and the elderly relative tended to contribute a set amount, as "board" money.

TABLE 3.16  
SOURCES OF HOUSEHOLD INCOME

	Responses*	Per Cent of Households
Wages and salary	28	37.3
Income from business	-	-
Rent from property	1	1.3
Dividends, interest etc.	3	4.0
Age pension	66	88.0
Widow's pension	6	8.0
Supporting Parent's Benefit	3	4.0
War disability pension	5	6.6
Service pension	6	8.0
Special benefit	1	1.3
Unemployment benefit	1	1.3
Superannuation, Retirement pension	9	12.0
Invalid pension	6	8.0
War Widow's pension	3	4.0
DNCB	61	81.3
Family Allowance	2	2.6

\*Multiple Responses

Very few respondents considered that caring for an elderly person was a drain on financial resources. However, this is perhaps not an accurate picture of the financial constraints that many families faced. Although the question regarding whether spending had been curtailed was mostly answered negatively, it could be hypothesised that as income levels declined, so did the spending pattern (often in an unconscious manner). Respondents' answers to expenditure questions were often contradictory. Many had been

obliged to buy surgical aids and appliances (sheepskin rugs, wheelchairs, bed protectors, night communication equipment) to assist with the caring - all fairly expensive items. What seems probable is that spending patterns become restricted in accordance with budget limitations, and although faced with financial hardship, the families manage to function effectively. Just how 'well' they manage is indicated by a majority feeling that the purchase of any additional aids or appliances would significantly lessen the burden of caring.

Some financial assistance and independence was provided to carers by way of the Domiciliary Nursing Care Benefit (DNCB) although, depending on which nursing service was used, its contribution to household income was eroded because of the charge of home nursing services. Of the 83 per cent who were receiving the benefit, some 64 per cent had been caring for over one year before they actually received it. Other carers had not been informed that the benefit was available (sometimes for upwards of one to two years), while some other carers refused to accept it because they felt it was wrong to accept payment for something they regarded as a family obligation.

Knowledge of the benefit came from a variety of sources including doctors, social workers, media and friends. Surprisingly, doctors who have the most contact with families who care, were an infrequent source of referral to the benefit. Since families who decide to provide long-term care are initially in contact with doctors, one solution to the problem of delays in application for the benefit may be to ensure that doctors are aware of its existence and inform families of their entitlement.

#### Services Knowledge and Usage

The study attempted to ascertain the extent of the respondents' knowledge of the types, location and availability of services within their area. As Table 3.17 (p. 49) indicates, respondents were asked about twelve services and asked to respond in one of six ways. The vast majority had never heard of most of the services. The service most heard of and used frequently was, as would be expected, the home nursing services, followed by day care centres and respite beds. Other services like granny sitting, shopping and home visiting services, fell predominantly into the 'never heard of' category. There were, however, significant differences between the Sydney and Tasmanian samples (see Table 3.18, p.50).

TABLE 3.17

## KNOWLEDGE AND USE OF SERVICES BY CARERS

Services	Heard of, available and used	%	Heard of, available but not used	%	Heard of but not available	%	Heard of but don't know if available	%	Applied but refused	%	Never heard of services	%	Total
Cleaning	1	1.3	8	10.7	1	1.3	1	1.3	-		64	85.3	75
Linen or Laundry Services	3	4	7	9.3	1	1.3	-		-		64	85.3	75
Home Help	4	5.3	18	24.0	1	1.3	10	13.3	-		42	56.0	75
Shopping or Delivery Services	-		3	4.0	-		3	4.0	-		69	92.0	75
Home Visiting Services	2	2.7	1	1.3	1	1.3	5	6.7	-		66	88.0	75
Grannysitting Service	5	6.7	1	1.3	-		6		-		63	84.0	75
Day Care Centres	12	16.0	15	20.0	-		8	10.7	-		40	53.3	75
Respite Beds	10	13.3	14	18.7	-		7	9.3	-		44	58.7	75
Home Nursing	69	92.0	1	1.3	-		5	6.7	-		-		75
Home Chiropody Service	6	8.0	8	10.7	1	1.3	6	8.0	-		54	72.0	75
Meals-on-Wheels	4	5.3	28	37.3	2	2.7	8	10.7	-		33	44.0	75
Other Meals Services	-		1	1.3	-		1	1.3	-		73	97.3	75

TABLE 3.18

PERCENTAGE NEVER HEARD OF SERVICE

Services	Sydney Sample	Tasmanian Sample
Cleaning	80	91
Linen or Laundry Services	100	68
Home Help	77	31
Shopping or delivery Services	92	91
Home Visiting Services	95	80
Grannysitting Service	87	80
Day Care Centres	75	28
Respite Beds	75	40
Home Nursing	-	-
Home Chiroprody Service	75	68
Meals-on-Wheels	65	20
Other Meals Services	95	71

Not only were services poorly utilised by the respondents but their claim on the amount of services used was limited. For example, it appears from our research that the home nursing service has two discrete functions. The visits by the nurse were either to ensure that adequate health care standards were being maintained or to bathe the elderly relative. On average each visit lasted 15-20 minutes three times per week. Thus, most families were claiming under one hour of assistance a week. The story does not end there. Since nursing services are currently overloaded, most of the carers had a routine whereby the elderly person was undressed and waiting for the nurse's visit along with a change of clothes for the nurse to dress the patient. Frequently the nurses, because they were hard-pressed, left the bathroom untidy and it was left to the carer to tidy up. This prompted some carers to say that in some respects, these visits actually increased the burden of nursing care.



It is of interest to note that several services were familiar to a significant proportion of respondents, were available in the area, but not used. Some 24 per cent of carers had heard of home help, 20 per cent had heard of day care centres, 19 per cent had knowledge of respite beds and 37 per cent knew about meal-on-wheels, yet these carers did not make use of these services. There seemed to be an obvious reluctance to accept help from some outside sources. Whether this reluctance would apply equally to other services is not known. Whether the service does not match their expectations or standards, or whether the intrusion of a formal service is unwelcome is not known. In answer to the question about problems they may have faced when confronted with a need for assistance, but without the knowledge of where to find it, most replied that such occasions had not been encountered during the period of caring. Yet there was some evidence to the contrary. Claims had been made that services were really not required, but when carers were asked how the lives of people caring could be made easier, their answers tended to refute these claims.

When asked, however, to nominate services which might make family care easier, there was no one suggestion which was made by a majority of respondents. Apart from short-term care (granny sitting/visiting service) the only other significant response was for better knowledge of services.

TABLE 3.19  
SUGGESTIONS FOR SERVICES TO MAKE FAMILY CARE EASIER

Suggestions for Services	Responses*	Per Cent of Respondents
Granny sitting/Visiting service	33	44.0
Knowledge of services	21	28.0
Transport services (e.g. shopping, recreation)	10	13.3
Granny flat	4	5.3
Home Help	9	12.0
Moral support service	5	6.6
Minding service to allow carer 1 week off in 4	10	13.3
Respite Care	10	13.3
None	11	14.6

\*Multiple Responses

The services nominated would not attempt to replace the existing system of care but complement it. It is important to note that the carers did not see themselves being replaced by the services but rather being assisted to perform more effectively and to alleviate temporarily the burden of care upon themselves. However, there is a particular dilemma relating to service knowledge and usage. Most services are already stretched to their limit and if more people were aware of the services an even greater crisis than presently exists could result. Service providers have a responsibility to let the potential clientele know of the service, but the catch 22 is once they inform people of the service the chances are they will not have the capacity to deliver the services adequately. This points to a situation that requires very careful bolstering and support.

#### IV CONCLUSIONS AND IMPLICATIONS FOR SOCIAL POLICY

In a recent revision of his famous 1960 study Filial Responsibility in the Modern American Family, Alvin Schorr points out that filial responsibility, i.e. the responsibility of children to care for their aged parents, as a precursor or alternative to care by government or charitable institutions, is a relatively modern idea and that it came into prominence only as economic changes loosened the grip of aged parents on property and income. For the bulk of the elderly, there was no golden age hundreds of years ago, where family care was more forthcoming than it is today. In the period, however, from the advent of the industrial wage system to the firm establishment of the Welfare State, dependent and poor elderly relatives usually had no place to go other than to their children. However, in this period lifespan was shorter than it is today and proportions of elderly people in the population were much lower. While there was no 'golden age' there certainly were, earlier this century, expectations of care. In the United States, however, in the quarter century from 1952 to 1976, the proportion of elderly people living with adult children halved. (It dropped from one third to one sixth - see Schorr 1980, p.13).

In all western nations provision for old age was regarded, until earlier this century, as a matter for the individual and his/her relatives. In the U.K. in 1954 the Phillips Committee (Report of the Committee on the Economics and Financial Problems of the Provision for Old Age, Cmnd 9333, HMSO - cited in Carter 1981b, p.223) endorsed the notion that community services should help old people stay in their own homes and argued that children should not sacrifice themselves to care for ageing relatives. As Carter (1981b, p.233) points out, a considerable social and attitudinal change came with the Phillips Committee's public endorsement of the 'right' of adult children to lead a social and economic life separate from that of their ageing parents.

This 'public endorsement' of household separation has in part formed the basis for the belief that families were no longer concerned to care for their elderly relatives. There was infused into social thinking a pervasive ideological myth that increased state provision in the form of social services and institutional care had eroded the basis of family care.

Data from our survey overwhelmingly demonstrates that the desire of families to provide care is extremely strong. Far from being isolated from the living circumstances of the elderly, the family appears to be the fulcrum around which are built the networks that sustain the well-being of the elderly. Over 75 per cent of the families assumed responsibility for care for reasons that otherwise would probably have resulted in the elderly person being admitted to some form of institutional care. The willingness of families to care is reinforced by the fact that some 65 per cent of families interviewed would only use institutional care as an extreme last resort while 35 per cent refused to even consider that an option of institutionalization existed.

Alvin Schorr argues that much of the sociological literature which characterizes living together as destructive of family life is off-target. Citing American studies, he suggests that the emphasis on the nuclear family as the norm, as the basic economic and emotional unit, means that living together is a recognition of failure, and ipso facto an imposition. The argument is ideological, for independent living is an article of the American creed and living together is a "lifeboat response" by family members when need is desperate and they cannot help in any other way (Schorr 1980, p.2). He suggests that evidence of severe family tensions and painful conflicts is often anecdotal, yet concedes that such arrangements "may cause problems", but that the studies "do not establish that it necessarily causes problems" (p.17). Our study was not one of cause and effect, but it did identify a greater degree of disharmony than Schorr suggests exists in the U.S.A. and it identified deteriorations in lifestyle.

The data showed convincingly that family care entails considerable financial, social and emotional costs to both the family and to the principal carer. This tends to negate the blanket assumption that families are mostly well equipped to provide and survive the totality of care required in caring for elderly relatives. There are direct costs borne by the family through expenditure on costly items such as rails for toilets and bathrooms, bathing accessories, inter-communication systems for reducing sleep disturbance, and bedding and linen. Indirect financial costs, fall mostly in the first instance on the carer through forgone income from involuntary withdrawal from paid work, and then on the family by reducing its disposable income.

In addition to the direct and indirect financial costs, families also experience tremendous emotional burdens. Considerable tension and conflict

is generated within the nuclear family unit and between members of the extended family. The outcome of the tension generated is unequally distributed within the family and usually falls heaviest on women, who in the majority, are principal carers. Apart from the loss of independence, a changed life-style for the worse and a resumption in many instances of economic dependence upon a spouse, or the state, there emerges a conflict of roles whereby the woman is faced by competing demands for her love and affection, a position that Brody (1981) has described as "being in the middle", of roles as mother, carer, worker, wife. Coupled with decreasing health status associated with ageing by the carers, it places women in an invidious position within the social construction of reality. Their reality becomes constrained within the parameters set by the experience and necessity of caring from which there appears no escape. Loss of employment usually means their status is devalued and because caring has no social status, they gain little positive reinforcement of and understanding about their new role. Exceptions to this are the carers from families of higher-socio-economic positions. In this instance larger family resources permit the luxury of purchasing market services and greatly increase the freedom and choice about social activities for these carers. There is not the same narrowing of social environment for carers within families imbued with greater market power and capacity.

It is often envisaged that family care equates to care being shared by members of the immediate family and also with members of the extended family. This in reality is not the case. Family care usually equates with care by women as Finch and Groves (1980) have pointed out, with minimal support ensuing from spouses and children and the extended family. Our data accord with British and American evidence that predominately one child was 'selected' for care and mostly other siblings gave token support such as visitations and infrequently day outings (Nissel and Bonnerjea, 1982; Cantor, 1981). Thus family care, instead of welding a family together rather tends to create rifts and divisions between relatives that ultimately lead to unequal distributions of care.

Besides the minimal support offered by relatives, as has been shown before, (Bayley, 1973; Nissel and Bonnerjea, 1982) carers often had little support to call upon from neighbours and friends. This depended partly on the carers' reluctance to intrude upon neighbours, on neighbours not really seeing a role for themselves, and partly because carers felt guilty about asking others for

help when they were actually responsible for care. This reluctance, whether it stemmed from fear of intrusion or guilt also permeated carers' attitudes to the use of social services. Some carers used day care and on occasions respite beds to provide breaks in care, and, while acknowledging that they were very helpful, were beset by feelings of guilt, first at wanting a break and second at placing their elderly relatives in the care of others.

The picture that emerges is of a caring situation that involves disruption and adjustment after resulting in the isolation of the caring family from almost all informal and formal networks. In turn, this isolation increases the pressures experienced by families providing care; pressures that result in cumulative social, emotional and financial costs. It is instructive that family care entails heavy costs because embodied in the current rhetoric is the belief that community care is a less costly form of care. On the basis of the findings of our study, it would be invaluable if a framework could be developed that would enable the relative costs of each form of care to be calculated. A recent background paper on the extra costs of disablement published by the Social Welfare Research Centre incorporates a framework for calculating the costs of disability for the disabled person and her/his family (Horn, 1981, pp22-24). A much broader framework has been proposed in a recent British study of family care of the handicapped (Nissel and Bonnerjea, 1982, p.59). Their framework accounts for the costs entailed in the provision of both family and community care, and encompasses both formal and informal services. They further divide the costs into direct and indirect costs within each sector of care. Only when all costs are calculated and compared, can any rational planning occur and the appropriate policy responses identified.

Any prescription proposed, however, must start from an ideological base and commensurate views about intervention into what might be regarded as personal, private family matters. Obviously different families will cope differently, but it would be erroneous to assume that solutions lie in the domain of better personal relations.

Our study sought to provide some reflections on and explanations of the process of family care. In doing so, it attempted to gather data that would go some way to answering the perplexing question of the role that the natural community supports (family, neighbourhoods) had in assisting in the care of the elderly and their interface with the state sector of care. The state/

family/voluntary relationship is ill-defined and precarious at best. Criticism has often been levelled at the state that it abrogates its responsibilities of care in favour of increased responsibility by the family/voluntary support systems.

While all social institutions, including "the family", change over time, a comprehensive study was recently carried out to assess whether the state is, in fact assuming more responsibility and the family less, in caring for disabled young, and frail elderly dependents. Basing his research in Britain, Robert Moroney found that families are "continuing to provide care and there is no evidence that families are actually transferring the caring function to the state or that they are becoming less viable social institutions" (Moroney, 1976, p.136). Moroney found that public sector expenditures tended to support the family rather than substitute for it.

It is important to note that family policy usually takes a dual thrust. On the one hand there are policies designed to affect families - to strengthen, enlarge or limit families. On the other there are policies designed to use, exploit or rely on families in carrying out social welfare functions (Macarov, 1978, pp.47-59). The dual aspects of family policy have already been placed on the political agenda in Australia and debated at length in the literature. Bettina Cass (1981; 1982) has traced how family policy has come onto the political agenda in Australia and argued that this has coincided with the period of "restructuring" of the welfare state in a time of a decline in the rate of economic growth and high rate of inflation and unemployment. After an extensive review of the evidence, Brian Head (1980, p.50) concludes that there seem to be no persuasive grounds for believing that governments in the advanced capitalist societies are likely to bring about major increases in the welfare of the poorer half of the people in the next decade or two. It is crucial to understand welfare politics, and the politics of backlash (see Graycar, 1979, Chap.9) as one contemplates policy options in the field of family care. The highly dependent situations which arise and deeply troubled aspects of caring will need, for their alleviation, an increase in public expenditure. It is difficult to pose options which do not involve expenditure increases. It would be dangerous to be lulled into the belief that expenditure cutbacks will be made good by informal care - care coming from family members and unpaid volunteers.

While families are not likely to be able to extend caring functions

policies must be developed that enhance the natural system of family care, rather than cause its disintegration and destruction.

From this study we have identified difficulties and problems that suggest that families providing care require two levels of supportive services. At one level services are needed to provide support to the family unit and at the other level, services ought to be provided which are directly aimed at aiding the principal carer, in an attempt to allow her to co-ordinate and fulfil her continuing role as worker, mother, wife and carer.

Services aimed at supporting and easing the burden of care for families include:

#### Day Care

Day care centres are those which offer some form of social contact and recreation during the day. This usually means that the activities incorporated into the centre are oriented mostly towards social activities, arts and crafts and a variety of treatments. Depending on their resource levels, some centres incorporate a rehabilitative function and offer more specialised forms of medical care (i.e. physiotherapy, occupational therapy). It has turned out that the most positive function of day care is in providing relief to the caring relative. In a recent study of Day Care, Jan Carter (1981b), points out that a significant number (varying from 1 in 4 to 1 in 7) of those working in day services of various sorts considered that one aim of the service was to give relief to families (p.219). This means that targets were not just the elderly but the family as well. As one occupational therapist interviewed said: "Success is when you see somebody helped to live at home and coping with their problems. Success is in helping their relatives". (Quoted by Carter, 1981b, p.219).

Overall, however, in British dayservices the aim of relieving relatives is "rarely fulfilled" at the present (Carter, 1981b, p.225). This is significant, because the U.K. has so many more services than Australia. Suggestions as to why this is so, range from the guilt that carers feel in using other avenues of care (Tinker, 1981) to the limitations of use imposed by the operating hours of day care centres. From our study, both elements existed but carers felt that they would like day care centres to operate on more flexible hours giving more opportunities for relief at night.



### Respite Care

This is offered to families on the basis of short term visits during crisis situations. Mostly it is used by families when illness prevents the carer from tending to her dependent elderly relative and substitute care is urgently required. Often families complain that the provision of respite care in residential settings leaves a lot to be desired in the form of care provided. Many complaints have arisen because upon returning home the elderly relative showed a marked deterioration in health status. This only adds to the burden of care and many families become extremely hesitant to use such care. A more beneficial service would be one that offers rehabilitative care that hopefully would maintain if not improve the current health status of the elderly relative. The services should also be expanded from a service that families use only in a crisis situation, to one that would provide relief to families on other occasions, for example, by giving them the opportunity to take short holidays. In effect, this enables them to have a break from caring, a need that families have as data from our study show.

### Gransitting/Home Visiting Services

Often the isolation of many families could be broken by services to families which provide for somebody either to stay with the elderly person while the carer goes out, or to visit with them. This provides a way of both giving carers a break and introducing to the elderly person a new point of social contact. Often the elderly relatives are bereft of outside sources of stimulation, and their lives and that of the carer tend to become inseparable. Outside stimulus could provide a whole different perspective by arousing other interests in what sometimes is a stultifying relationship.

As our study showed, the effects on the carers of family care were very damaging. Over 50 per cent were forced to give up a job and generally most experienced a deterioration in many aspects of their lifestyle. The loss of a job involves a consequent downgrading of status and for carers it means moving into an area of work that is unpaid and generally unrecognised as contributing to the productive endeavours of society. Thus they fall into a demeaning social position with many becoming isolated and removed from social relationships that bestow social identity. The conflicting roles of wife, mother and carer that they are expected to carry out generate great tension and anxiety. It would be very beneficial for them if there was social

recognition of their role and of its implications for the enhancement of a dependent population group. Carers could benefit from the establishment of organised carers' groups that endeavoured to provide a mutually reinforcing network for those experiencing any problems or difficulties. For example, these groups could help desensitize carers from feeling guilty over seeking an alternative form of short-term care.

Our study gives weight to the already established fact that family care is central to the welfare of the elderly and what is required now is a range of services to support the family in its role. Social policy should aim at establishing a fully integrative social care system incorporating a floor of formal services to complement and supplement the existing range of community care services.

Although the major portion of care is provided by families, under present economic exigencies we are beginning to see the emergence of an ideology which limits acceptance of public responsibility in the provision of services, unless they are being directed to the "truly needy", these being elderly people totally without informal and family support systems. As a recent British study points out the burden of care falls upon formal systems of care only when other informal support systems are non-existent or break down (Nissel and Bonnerjea, 1982).

It must be realised that the family is currently acting as a hidden welfare service and is facing increasing pressure to enlarge its supportive functions as institutional care becomes less favourably regarded than community care. Retention in the community is increasingly viewed as a positive public goal yet there has been a singular lack of provision of support services and programs for families who provide longer-term care, who accept the culturally imposed filial responsibility and who erroneously accept the guilt imposed about their inability to meet parents' needs by seeking institutionalization. The study highlights the family as a useful functionary of care but one that has strict limitations. Social policy must adduce the point at which the family becomes a limited functionary and recognise that there will be numerous burdens imposed if continued pressure is placed on the family to provide intensive care (Ward 1978).

# BIBLIOGRAPHY

- Abrams, P. (1977), 'Community care : some research problems and priorities', Policy and Politics, 6(2) : 125-51.
- Australian Bureau of Statistics (ABS) (1977-78), Australian Health Survey : Chronic Conditions, Cat.No.4314.0.
- Barnes, J. & Connelly, N. (1970), Social Care Research (London: Bedford Square Press).
- Bayley, M. (1973), Mental Handicap and Community Care, (London: Routledge and Kegan Paul).
- Borrie, W.D. (1981), 'Australia's population structure and trends', Paper presented at Implications of Australian Population Trends Conference, Academy of Social Sciences in Australia and Department of Immigration and Ethnic Affairs, Canberra, 22 September (mimeo).
- Brody, E.M. (1981), 'Women in the middle and family help to older people', Gerontologist, 21(5) : 471-480.
- Cantor, M. (1981), 'Social care for the aged in the United States : issues and challenges', Paper presented at the International Congress of Gerontology, Hamburg, West Germany, June (mimeo).
- Carter, J. (1981a), States of Confusion: Australian Policies and the Elderly Confused, (Kensington, N.S.W.: S.W.R.C. R & P No.4).
- Carter, J. (1981b), Day Services for Adults, (London : George Allen & Unwin).
- Cass, B. (1981a), 'Wages, women and children' in R.F. Henderson, (ed), The Welfare Stakes, (Melbourne : I.A.E.S.R.), Chap.3.
- Cass, B. (1981b), 'The social impact : changes in paid and unpaid work', in J. Wilkes (ed), The Future of Work, (Sydney : George Allen & Unwin).
- Cass, B. (1982), Family Policies in Australia : Contest over the Social Wage, (Kensington, N.S.W.: S.W.R.C. R & P No.21).
- Crossman, L., London, C. & Barry, C. (1981), 'Older women caring for disabled spouses: a model for supportive services', Gerontologist, 21(5) : 464-470.
- Fanshel, S. (1975), 'The welfare of the elderly : A systems analysis viewpoint', Policy Sciences, 6: 343-357.
- Fengler, A.P. & Goodrich, N. (1979), 'Wives of elderly disabled men : the hidden patients', Gerontologist, 19(2) : 175-183.
- Ferlic, E. & Judge, K. (1981), 'Retrenchment and rationality in the personal social services', Policy and Politics, 9(3) : 311-330.
- Finch, J. & Groves, D. (1980), 'Community care and care in the family : a case for equal opportunities?', Journal of Social Policy, 9(4) : 487-511.
- Gough, I. (1979), The Political Economy of the Welfare State, (London : Macmillan).
- Graycar, A. (1979), Welfare Politics in Australia : A Study in Policy Analysis, (Melbourne : Macmillan).
- Graycar, A. (1981), 'Ageing in Australia : a pointer to political dilemmas', The Australian Quarterly, 54(3) : 280-300.

- Graycar, A. (ed) (1982), Age Care - Whose Responsibility? (Kensington, N.S.W.: S.W.R.C. R & P No.20).
- Graycar, A. & Kinnear, D. (1981), The Aged and the State, (Kensington, N.S.W.: S.W.R.C. R & P No.5).
- Hadley, R. & Hatch, S. (1981), Social Welfare and the Failure of the State (London : George Allen & Unwin).
- Head, B.W. (1980), 'Inequality, welfare and the state : distribution and redistribution in Australia', Australian and New Zealand Journal of Sociology, 16(3) : 44-51.
- Horn, R.V. (1981), Extra Costs of Disablement: Background for an Australian Study, (Kensington, N.S.W.: S.W.R.C. R & P No.5).
- Horowitz, A. (1978), 'Families who care : a study of natural support systems of the elderly', Paper presented at the 31st Annual Scientific Meeting of the Gerontological Society, Dallas, Texas, November (mimeo).
- Howe, A.L. (1979), 'Family support of the aged : some evidence and interpretation', Australian Journal of Social Issues, 14(4) : 259-273.
- Hudson, R.B. (1978), 'The "graying" of the federal budget and its consequences for old-age policy', Gerontologist, 18(5) : 428-440.
- Hunt, A. (1978), The Elderly at Home, (London : Her Majesty's Stationery Office).
- Kewley, T.H. (1965), Social Security in Australia : the Development of Social Security and Health Benefits from 1900 to the Present. (Sydney : Sydney University Press).
- Kistin, H. & Morris, R. (1972), 'Alternatives to institutional care for the elderly and disabled', Gerontologist, 12(2) : 139-142.
- Lefroy, R.B. (1977), 'The elderly person and family life', Australian Journal of Social Issues, 12(1) : 33-42.
- Macarov, D. (1978), The Design of Social Welfare (New York : Holt, Rinehart and Winston).
- McKenzie, R. (1981), 'Sydney home nursing service restricted', Inner Voice, 23 : 66.
- Moroney, R.M. (1976), The Family and the State. (London : Longman).
- Navarro, V. (1982), 'The crisis of the international capitalist order and its implications for the welfare state', Critical Social Policy, 2(1) : 43-62.
- N.S.W. Council of Social Service (1981), Rockbottom. A Report on the Developing Crisis for Home Support Services in N.S.W. (Sydney, N.S.W.: N.C.O.S.S.).
- N.S.W. Council on the Ageing (1976), Dedication - a Report of a Survey on Caring for the Aged at Home, (Sydney : N.S.W., C.O.T.A.).
- Nissel, M. & Bonnerjea, L. (1982), Family Care of the Handicapped Elderly. (London : Policy Studies Institute).
- O'Connor, J. (1973), The Fiscal Crisis of the State (New York : St. Martins Press).
- Rowland, D.T. (1980), 'Living arrangements and the later family life cycle in Australia', Paper presented at the Regional Congress of the International Association of Gerontology. Melbourne, December (mimeo).
- Rowland, D.T. (1981a), Sixty-five not out : Consequences of the Ageing of Australia's Population. (Sydney, N.S.W.: Institute of Public Affairs).

- Rowland, D.T. (1981b), 'Vulnerability and household composition. Characteristics of the elderly in Sydney. Paper presented at the 51st A.N.Z.A.A.S. Congress, Brisbane, May (mimeo).
- Sarantakos, S. (1980), 'The aged and their families : towards integration', Australian Social Work, 33(3) : 13-21.
- Sax, S. & Staines, V. (1981), 'Welfare consequences of population trends', Paper presented at Implications of Australian Population Trends Conference, Academy of Social Sciences in Australia and Department of Immigration and Ethnic Affairs, Canberra, 22 September (mimeo).
- Schorr, A. (1980), '...Thy Father and Thy Mother... A Second Look at Filial Responsibility and Family Policy, (Washington : U.S. Dept. of Health and Human Services SSA Publication No.13-11953).
- Shanas, E. (1979a), 'The family as a social support system in old age', Gerontologist, 19(2) : 169-174.
- Shanas, E. (1979b), 'Social myth as hypothesis : the case of the family relations of old people', Gerontologist, 19(1) : 3-9.
- Spencer, M. & Dorr, C. (eds) (1975), Understanding Aging : A Multi-disciplinary Approach (New York : Appleton, Century-Crofts).
- Tinker, A. (1981), The Elderly in Modern Society, (London : Longman).
- Titmuss, R.M. (1963), Essays on the Welfare State, (London : George Allen & Unwin).
- Titmuss, R.M. (1968), Commitment to Welfare, (London : George Allen & Unwin).
- Townsend, P. (1963), The Family Life of Old People, (Harmondsworth : Penguin).
- Townsend, P. (1965), 'The effects of family structure on the likelihood of admission to an institution in old age : The application of a general theory', in E. Shanas and G.F. Streib (eds), Social Structure and the Family : Generational Relations. (London : Prentice-Hall).
- Townsend, P. (1981), 'The structured dependency of the elderly : a creation of social policy in the twentieth century'. Ageing and Society, 1(1) : 5-28.
- Walker, A. (1980), 'The social creation of poverty and dependency in old age', Journal of Social Policy, 9(1) : 49-75.
- Walker, A. (1981), 'The Concept of Dependency and its Application to Old Age', University of Sheffield, April (mimeo).
- Ward, R.A. (1977), 'Services for older people : an integrated framework for research', Journal of Health and Social Behaviour, 18 March : 61-70.

- No. 1 J. Moller (ed), Data for Welfare Decision Making, September 1980.\*
- No. 2 Peter Saunders (ed), The Poverty Line : Methodology and Measurement, October 1980, \$3.\*
- No. 3 Michael Morrissey and Andrew Jakubowicz, Migrants and Occupational Health : A Report, November 1980, \$3.
- No. 4 Jan Carter, States of Confusion : Australian Policies and the Elderly Confused, January 1981.\*
- No. 5 Adam Graycar and David Kinnear, The Aged and the State : A Working Paper, April 1981, \$4.
- No. 6 Michael Liffman, Immigrant Welfare : A Research Perspective, April 1981.\*
- No. 7 Bettina Cass, Unemployment and the Family : The Social Impact of the Restructuring of the Australian Labour Market, April 1981, \$3.
- No. 8 Adam Jamrozik and Marilyn Hoey, Workforce in Transition : Implications for Welfare, May 1981.\*
- No. 9 Robert V. Horn, Fiscal Welfare Effects of Changes in Australian Income Tax, 1972-73 to 1980-81, May 1981, \$3.\*
- No. 10 Concetta Benn, The Developmental Approach : Demonstration Programs in the Brotherhood of St. Laurence, May 1981, \$2.50.
- No. 11 Bettina Cass (ed), Unemployment : Causes, Consequences and Policy Implications, August 1981, \$3.
- No. 12 Adam Jamrozik and Robin Beck, Worker Co-operatives : An Evaluative Study of the New South Wales Worker Co-operative Programme, August 1981.
- No. 13 Robert V. Horn, Extra Costs of Disablement : Background for an Australian Study, September 1981, \$2.50.
- No. 14 P.R. Kaim-Caudle, Cross National Comparisons of Social Service Pensions for the Elderly, September 1981, \$3.
- No. 15 Adam Jamrozik, Marilyn Hoey, Marilyn Leeds, Employment Benefits : Private or Public Welfare?, November 1981, \$4.
- No. 16 Linda Rosenman, Widowhood and Social Welfare Policy in Australia, January 1982, \$3.
- No. 17 Adam Graycar and Wendy Silver, Funding of Non-Government Welfare : Agencies Serving Disabled People in Western Australia, January 1982, \$3.
- No. 18 Vivienne Milligan and Margaret McAllister, Housing and Local Government : An Evaluation of the Waverley Community Housing Officer Project, February 1982, \$3.
- No. 19 Tania Sweeney and Adam Jamrozik, Services for Young Children : Welfare Service or Social Parenthood?, March 1982, \$4.
- No. 20 Adam Graycar (ed), Age Care - Whose Responsibility?, March 1982, \$3.
- No. 21 Bettina Cass, Family Policies in Australia : Contest over the Social Wage, May 1982, \$3.
- No. 22 Tania Sweeney, An Analysis of Federal Funding of Children's Services - A Sourcebook, May 1982, \$3.
- No. 23 David Kinnear and Adam Graycar, Family Care of Elderly People : Australian Perspectives, May 1982, \$3.
- No. 24 Carol Keens and Bettina Cass, Fiscal Welfare : Some Aspects of Australian Tax Policy. Class and Gender Considerations, September 1982, \$3.
- No. 25 Jill Hardwick and Adam Graycar, Volunteers in Non-Government Welfare Organisations in Australia : A Working Paper, September 1982, \$3.
- No. 26 Robert Pinker, Theory, Ideology and Social Policy, October 1982, \$2.
- No. 27 Adam Jamrozik and Marilyn Hoey, Dynamic Labour Market or Work on the Wane? Trends in the Australian Labour Force 1966-1981, December 1982, \$4.
- No. 28 Adam Graycar, Government Officers' Expectations of Non-Government Welfare Organizations: A Discussion Paper, December 1982, \$3.
- No. 29 Jan Carter, Protection to Prevention: Child Welfare Policies, January, 1983, \$3.