4 Scenario projections 2003–2013

4.1 Background

A review of United Kingdom literature by Pickard et al. (2000) identified a number of reasons for anticipating a potential decline in the availability of informal care. These include the social changes touched on in Chapter 3, such as the changing structure of the population, rising childlessness, decline in family size, changing living arrangements, shifts in the perceptions of family obligation and commitment, rising divorce rates and rising female employment rates. Many of these trends are evident in the Australian context however; characteristics of the Australian situation compared to that of other developed nations offer greater optimism. Although fertility rates are currently declining, the impact of fewer children per family on informal care capacity may not be seen until the baby-boomers replace their parents at the top of the population pyramid around 2040. In Australia, the post-Second World War 'baby boom' was notably later and longer than many other countries, thus delaying this decline in family size. The 1990–91 Mid Term Review of the Aged Care Reform Strategy concluded that this factor and sustained immigration would contribute to continued growth in the availability of potential carers for some three decades (DHHCS 1991:13).

There remains some evidence of a decreasing rate of informal care, at least in terms of the number of primary carers. Population estimates for the number of carers in Australia were obtained from national surveys conducted in 1993 and 1998 by the ABS. Changes in the methodology for the identification of carers who lived with their care recipients cast some doubt on the validity of comparing the results for these two surveys. Nevertheless, there was a small decrease over time in the number of carers reported in the two surveys and this decrease was more marked among non-resident carers (for whom the methodology did not change) than among co-resident carers.

While hypotheses about the future availability of carers abound, there is inadequate quantitative information on which to make an informed judgment. This chapter presents the results of an AIHW analysis designed to isolate the impact of certain factors on future numbers of primary carers (Jenkins et al. 2003). The analysis did not aim to forecast the future supply of informal care based on the likely effects of a complex milieu of relevant variables, nor was it designed to resolve the debate around the influence of the range of social changes on future carer availability. Its main contribution is to quantify the potential impact of particular social changes should they occur in the context of current demographic trends and under a set of reasonable assumptions. In particular, the project explored the consequences of:

- a continuation of the 'status quo', incorporating demographic and labour market participation trends that were discernible in 1998
- an overall decline in the willingness to care among men and women of all ages
- a decrease in the number of carers that could result from a reduced willingness of women to reduce their hours of paid employment to take on a caring role
- an increase in the number of carers that could result from higher numbers of co-resident spouses and partners.

The projections serve to illustrate future situations that could occur if certain assumptions apply over the projection period (from the observed situation in 1998 to 2003, 2008, and 2013). The scenarios include a future 'baseline propensity to care' scenario, which is calculated as the estimated number of carers that will be available given population growth and projected changes in the population composition with respect to changing labour force participation trends in the working-age population and changing patterns of living arrangement in the older population (presence of a spouse or partner). Baseline carer rates, are, therefore, the proportions of primary carers observed in 1998 for each age group by sex, labour force participation category for the working-age population, and living arrangement category for the population aged 60 years and over. Projections of carer numbers under this scenario are driven by projected changes in the age and sex composition of the population, and projected changes in living arrangement at older ages and workforce participation in the working-age population throughout the projection period. The 'baseline propensity to care' scenario, using 1998 rates, is not necessarily intended to represent the most likely outcome. Rather, it provides a point of reference if current patterns continue and against which the effects of other changes can be compared.

4.2 Approach

Supply and demand based projections

Pickard et al. (2000) notes that two approaches to projecting future levels of informal care dominate the fairly small base of quantitative research in this field. Both have their origins in economic models. In one approach, projections of informal care are demand-led, insofar as the need for care drives the projections of the informal care that is required. In the other approach, projections of informal care are supply-led, in that projections of informal care are determined by how much will be supplied. It is the supply side issues, in terms of the likely future availability of carers, which are of most concern for long-term care planning.

To propose that the supply of informal care bears little relation to the demand for care would be to take an extreme theoretical position. This would imply that the drivers of social change will act to reduce the number of carers regardless of the growing needs of those affected by disability or illness. Nevertheless, it has been observed that many people with considerable care needs do not have a primary carer. In 1998, an estimated 1 million people experienced a severe or profound restriction and the ABS survey estimated approximately 450,900 primary carers, 20% of whom provided assistance to more than one person. However, Chapter 5 highlights the fact that carers, including primary carers, supported approximately 94% of people with a severe or profound restriction. Clearly, the relationship between the need for assistance and availability of informal care is complex and multifaceted. Informal care is sourced from social networks that might or might not include a primary carer. Moreover, informal care can be provided at differing levels depending on the type of help required. For example, Parker and Lawton (1994) observed that help with personal or physical tasks is more likely to come from within the household. The extent to which self-reported receipt of assistance might under estimate the need for assistance, simply because the help received is integral to interpersonal relationships and long-term living arrangements, is unknown.

It is beyond the scope of this report to resolve the debate surrounding the nature of the relationship between the need for, and availability of, informal care. However, some observations about how demand might alter over the projection period and assumptions about how this may affect supply are warranted. The projections of the supply of informal care in the future that are presented in this chapter are based on the number of people responding to the care needs of others by acting in a primary care role in 1998, with future projections based on specified changes in certain variables. Thus, the projections are based on conditions and characteristics that have resulted in the population of carers evident in 1998, including the prevalence of disability. In assuming that disability prevalence remains constant over the next decade, a key factor that could in reality influence supply is held constant in the scenarios presented here.

Projection methodology

It would be optimal to base projections of the future availability of carers on the findings of a time series analysis. Using time series data, the trend observed over a previous period is extrapolated over a future period, taking into account change in other variables. Three techniques based on this methodology were considered: macrosimulation, dynamic microsimulation or the propensity method[4]. In each case, however, insufficient or inadequate data were available to support the use of the technique.

Although carers in the 1993 and 1998 ABS surveys are conceptually the same, the methods used to collect the data were different. The same method was used to identify people who cared for someone outside the household but different methods were involved in identifying carers who cared for someone within the household. In 1998, any responsible adult in the household was asked if there was a carer living in the household. If a carer was identified, he or she was asked a series of questions to determine if they cared for someone inside or outside the household. This method was used in 1993 to identify carers in the household who were caring for someone outside the household. To identify co-resident carers, however, any responsible adult was asked if there was someone with a disability in the household and, if so, the person with the disability was asked a series of questions to identify their carer. If the person identified was another member of the household, then that person was interviewed to determine if he or she was indeed a primary carer.

This difference in survey methodology makes the carer populations measured in 1993 and 1998 incomparable. Further, the 1993 survey resulted in a very small number of carers aged 70 and over and a high number of employed male carers, both of which were considered to be unrepresentative of the carer population. Of the two, the 1998 survey is considered to have generated more reliable estimates of the age distribution of carers and the proportion of employed males who are carers.

The significantly different carer distributions in 1993 and 1998 and the unreliable components of the 1993 survey data mean that projection methods based on time series data cannot be used. A scenarios approach was therefore adopted to overcome data limitations and produce a number of projections based on different assumptions.

The scenarios approach

This chapter looks at alternative scenarios of the availability of primary carers in 2003, 2008 and 2013. The basis for the projections are the findings of the 1998 ABS Disability, Ageing and Carers Survey, specifically, the estimated carer rates that it generated. Carer rates refer

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[4] See glossary for brief descriptions of these projection techniques.

to the number of carers per 1,000 population in a specific category, such as the number of male carers per 1,000 males aged 60 to 64 years who are living with a spouse or partner. In using a scenarios approach, carer rates were applied to projected populations for 2003, 2008 and 2013. Projected populations take into account the changing age and sex distribution of the population and any other variable that is to stratify the population figures. Carer rates and population projections must be available for the same population subgroups because the projections are calculated by multiplying the matrix of population projections by a corresponding matrix of carer rates. Hence, the level of detail that can be incorporated into the projections depends on the availability of population projections at that level of detail that can be used to derive appropriate carer rates.

While it is not difficult to obtain carer rates and population projections for the same groupings of age and sex, for other variables of interest the methodology becomes more complex. For the specific questions that were addressed in this analysis, carer rates and population projections were required to be further broken down by labour force status, and living arrangement. A limitation of very detailed breakdown is that small estimates from the ABS Survey of Disability, Ageing and Carers are subject to high sampling error. To overcome this problem, carer rates for some groups (particularly in relation to male carers) were combined for improved reliability.

4.3 Measures and data sources

Carers

The 1998 ABS Survey of Disability, Ageing and Carers collected information about informal assistance provided by carers according to ABS definitions of 'carer' and 'primary carer' (see Box 1.1)[5]. The main differences between a carer and a primary carer are:

- a primary carer must provide 'the most' informal assistance
- the care recipient of a primary carer must be a person with a disability (as opposed to a person aged 60 or over without a disability as defined in the survey)
- for a primary carer, the assistance provided must relate to one or more core activities.

The projections presented in this chapter relate only to primary carers, since this is the group that provides the most assistance to people with core activity restrictions. Further, information on carers' demographic and labour force characteristics, the care they give, the support they receive, their relationship with the care recipient and the impact of the caring role on their lives is gathered comprehensively for this group and less so, or not at all, for non-primary carers. In this chapter, the terms 'carer', and 'primary carer' are used interchangeably. Scenario projections, therefore, describe possible future outcomes in the size of the same population of carers discussed in chapters 1 and 2.

Carers included in the analysis are those aged 10 years and over. Methodological constraints have precluded the examination of carers aged less than 10 years. However, as the Young Carers Research Project has noted, 'In Australia, young carers have been identified by

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[5] Further information regarding the methodology used in the Survey of Disability, Ageing and Carers can be obtained from ABS 1999a.

services as being as young as 6 years of age, and just under half of young carers are below 18 years of age' (DFaCS 2002:10).

Age, sex and labour force participation

Population projections by age and sex supplied by the Department of Treasury were used in conjunction with the 1998 ABS survey to project the number of carers in each age group by sex. Labour force projections, also provided by the Department of Treasury and consistent with those used in the Intergenerational Report (Costello 2002) are used in the scenarios for which labour force participation is included as a factor in the projection. These labour force projections assume that past trends of increasing female labour force participation and decreasing male labour force participation will continue but taper off as they approach each other. Age-specific population projections for the working-age population were further broken down into labour force participation categories of employed and unemployed/not in the labour force for males and full-time employed, part-time employed and unemployed/not in the labour force for females. The full-time/part-time separation could not be used for males, due to unstable carer rates in certain age groups within these labour force categories.

The ABS Survey of Disability, Ageing and Carers identifies the labour force status of carers, including whether those who are employed work full-time (35 hours or more per week) or part-time (less than 35 hours per week). For the scenario analysis, it was necessary to define 'working-age', conventionally defined as ages 15–64 years, to be between 25 and 59 years, due to high sampling error in estimated carer rates by labour force participation at younger and older ages.

Living arrangement: co-resident spouse or partner

Population projections by living arrangement category were taken from the ABS household and family projections report and are based on the three previous censuses of population and housing (ABS 1999b). The ABS household and family projections were calculated using the propensity method where an assumed proportional distribution of characteristics is applied to population projections by age and sex. This method assumes that trends over the past three censuses accurately reflect underlying changes in living arrangement characteristics, and that this trend will continue to 2013.

In the ABS household and family projections report, living arrangement combines the concepts of 'relationship in the household', 'family type' and 'household type'. Household types include 'family households', 'group households' and 'lone-person households'. Family types include 'couple family with children', 'couple family without children', 'one-parent family' and 'other families'. For couple families without children, two relationships are defined, which are 'husband, wife or partner' and 'other related individual'. For the purpose of the projections reported here, the family types 'couple family with children' and 'couple family without children' with the relationship 'husband, wife or partner' were the categories of interest. ABS projections for all other living arrangement categories were collapsed into one category, identified as 'Other living arrangement'.

The 1998 ABS survey identifies the relationship of the carer to the care recipient and identifies whether carers are usually living with the main care recipient. The relationship category of 'spouse or partner' is the relationship category of interest, in conjunction with co-resident status. For compatibility with the ABS living arrangement projection categories, other relationships and living arrangement categories were collapsed into one.

The Treasury population projections do not contain living arrangement data. For each age and sex category of the Treasury population projections, population proportions projected by the ABS to be in each living arrangement were applied.

An additional assumption was of equal numbers of males and females with a spouse or partner. This was necessary, as the projected ABS living arrangement categories do not provide this data by sex. While the number of same-sex partners is considered to be small, accurate estimates are not available for the period of interest. In addition, same-sex couples are not included as spouses and partners in the ABS Survey of Disability, Ageing and Carers.

4.4 Construction of future scenarios

Scenario projections were calculated separately for three broad age groups, 10–24 years, 25–59 years and 60 years or over. In the youngest group, sex is the only factor in the projection model because more detailed projections involving age and labour force participation category would be susceptible to the effects of unreliable carer estimates from the survey data. In the middle age range, projections were made for every combination of age (25–34, 35–44, 45–54 and 55–59 years), sex, and labour force participation category as previously outlined (see 4.3: Age, sex and labour force participation). Therefore, each scenario for this population group automatically incorporates projected changes in the age and sex structure, and changing patterns of labour force participation in the population at these ages. For the older population (60 years or over), presence of a co-resident spouse or partner was considered a more salient factor in determining primary carer availability than labour force participation. Hence, for this group projections were made for every combination of 5-year age group up to 80 years and over, sex, and living arrangement (co-resident spouse/partner or 'other living arrangement'). Since age, sex and living arrangement form the axes of the projections in the older age group, changing patterns in the age and sex structure of the older population and projected trends in living arrangements are automatically included in the scenario projections.

A 'baseline propensity to care' scenario was constructed for each age group, 10–24 years, 25–59 years, and 60 years or over. This scenario applies 1998 carer rates by projection category to the projected population in that category for each of the projection years 2003, 2008 and 2013. In this way, projected population changes with regard to age, sex, labour force participation (at ages 25–59 years) and living arrangement (at ages 60 years and over) drive the baseline projections. The 'baseline propensity to care' scenario assumes that the ratio of carers to non-carers in each projection category defined by sex, age group and labour force status or living arrangement, estimated from results of the 1998 ABS Survey of Disability, Ageing and Carers, holds throughout the projection period. This is not presented as necessarily the most likely outcome in informal care, but as a baseline against which to compare projections from other future scenarios.

Scenarios other than the baseline propensity to care scenario were constructed to separately consider questions concerning the willingness of women to reduce hours of paid employment in order to care, an increase in older spouse or partners, and an overall decline in the propensity to provide care. The following projection scenarios present a range of plausible future patterns concerning the availability of carers in each broad age group.

Future scenarios for carers aged 10–24 years

Two scenarios for the 10–24 year sage group are common to the other two age groups: the baseline propensity to care scenario and the overall decreasing propensity to care scenario. The results of these two scenarios are combined, as appropriate, with the scenario projections for the 25–59 years and 60 years and over age groups.

Baseline propensity to care scenario

In the baseline scenario, 1998 rates of male and female carers aged 10–24 years were applied to projected populations for this age group. No further breakdown by labour force status or living arrangement was undertaken due to the data limitations discussed above. Projections of carers aged 10–24 years using male and female baseline propensities are compatible with scenarios for the other age groups that assume baseline propensity to care in this younger age group.

Decreasing propensity to care scenario

For the decreasing propensity to care scenario, the rates of carers among males and females in this age group were discounted to achieve a 20% decrease by 2013. This assumption is compatible with the decreasing propensity to care scenario for the 25–59 years and 60 years or over age groups.

Future scenarios for carers aged 25 to 59 years

Factors included in all scenario projections for the 25–59 years age group include age, sex and labour force participation category. Baseline projections for this age group were calculated on the basis of these factors alone. Two other scenarios for this age group describe further assumptions that could impact on the propensity to care in the working-age population, over and above projected population changes with respect to the baseline factors.

Baseline propensity to care scenario

The first scenario for the 25–59 years age group assumes that 1998 patterns of care continue, in relation to each age, sex and labour force participation category in the model. This is the baseline propensity to care scenario, in which the driving forces in the projection model are assumed to be the changing age and sex structure of the population and changing patterns of labour force participation. These include the increasing labour force participation of women that is reflected in the projected population of women in full-time and part-time employment in 2003, 2008 and 2013. According to this scenario, it is assumed that successive cohorts of people aged 25–59 years will respond to the care needs of others by becoming primary carers with the same propensity to care (taking into account age, sex and labour force status) in the future as they did in 1998. This scenario of 'baseline propensity to care' is used as a baseline against which other scenarios will be compared for the younger carers. The scenario is not necessarily proposed as the most likely outcome but rather as a starting point from which the effect of other changes can be assessed.

Women’s career preference scenario

A second scenario assumes that, over the projection period, 20% fewer women in this age group relative to the proportion in 1998 will be prepared to leave work or reduce the number of hours of employment in order to undertake primary carer responsibilities. In 1998, an estimated 22,800 (7%) female primary carers had reduced the number of hours of paid employment, or resigned from a paid position, in order to provide care. According to this scenario this proportion will reduce linearly over the 15-year projection period by up to 20% in 2013. The 1998 patterns of care (baseline propensity scenarios) are assumed to continue, in relation to each age, sex and labour force participation category for all other groups including the 10–to 24–years age group, men aged 25–59 years, and the 60 years and over age group. While the proportion of 20% is chosen arbitrarily, it demonstrates the impact on the supply of carers if there is a significant decrease in the willingness of women to leave work or decrease their work hours to take on the caring role.

Decreased propensity to care scenario

The third scenario assumes a linear decrease of up to 20% by 2013 in the proportion of people aged 25–59 years who are carers in each age group within this range, and across sex and labour force participation categories. While it is not possible currently to quantify the change in the availability of carers that has been occurring over time, there is some indication that the direction of the trend may be towards a decline, at least among non-co-resident carers. This scenario projects the number of carers in future years given what might be considered a pessimistic outlook in which there is an overall decline in willingness or ability to care. The proportion of 20% has been selected to reflect this outlook while remaining within the bounds of what might reasonably be expected given current knowledge.

Future scenarios for carers aged 60 and over

Scenarios for future availability of primary carers aged 60 years or over all recognise age, sex and the availability of a co-resident spouse or partner as the main factors in the projections. Labour force status is not explicitly modelled in the scenarios for older carers.

Baseline propensity to care scenario

The baseline scenario for older carers assumes that 1998 patterns of care continue in relation to each age, sex and living arrangement category in the model and so constitutes the ‘baseline propensity to care’ scenario for older people. The driving forces in the projection model are the changing age and sex structure of the population in this age group, and changing patterns of living arrangement in terms of the presence of a co-resident spouse or partner.

According to this scenario, it is assumed that successive cohorts of people aged 60 years or over will respond to the care needs of others by becoming primary carers in the same proportions (according to age, sex and living arrangement) in the future as they did in 1998. This scenario is not necessarily proposed as the most likely outcome but a baseline against which other scenarios for this older age group can be compared.

Converging life expectancies scenario

The second scenario for the older population assumes linear increase of up to 20% in the proportion of spouse or partner carers over the 15-year period as a result of improving male longevity. Although 20% is chosen arbitrarily, it demonstrates the impact on the supply of carers if there is a significant increase in the proportion of co-resident spouse or partner carers. This increase is a plausible scenario in future years given increases in healthy life expectancy and the consequent probability that more spouses or partners will be available to care for people with a severe or profound restriction. It was assumed that 1998 patterns of care continue in relation to age and sex for older people who are not living with a spouse or partner. The scenario takes into account projected demographic changes in age, sex and living arrangement which are incorporated in the underlying population projections.

Decreasing propensity to care scenario

The final scenario for the future of caring in the older population assumes a linear decrease of up to 20% over the projection period in the proportion of older carers across all age, sex and living arrangement categories, taking into account projected demographic changes in these categories. As mentioned in relation to the decreased propensity to care scenario for the 25–59 years age group, it is not currently possible to quantify the trend over time in relation to carer availability but there is some indication of a decline, at least among non-co-resident carers. This scenario replicates the decreasing propensity to care scenarios for the 10–24 and 25–59 years age groups, as it examines carer availability under the assumption that the proportion of older carers decreases to a notable degree over time.

4.5 Outline of the projection analysis

This section presents the projection results for each scenario. Some results from the 1998 ABS survey that are particularly relevant in this context are presented first, including the population estimates for the variables of age, sex, living arrangement (co-resident spouse or partners) and labour force status. This is followed by the presentation and discussion of future scenarios of informal care for 2003, 2008 and 2013. This section is divided into three parts corresponding to the following age groups:

- carers aged 10–24 years
- carers aged 25–59 years, where labour force participation is used, in conjunction with age and sex, to drive the model
- carers aged 60 years and over, where living arrangement, again in conjunction with age and sex, is employed as the basis for the projection.

The full set of tables for the scenarios, by age and sex, are contained in an AIHW information paper (Jenkins et al. 2003).

4.6 Informal care in 1998

Chapter 1 presented a demographic profile of the 450,900 primary carers in 1998. This population forms the baseline for comparison of each of the projection scenarios. To recap on the main points, the 1998 ABS Survey of Disability, Ageing and Carers revealed that 70% of primary carers were women and an estimated 79% of all primary carers lived with the main recipient of care. An estimated 301,700 primary carers (67%) were aged between 25 and 59 years and another 132,800 carers were aged 60 years or over (29%). Male carers had an older age structure than female carers, with 59% of male carers aged 25–59 years and 36% aged 60 years or over, compared to 70% and 27% of female carers respectively. Eighty per cent of parents who were carers for their child lived with that child. Carers who were children, students or siblings all lived with the recipient of their care. Carers who cared for friends were less likely to live with the care recipient (19%). These trends were similar for both sexes (Table A6).

It is recognised that it would be desirable to project carer availability by carer relationship to the recipient and whether the recipient lives with the carer. This is not possible due to small estimates for carers not living with the recipient and the problem of finding an appropriate base for a carer rate when the caring population is split by a characteristic of the person for whom they care. It is, however, possible to look at this breakdown in 1998 (see Table A6).

Carers aged 25–59 years in 1998

A much lower proportion of carers (48%) aged 25–59 years in 1998 were employed compared to the same age group in the total population (78%; ABS 1999c). This is not surprising given the demanding nature of the caring role as discussed in Chapter 3. Of male carers aged 25–59 years, 55% were employed, compared with 46% of female carers in this age group (Table 4.1).

Table 4.1: Primary carers aged 25–59 years, by age, sex and labour force participation, 1998

Age/sex	Full-time	Part-time	U & NILF[a]	Total carers
Females				
25–34	*5,400	12,100	23,500	41,000
35–44	10,900	29,400	33,700	74,000
45–54	17,500	19,700	42,500	79,800
55–59	**1,900	*5,300	21,000	28,200
Total 25–59	*35,700*	*66,600*	*120,700*	*223,100*
Males		**Employed[b]**	**U & NILF**	**Total carers**
25–34		*3,900	*2,600	*6,500
35–44		12,600	10,300	22,900
45–54		20,200	14,600	34,900
55–59		*6,700	*7,800	14,500
Total 25–59		*43,300*	*35,300*	*78,700*
Persons		**Employed**	**U & NILF**	**Total carers**
25–34		21,400	26,100	47,500
35–44		52,900	44,000	96,900
45–54		57,500	57,200	114,600
55–59		13,900	28,800	42,700
Total 25–59		**145,700**	**156,000**	**301,700**

(a) U & NILF is the sum of the categories unemployed and not in the labour force.

(b) Male labour force participation is not split into full- and part-time because the relative standard errors in the part-time categories were too high to produce reliable estimates.

Source: Jenkins et al. (2003: Table 2).

The majority (79%) of employed male carers aged 25–59 years were in full-time employment. The corresponding proportion for female carers was 35%.

Carers aged 60 years or over in 1998

The majority of carers aged 60 years or over lived with and cared for a spouse or partner (68%). Male carers in this age group were more likely to be caring for a spouse or partner than their female counterparts (88% compared with 57% of female carers). Anecdotally, women take on a wider range of caring roles than men and this is supported by the higher proportion of older female carers who were caring for someone other than their spouse or partner. Only a small proportion of older carers who lived with a spouse or partner were aged 80 years or more (11%; Table 4.2). This is hardly surprising, given that carers aged 80 years or over can become incapable of caring, they or the care recipient might die, or the care recipient might move into residential aged care.

Table 4.2: Primary carers aged 60 years or over, by age, sex and whether they live with a care recipient who is a spouse or partner, 1998

	Relationship to care recipient		
Carer age/sex	**Spouse or partner in same household**	**Other[(a)]**	**Total**
Females			
60–79	44,700	34,900	79,600
80+	*3,300	**1,300	*4,600
Total 60+	*48,100*	*36,100*	*84,200*
Males			
60–79	36,400	*5,700	42,200
80+	*6,400	—	*6,400
Total 60+	*42,900*	**5,700*	*48,600*
Persons			
60–79	81,200	40,600	121,800
80+	9,800	**1,300	11,000
Total 60+	**90,900**	**41,800**	**132,800**

(a) Includes parent, child, other relative or friend in the same or a different household, or spouse/partner in a different household.

— There were no carers in the survey sample in this category.

Source: Jenkins et al. (2003: Table 3).

4.7 Projection results

Projected carers aged 10 to 24 years

Baseline propensity to care scenario

If carer rates remain at 1998 levels by age and sex , primary carers aged 10–24 years will increase in number from an estimated 16,900 in 2003 to around 17,300 by 2013.[6] This represents a 6% increase over the 15-year projection period from 1998 (Table 4.3). By 2013, 10,600 of the 17,300 carers will be female.

Table 4.3: Estimated and projected carers aged 10–24 years using 1998 carer rates, by sex, 1998, 2003, 2008 and 2013

Sex	1998	2003	2008	2013
Females	10,100	10,400	10,600	10,600
Males	*6,200	6,500	6,600	6,700
Persons	**16,300**	**16,900**	**17,300**	**17,300**

Source: Jenkins et al. (2003: Table 4).

Decreasing propensity to care scenario

If carer rates decrease by up to 20% over the 15-year period, an estimated 15,800 carers aged between 10 and 24 years in 2003 will decrease to 13,800 by 2013 (Table 4.4). By 2013, 8,500 (62%) of the 13,800 carers will be female.

Table 4.4: Estimated and projected carers aged 10–24 years given decreasing carer rates (20%), by sex, 1998, 2003, 2008 and 2013

Sex	1998	2003	2008	2013
Females	10,100	9,700	9,200	8,500
Males	*6,200	6,100	5,800	5,300
Persons	**16,300**	**15,800**	**15,000**	**13,800**

Source: Jenkins et al. (2003: Table 5).

Projected carers aged 25 to 59 years

Baseline propensity to care scenario

The variables under examination in the scenarios for carers aged 25–59 are age, sex, and labour force participation category with the distinction between full-time and part-time

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[6] All projections are based on Treasury population projections for 2003, 2008 and 2013, by age and sex.

employment for women. In the baseline propensity to care scenario for this age group, the number of primary carers is projected to increase from 301,700 in 1998 to 361,600 carers in 2013 (Table 4.5). This increase is solely due to projected changes in the age and sex structure of the population and changing patterns of labour force participation in conjunction with 1998 primary carer rates. In this scenario, 265,200 of the 361,600 carers in 2013 will be women. Of these, 121,900 (46%) will be unemployed or not in the labour force, 91,900 will be working part-time and 51,400 will be working full-time. Of the projected 96,400 male carers in 2013, 43,400 will be unemployed or not in the labour force and 53,000 will be employed.

Table 4.5: Estimated and projected carers aged 25–59 years using 1998 carer rates, by sex and labour force status, 1998, 2003, 2008 and 2013

Sex/labour force	1998	2003	2008	2013
Females				
Full-time	35,700	42,500	48,300	51,400
Part-time	66,600	77,200	86,200	91,900
U & NILF[(a)]	120,700	123,400	122,700	121,900
Total	*223,100*	*243,100*	*257,200*	*265,200*
Males				
Employed[(b)]	43,300	47,700	51,800	53,000
U & NILF[(a)]	35,300	39,300	41,100	43,400
Total	*78,700*	*87,000*	*92,900*	*96,400*
Persons				
Employed	145,700	167,500	186,300	196,300
U & NILF[(a)]	156,000	162,700	163,800	165,300
Total	**301,700**	**330,100**	**350,100**	**361,600**

(a) U & NILF is the sum of the categories unemployed and not in the labour force.

(b) Male labour force participation is not split into full- and part-time because the relative standard errors in the part-time categories were too high to be reliable.

Source: Jenkins et al. (2003: Table 6).

Women's career preference scenario

The trend towards greater workforce participation by women, particularly those in the later stages of life, has raised concerns about the impact on the availability of carers. The 1998 ABS survey shows that an estimated 22,800 female carers (7% of female carers) had either reduced the number of hours of paid employment, or resigned from a paid position, in order to care. A key question is whether, in future, women will be less likely to do so and how this might affect the number of primary carers. This possibility was examined by considering the case in which, compared to 1998 proportions, by 2013 up to 20% fewer women will be prepared to reduce their hours of work in order to take up the role as a carer. It is further assumed that this group will not be prepared to undertake a primary care role at all. Carer rates for other projection categories pertaining to the population aged 25 to 59 years are those of the baseline propensity to care scenario, i.e. the 1998 carer rates in each projection category apart from employed women.

The number of female carers in each labour force category is projected to increase despite the 20% reduction in willingness to reduce paid employment (Table 4.6). These increases are the result of projected population growth by age, sex and labour force participation outweighing the scenario effect.

There are projected to be 121,000 female carers unemployed or not in the labour force in 2013, 51,100 working full-time and 87,800 working part-time. Thus, if 20% fewer women are willing to reduce their hours of work to care than was the case in 1998, there will be 356,200 carers aged 25–59 years in 2013 instead of the 361,600 carers projected under the baseline propensity to care scenario for this age group. The projected 5,400 fewer carers aged 25 to 59 years in 2013 represent a reduction of only 1.5% from the baseline scenario. This projection suggests that a substantial drop in the willingness of women to take on a primary carer role because they are not prepared to forgo paid work is unlikely to have a marked impact on the availability of carers to 2013.

To examine the sensitivity of this scenario, projections were also calculated assuming 10% and 30% decreases in the proportion of women who leave work or reduce hours of work to care. This did not notably affect the total number of carers (Jenkins et al. 2003: tables A10 and A11).

Table 4.6: Estimated and projected primary carers aged 25–59 years given a decrease (20%) in the proportion of women who reduce their hours of work to care, by sex and labour force, 1998, 2003, 2008 and 2013

Sex/labour force	1998	2003	2008	2013
Females				
Full-time	35,700	42,400	48,100	51,100
Part-time	66,600	76,100	83,600	87,800
U & NILF[(a)]	120,700	123,100	122,100	121,000
Total	*223,100*	*241,500*	*253,800*	*259,900*
Males				
Employed[(b)]	43,300	47,700	51,800	53,000
U & NILF[(a)]	35,300	39,300	41,100	43,400
Total	*78,700*	*87,000*	*92,900*	*96,400*
Persons				
Employed	145,700	166,200	183,500	191,800
U & NILF[(a)]	156,000	162,400	163,200	164,500
Total persons	**301,700**	**328,500**	**346,700**	**356,200**

(a) U & NILF is the sum of the categories unemployed and not in the labour force.

(b) Male labour force participation is not split into full- and part-time because the relative standard errors in the part-time categories were too high to be reliable.

Source: Jenkins et al. (2003: Table 7).

Decreasing propensity to care scenario

The third scenario for the population aged 25 to 59 years assumes a decrease of up to 20% by 2013 in carer rates by age, sex, and labour force participation category. In this scenario, population growth offsets the 6.7% decline in propensity to care between 1998 and 2003 to realise an increase in carers in this age group from 301,700 to 308,100 (Table 4.7). Thereafter, the decreasing propensity to care results in decreasing numbers of carers aged 25–59 years, to 303,400 in 2008 and 289,300 in 2013. This scenario projects 12,400 fewer carers in this age group in 2013 than there were in 1998. Compared to the baseline propensity to care scenario for this age group, the decreasing propensity to care scenario projects 72,300 fewer carers in 2013.

To examine the sensitivity of this scenario, the projections were also calculated assuming a 10% and 30% decrease in carer rates. Estimates of the number of available carers varied considerably under these alternative conditions. A 30% decrease in carers aged between 25 and 59 years in each projection category (age by sex by labour force participation) would result in approximately 253,100 carers in 2013, whereas a smaller decrease of 10% would result in 325,400 carers aged 25 to 59 years in 2013 (Jenkins et al. 2003 tables A15 and A16).

Table 4.7: Estimated and projected primary carers aged 25–59 years given decreasing carer rates (20%), by sex and labour force status, 1998, 2003, 2008 and 2013

Sex/labour force	1998	2003	2008	2013
Females				
Full-time	35,700	39,700	41,900	41,100
Part-time	66,600	72,100	74,700	73,500
U & NILF[(a)]	120,700	115,100	106,400	97,500
Total	*223,100*	*226,900*	*222,900*	*212,200*
Males				
Employed[(b)]	43,300	44,500	44,900	42,400
U & NILF[(a)]	35,300	36,700	35,600	34,700
Total	*78,700*	*81,200*	*80,500*	*77,100*
Persons				
Employed	145,700	156,300	161,500	157,000
U & NILF[(a)]	156,000	151,800	142,000	132,300
Total	**301,700**	**308,100**	**303,400**	**289,300**

(a) U & NILF is the sum of the categories unemployed and not in the labour force.

(b) Male labour force participation is not split into full- and part-time because the relative standard errors in the part-time categories were too high to be reliable.

Source: Jenkins et al. (2003: Table 8).

Projected carers aged 60 years or over

Baseline propensity to care scenario

The baseline scenario for the population aged 60 years or over assumes that the 1998 carer rate within each 5-year age interval by sex and living arrangement (co-resident spouse or partner versus 'other') is sustained throughout the 15-year projection period. A projected increase from 132,800 carers aged 60 years or over in 1998 to 195,100 in 2013 would result from projected changes in the age, sex and living arrangement composition of the older population (Table 4.8).

The population of older people is growing substantially in size, which results in a larger number of older carers—145,700 carers aged 60 or over in 2003, or a 10% increase on the estimated number in 1998. The number of male carers increases faster than the number of female carers, reflecting a more rapid rise in the older male population. The number of male carers aged 60 years or over is projected to have increased by 14% between 1998 and 2003.

Table 4.8: Estimated and projected carers aged 60 years or over given 1998 carer rates, by sex and whether they live with a care recipient who is a spouse or partner, 1998, 2003, 2008 and 2013

Sex/relationship	1998	2003	2008	2013
Females				
Spouse or partner	48,100	52,900	60,000	69,800
Other[(a)]	36,100	37,600	43,700	52,600
Total	*84,200*	*90,500*	*103,700*	*122,400*
Males				
Spouse or partner	42,900	48,600	55,700	63,800
Other[(a)]	*5,700	*6,600	*8,000	*8,900
Total	*48,600*	*55,200*	*63,700*	*72,700*
Persons				
Spouse or partner	90,900	101,500	115,700	133,600
Other[(a)]	41,800	44,200	51,700	61,500
Total	**132,800**	**145,700**	**167,400**	**195,100**

(a) Includes parent, child, other relative and friend, in the same or a different household, or spouse or partner in a different household.

Source: Jenkins et al. (2003: Table 9).

Converging life expectancies scenario

This scenario assumes an increase in the proportion of co-resident spouses and partners aged 60 years or over who are carers, whilst 1998 patterns of care are assumed to continue for carers whose relationship with the care recipient falls into the 'other' category (and other age groups). As is the case in all scenarios, changes in the number of carers also reflect increasing population size at these ages, and changes in the age and sex structure of the population that are implicit in the underlying population projections for 2003, 2008 and 2013. It is plausible that, as spouses or partners are one of the most willing groups of carers, an increase in the number of couples at older ages will mean higher rates of spouse and partner carers. If this was to amount to a linear increase throughout the projection period, reaching 20% by 2013, then it is expected that there will be 221,800 primary carers aged 60 years or over in 2013, compared with 195,100 under baseline propensity to care conditions for this age group (Table 4.9).

To examine the sensitivity of this scenario, the projections were also calculated assuming 10% and 30% increases in the proportion of spouse/partner carers, which would vary the 2013 projection from 208,400 to 235,200 carers respectively (Jenkins et al. 2003 tables A23 and A24).

Table 4.9: Estimated and projected carers aged 60 years or over given an increase in the proportion of spouse/partner carers (20%), by sex and whether they live with a care recipient who is a spouse or partner, 1998, 2003, 2008 and 2013

Sex/relationship	1998	2003	2008	2013
Females				
Spouse or partner	48,100	56,400	68,000	83,800
Other[(a)]	36,100	37,600	43,700	52,600
Total	*84,200*	*94,000*	*111,700*	*136,400*
Males				
Spouse or partner	42,900	51,800	63,100	76,500
Other[(a)]	*5,700	*6,600	*8,000	*8,900
Total	*48,600*	*58,400*	*71,100*	*85,400*
Persons				
Spouse or partner	90,900	108,300	131,100	160,300
Other[(a)]	41,800	44,200	51,700	61,500
Total	**132,800**	**152,400**	**182,800**	**221,800**

(a) Includes parent, child, other relative and friend, in the same or a different household, or spouse or partner in a different household.

Source: Jenkins et al. (2003: Table 10).

Decreasing propensity to care scenario

The final scenario for the older population assumes a linear decrease in all carer rates over the projection period at ages 60 and over, reaching a 20% decrease by 2013. The decrease applies to the projected population in each projection category in 2003, 2008 and 2013. The scenario implicitly models the changing age and sex composition of the older population, and altered patterns of living arrangement throughout the 15-year projection period. If an across-the-board 20% decrease in the propensity to care were to occur by 2013, there would be 156,100 carers aged 60 years or over in 2013, compared with 195,100 in the baseline propensity to care scenario (tables 4.8 and 4.10). Thus, a 20% decrease in the propensity to care among older carers by age, sex and living arrangement would result in 39,000 fewer carers than if rates remained at 1998 levels by age, sex and living arrangement for this age group.

To examine the sensitivity of this scenario, the projections were also calculated assuming 10% and 30% decreases in carer rates by projection category. Estimates of the number of carers vary considerably under these alternative conditions, from 136,500 for a 30% decrease in rates to 175,600 for a 10% decrease in rates (Jenkins et al. 2003 tables A28 and A29).

Table 4.10: Estimated and projected carers aged 60 years or over given a decrease in carer rates (20%), by sex and whether they live with a care recipient who is a spouse or partner, 1998, 2003, 2008 and 2013

Sex/relationship	1998	2003	2008	2013
Females				
Spouse or partner	48,100	49,400	52,000	55,800
Other[(a)]	36,100	35,100	37,900	42,100
Total	*84,200*	*84,400*	*89,900*	*97,900*
Males				
Spouse or partner	42,900	45,300	48,300	51,000
Other[(a)]	*5,700	*6,200	*6,900	*7,100
Total	*48,600*	*51,500*	*55,200*	*58,100*
Persons				
Spouse or partner	90,900	94,700	100,200	106,900
Other[(a)]	41,800	41,300	44,800	49,200
Total	**132,800**	**136,000**	**145,100**	**156,100**

(a) Includes parent, child, other relative and friend, in the same or a different household, or spouse or partner in a different household.

Source: Jenkins et al. (2003: Table 11).

4.8 Projected total carer pools

The scenarios presented so far have provided projections of the number of available carers for the age groups 10–24 years, 25–59 years and 60 years or over. The total pool of available carers at each of the future projection years can be calculated by combining these scenarios where appropriate.

Projections from the baseline propensity to care scenario for each age group were summed to generate the projected total carer pool under consistent assumptions of baseline propensity to care. Likewise, projections from the decreasing propensity to care scenario for each age group were combined to produce an overall decreasing propensity to care scenario. The projected total carer pool for the women's career preference scenario was calculated as the sum of that scenario projection for the population aged 25–59 years and baseline propensity to care projections for the 10–24 years and 60 years or over age groups. Baseline propensity to care projections for the 10–24 years and 25–59 years age groups were also used in conjunction with the converging life expectancies projections for the 60 years and over age group to generate a total carer pool for that scenario. In this way, the difference between the projected total carer pools for the baseline propensity to care scenario and any one of the other scenarios measures the possible effect of the type and degree of change described by the other scenario. Every scenario incorporates projected population changes with respect to age, sex, labour force participation (for the 25–59 years age group), and living arrangement (for the 60 years or over age group) since these are incorporated into the underlying population projections for 2003, 2008 and 2013. Consequently, differences in the total carer pools of the baseline scenario and each of the other scenarios measure change that is over and above that which is due to demographic and labour force trends throughout the projection period.

Table 4.11 summarises the projected total carer pool in 2013 for each combined scenario. Combined baseline propensity to care projections are the likely outcome if caring rates remain at 1998 levels within each projection category for each of the broad age groups, but the age, sex, labour force participation and living arrangements of the population change in line with current population projections. In other words, the population continues to age, labour force participation rates for women increase, and, at older ages, there is an increasing proportion of intact marriages owing to improving male longevity. The results of this scenario show that in 2013 there would be 573,900 primary carers in a population with a projected 1.4 million persons with a severe or profound restriction[7]. In 2013, on the basis of this baseline propensity to care scenario, there would be around 40 primary carers to 100 persons with a severe or profound restriction (i.e. a care ratio of 0.40). This compares to the 1998 survey estimate of 43 primary carers to 100 persons with a severe or profound restriction, or a care ratio of 0.43.

Table 4.11: Estimated and projected primary carers aged 10 years and over, by sex, 1998, 2003, 2008 and 2013[(a)]

Scenario	1998	2003	2008	2013
		Males		
Baseline propensity to care	133,500	148,700	163,200	175,700
Overall decreasing propensity to care	n.a.	138,800	141,400	140,600
Women’s career preference	n.a.	148,700	163,200	175,700
Converging life expectancies	n.a.	151,900	170,600	188,500
		Females		
Baseline propensity to care	317,300	344,000	371,600	398,200
Overall decreasing propensity to care	n.a.	321,100	322,000	318,600
Women’s career preference	n.a.	342,400	368,100	392,900
Converging life expectancies		347,600	379,600	412,200
		Persons		
Baseline propensity to care	450,900	492,700	534,800	573,900
Overall decreasing propensity to care	n.a.	459,900	463,500	459,200
Women’s career preference	n.a.	491,100	531,300	568,600
Converging life expectancies	n.a.	499,500	550,200	600,700

(a) Differences between the total carer pools of the baseline and other scenarios may vary from differences seen in the age-specific scenario projections to within 100 carers. This is due to rounding.

Source: Tables 4.3–4.10; Table A5 (1998).

The overall decrease in propensity to care scenario, which combines the decreasing propensity to care projections across the three age groups, assumes that carer rates within each projection category decrease linearly over the projection period, up to a 20% decrease by 2013. Again, the previously described age, sex, living arrangement and labour force participation rates continue to change in line with population projections. The projections under this scenario might be considered a ‘worst case’ scenario, in which the decline in carer availability occurs across all ages, for both sexes and across all categories of living

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[7] Numbers of persons with a severe or profound restriction were projected by applying the 1998 rate of people with a severe or profound restriction by age and sex to the projected total populations for 2003, 2008 and 2013 supplied by the Department of Treasury (Jenkins et al. 2003: Table A1).

arrangement and labour force participation. In this scenario, the total number of carers in 2013 is projected to be 459,200, compared to an estimated 450,900 carers in 1998, and a projected 573,900 in 2013 under baseline propensity to care conditions throughout the projection period. In this instance, the ratio of carers to people with a severe or profound restriction would be around 32 to 100 (0.32) in 2013, compared with 43 to 100 (0.43) in 1998, or 40 to 100 (0.40) in 2013 if 1998 caring rates are sustained.

Two other scenarios were considered. One assumes that there will be an increase in the proportion of older spouses and partners who will undertake the caring role (the converging life expectancies scenario). This scenario was calculated on the basis of an increase in the rate of co-resident spouses and partners aged 60 years or over who take on a caring role. The increase is assumed to be linear throughout the projection period, reaching a 20% increase in each projection category (5-year age interval, sex, and living arrangement) by 2013. This scenario projects a total of 221,800 carers aged 60 years or over in 2013 (Table 4.9). In combination with the baseline propensity to care projections for people aged under 60 years, the result is a projected 600,700 carers aged 10 years and over in 2013. Under these conditions, the 2013 care ratio is expected to be 42 primary carers to every 100 persons with a severe or profound restriction (0.42).

Finally, the analysis explored the possibility that women will be less willing in the future to reduce their hours of paid work to care, the so-called 'women's career preference scenario'. The calculation focuses on female carers aged 25 to 59 years. It estimates the impact of a reduction in their willingness to reduce paid employment based on the 1998 proportions who were willing to do so. The decrease is linear throughout the projection period, reaching a 20% decrease in the rate by 2013. Combined with baseline propensity to care projections for age groups 10–24 years and 60 years and over, this scenario yields a total of 568,600 carers in 2013, equating to a ratio of 40 carers to every 100 persons with a severe or profound restriction (i.e. a care ratio of 0.40).

Compared with the baseline propensity to care scenario that applies 1998 rates in all projection categories across the three main age groups, only the overall decrease in propensity to care scenario shows a marked impact on the number of primary carers to 2013 (Figure 4.1). According to this projection, there would be 114,700 fewer carers than if carer rates remain at 1998 levels and the projected population changes in regard to age, sex, labour force participation and living arrangement occur. The scenario with the least impact on the number of carers in 2013 is that of a reduced willingness of women to give up paid employment to care. Under an assumption of a 20% decrease by 2013 in the proportion of women who are prepared to do so, there would be possibly be as little as 5,400[8] fewer carers in 2013 than if 1998 carer rates by projection category are sustained throughout the projection period. It should be remembered that the population projections themselves reflect a continuing increase in female labour force participation and take stock of the relationship between propensity to care and full-time or part-time female employment. The women's career preference scenario models an effect over and above trends in female labour force participation. Significantly, over this particular 15-year projection period, ageing baby-boomers move into age groups that have traditionally registered high proportions of primary carers. For this reason, conclusions based on a comparison of the scenario projections with informal care in 1998 should be viewed in the context of this demographically unique period in time.

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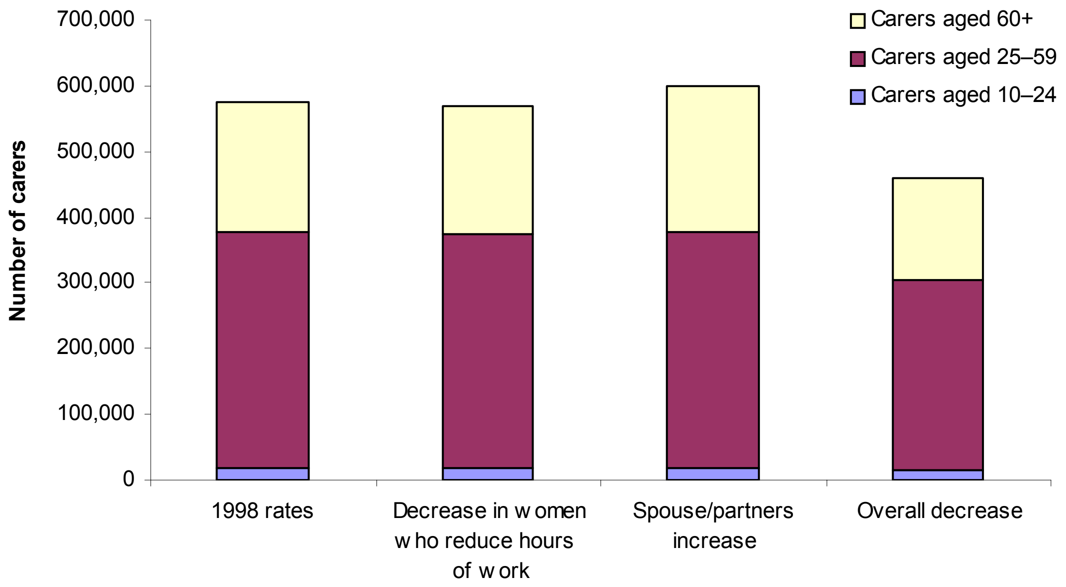
[8] Rounding to the nearest 100 carers in the calculation of the total carer pool increases the difference of 5,300 carers reported in the women's career preference scenario under Projected carers 25–59 years.



Source: Tables 4.3–4.10.

Figure 4.1: Total projected carers for combined scenarios, by age, 2013

4.9 Conclusion

This chapter presents projections of the supply of carers at 5-year intervals from the base year of 1998 through to 2013. Results of the 1998 ABS Survey of Disability, Ageing and Carers were used to describe the characteristics of carers on which these future projections are based. Projected changes in population age and sex distribution and labour force status, as calculated by the Department of Treasury, and changes in living arrangement, as calculated by the ABS, were used to calculate projections based on a set of assumptions about trends in informal care. The four scenarios are:

- existing patterns of caring continue, taking into account the changing trends in demographic structure, labour force participation and living arrangement
- an across-the board 20% decrease by 2013 in the willingness of people to provide ongoing care
- a 20% decrease by 2013 in the proportion of women who have (historically) reduced their hours of paid work, or resigned from a paid position, in order to take on a caring role
- a 20% increase by 2013 in the proportion of older spouses and partners who take on a caring role.

Contrary to the concerns and expectations of some commentators, the results of these projections indicate that a substantial reduction in the willingness of women to substitute time spent in unpaid caring for paid employment is unlikely to have a marked impact on the availability of carers over the next decade. While female workforce participation is projected to rise over the next decade, particularly for women aged 55 years and over, it is unlikely that all of those women continuing or returning to work will not provide care in some capacity. Other research has suggested that women are more likely than men to arrange their working hours to fit in with family caring responsibilities (Fine 1994). Thus, the proposed scenario could be considered an extreme position. The result of projecting the availability of primary carers to 2013 based on this scenario is the same as if there were no change in carer rates over the projection period (both scenarios yield a 'care ratio' of 0.40).

The unique characteristics of the period 1998 to 2013, in terms of demographic change, contribute to this result. This period will see large population increases in age groups that are the traditional source of primary carers. In 1998, women aged between 35 and 64 years accounted for 65% of all female primary carers (ABS 1999a: Table 28). Baby-boomers who survive the projection period will age from between 37 and 51 years in 1998 to between 52 and 66 years respectively in 2013. The women's career preference scenario projection, relative to the situation in 1998, reflects the fact that throughout the projection period the effect of ageing baby-boomers on the primary carer pool will probably mask any decreased propensity to care among employed women.

Nevertheless, these results emphasise the point that a large proportion of female carers is actually in the labour force, highlighting the need to specifically consider employed carers in the ongoing development of carer support programs. Employed women accounted for 34% (102,400) of all primary carers in 1998 and working-age women made up a high proportion of carers of older people. The ability of many women to balance work and family caring responsibilities and to continue to do so into the future will no doubt depend upon the availability of other family and community supports. As the 1999 National Survey of Carer Health and Wellbeing reports, respite care and other services are seen by carers as an integral part of their lives and essential to their ability to continue in their role as carers (CAA 2000). Furthermore, the scenario examines the effect of a reduction in the proportion of women who are prepared to sacrifice employment to provide care, based on a pool of female carers whose motivations and aspirations may be very different to another pool of same-aged potential carers at a future point in time.

The projections also indicate that an increase in the number of older co-resident spouse or partner carers is likely to be the source of a relatively small number of additional carers over the next decade. A scenario which posits a 20% increase in the proportion of co-resident spouse or partner carers over the projection period is likely to differ little from the 1998 situation of 43 primary carers per 100 persons with a severe or profound restriction. This is perhaps an optimistic scenario. It assumes that surviving partners will remain married rather than become divorced or separated, and that, in addition to physical wellbeing, these partners will have the necessary skills and emotional capacity to undertake a caring role. These assumptions may not always find support in reality. For example, Sammut (1996) describes some of the difficulties faced by carers of those with dementia who can sometimes exhibit disturbing and physically exhausting symptoms.

While projections for the career preference and converging life expectancies scenario do not point to any dramatic shift in the level of informal care, measured as the number of primary carers, a 20% decline in the proportion of carers across all age and sex categories and across all labour force and living arrangement categories would have serious consequences. This latter scenario projects a decline from 43 primary carers per 100 persons with a severe or profound restriction in 1998 to only 32 primary carers per 100 persons in 2013. Even compared to the baseline scenario result for 2013 of 40 primary carers per 100 persons with a severe or profound restriction, this represents a marked decline in informal care. It would necessitate looser informal care networks together with formal sources of assistance caring for people who most likely need constant supervision and guidance with core daily activities.

The plausibility of a broad decline in carer availability is difficult to assess, not least because of the multitude of variables relevant in determining carer supply, many of which are not well understood. This report has only investigated the impact of some of these factors and even then only in the artificial environment of holding all other factors constant at 1998 levels, including the provision of cared accommodation. Developing a detailed predictive model to fully address the question of the future supply of carers would require a level of detail in the data, together with time series data, which is not currently available. The absence of time series data from which a trend could be determined also adds to the difficulty of projecting future carer supply. It is not surprising that, until now, there has been no published research into the likely future number of carers in Australia.

4.10 Discussion

Given the constraints imposed by existing national data collections, the most robust methodology in addressing questions about future supply is to construct a set of scenarios which describe a clear set of assumptions and a corresponding range of possible future outcomes. The analysis presented in this chapter follows such an approach, applying trend data for the key variables of population change, labour force participation, and shifts in living arrangement over time. The most common assumption in the absence of actual analysis has been that the future will see a shortage of carers owing to the increasing labour force participation of women. Reality is likely to be much more complex, as many factors come into play in the decision to care.

The projections examined in this report are based on data for primary carers: that is, individuals providing the most assistance to persons with a disability. Many people with a disability receive help from more than one person, usually other family members (Miller & McFall 1991). This group of additional carers is not included in the projections. Thus, scenarios that project a decline in primary carers do not allow for the possibility that these carers will be replaced by carers in other circumstances beyond those identified in the model. A survey of carers by Braithwaite (1990) found that 25% of primary carers took on the role because there was no one else to do so, and 28% of carers said that other potential carers had refused. According to the 1998 Survey of Disability, Ageing and Carers (ABS 1999a), 30% of carers of parents felt that there were no other family or friends available and 19% felt that no one else was willing to take on the role of primary carer. In contrast, Miller and McFall (1991) have observed that additional informal assistance varies in intensity and size (in terms of the number of additional carers) as a function of, among other things, the need of the recipient, with greater care needs finding more support from an additional carer network. The contribution of additional carers and the implications of this for future care burden are difficult to assess and beyond the scope of this report.

Carer accessibility, in terms of geographic location, is a further consideration in the interpretation of the scenario projections presented here. An implicit assumption in the scenario projections is that additional primary carers arising from population growth and ageing will be available in a practical sense. However, the phenomenon of geographic ageing and the tendency of many people to retire to coastal locations will play a part in future patterns of informal care.

While these limitations are important to note, they do not detract from the strength of the conclusions. The scenario projections offer an empirical base for some likely future trends. An overall reduction in people's motivation to provide care, as opposed to the projected increase in female labour force participation, emerges as the main potential threat to the future availability of informal care. Reports from primary carers on the subject of motivation confirm that sense of responsibility and obligation that comes from interpersonal relationship is a prime motivating factor for the majority of carers. Any shift in the balance of care that results from the changing availability of the group identified as primary carers will have implications for the demands placed on formal services and secondary carers.

Jones and Cullis (2003) argue that 'perceptions of the intrinsic value of altruism rely on signals that intrinsic value is acknowledged'. To rely primarily on intrinsic motivation as a driver for the provision of informal care is unlikely to fully realise the capacity of families to care for their own. Family, community and government support for primary carers provides a vital positive signal to continuing and potential carers. Chapter 5 examines formal service use with informal care and describes some important national carer support programs.

5 Informal care and formal services

5.1 Introduction

Formal services provided under the auspices of the Commonwealth–State/Territory Disability Agreement (CSTDA) and programs such as Home and Community Care (HACC), Community Aged Care Packages (CACP), Extended Aged Care at Home (EACH), Veterans' Home Care, and Day Therapy Centres complement the assistance provided by primary and other carers and support people with limited access to informal care. Among all people with a severe or profound restriction in 1998, 46% said they received assistance only from carers, 3% said they were assisted only by formal services, and 48% said they received assistance from carers and formal services (Table 5.1). Formal aged-care and disability services have evolved to offer packages of assistance that are designed to meet the needs of people living in the community. Carers provide direct care and act as advocates in organising and facilitating contact with health and welfare services.

Table 5.1: Type of assistance received by people with a severe or profound restriction living in households, 1998

	Age (years) of person with a severe or profound restriction							
	0–24		25–64		65+		All ages	
Type of assistance	'000	Per cent	'000	Per cent	'000	Per cent	'000	Percent
Informal only	72.8	37.4	257.1	58.3	110.1	33.8	440.0	45.7
Informal and formal	107.1	55.0	160.2	36.3	198.7	61.0	466.0	48.5
Formal only	*8.0	*4.1	*7.4	*1.7	11.5	3.5	26.9	2.8
Not applicable or none specified	*6.8	*3.5	16.5	3.7	*5.3	*1.6	28.7	3.0
Total	**194.7**	**100.0**	**441.3**	**100.0**	**325.6**	**100.0**	**961.6**	**100.0**

Source: AIHW analysis of 1998 ABS Survey of Disability, Ageing and Carers Confidentialised Unit Record File.

Differences in the mix of informal care and formal service use are apparent across the age groups. Age groups in Table 5.1 were constructed to produce reliable estimates whilst still discerning age-related patterns. A breakdown of the middle age group into those aged 25–44 and 45–64 years revealed similar patterns of sources of assistance, so these age groups were combined. Around one-third of people with a severe or profound restriction aged under 25 years and 65 years or over in 1998 relied solely on assistance from carers. The majority of people in these age groups reported having received assistance from both formal services and carers (55% and 61% respectively). The pattern is reversed in people aged between 25 and 64 years, 58% of whom received assistance only from carers (Table 5.1). Total reliance on formal services appears to have been higher in the younger and older age groups in the household population, although some age-specific estimates are subject to moderately high sampling error.

Of interest, then, is whether different patterns of uptake of formal services according to the presence or absence of a primary carer are seen in program data at the national level. Analysis of this question is complicated because carer availability is itself associated with level of need and age. Therefore, some measure of client dependency or, alternatively, client population screening, is required. It is also important to recognise that utilisation statistics can reflect supply constraints.

Utilisation data for the HACC program and CSTDA that were available for this publication are not amenable for analysis of patterns of formal service use with informal care. The current HACC national data collection does not contain client dependency information. Prior to September 2004, data on services delivered under the CSTDA data do not contain carer items. The 2002 Day Therapy Centre census specified carer and dependency data items for collection. However, the data returned contained as many records with missing as with valid values for the carer items.

Ongoing data development is leading to improvements in the national collections so that, in future, it should be possible to make comparisons of formal service use between the with- and without-carer client groups in the wider population of care recipients. Data on 2002–03 activity under the CSTDA becomes available in late-2004 will for the first time include items related to the presence of a carer who provides support to the service user. These items include existence of carer, whether the carer lives in the same household, the relationship between the carer and the service user, and the carer's age group. The redeveloped collection will give new information on carers in Australia, in particular the relationship between formal services and informal care. Likewise, the HACC Data Reform Working Group is developing a framework for client dependency data in the HACC national minimum data set. Inclusion of standard dependency data items will facilitate analysis of service utilisation by carer availability among HACC clients. However, the timeframe for the supply of nationally consistent sets of HACC client dependency data by the states and territories is not yet clear.

This chapter examines data collected in the 2002 CACP census (AIHW 2004a), which is arguably the most reliable national program data available for the purpose at hand. CACPs target older people in the community with complex care needs. Approximately 93% of package recipients are aged 65 years or over. Lack of comprehensive data for HACC and CSTDA clients, as discussed above precludes a more complete coverage of patterns of formal service use with informal care.

5.2 Patterns of service use by carer availability among CACP recipients

A census of 25,439 CACP clients conducted in September and October 2002 enumerated clients by service type and carer status. Dependency is expressed in terms of need for assistance and diagnosis of dementia. These data are amenable to a descriptive comparison of service utilisation in the with-carer and without-carer client groups. The following comparison is inclusive of 23,286 clients aged 65 years or over (72% female) with valid data for age and carer status. Of these, 13,297 (57%) clients had an unpaid carer and 9,989 (43%) clients did not have a carer.

Women comprised just over 70% of both with-carer and without-carer groups. Similar proportions of men and women said they had a carer (57% of female clients and 59% of male clients). The median age of the two groups was similar—83 years for clients with carers and 82 years for clients without carers. There was a higher proportion of clients aged 85 years or over in the with-carer group (39% versus 27% of clients without a carer). This group also recorded a higher rate of diagnosed dementia (25% versus 12%) (AIHW analysis of 2002 CACP census data).

The types of assistance provided under the CACP program can be classified into case management and 10 categories of direct assistance. Figure 5.1 shows the percentage of clients in the with-carer and without-carer groups who used each type of direct assistance during the census period. Delivered meals and food preparation services are combined under the heading 'Food services'. Linen services are not shown because of the low number of clients recorded against this service type. The majority of clients with a carer (80%) and those without a carer (88%) used domestic assistance services during the census period. This type of assistance was used more by more clients in each group than any other service type. Higher proportions of clients without a carer were recorded against each service type apart from personal care and temporary respite care[9].

A higher proportion of clients with a carer used personal care services (59% versus 49% of those without a carer), suggesting that clients with a carer may be a more dependent group (and is possibly associated with the higher rate of diagnosed dementia among clients with a carer). This margin is consistent across the age groups 65–74, 75–84 and 85 years or over (Table A7). It is not immediately obvious that a person who receives formal assistance for personal care is more likely to have a primary carer. Firstly, most older primary carers are spouses of their care recipients so that the caring role is inseparable from marriage and cohabitation, neither of which is necessarily correlated with level of need for personal care at older ages. Secondly the capacity for a person with high personal care needs to remain at home depends on the total amount of personal assistance that is available from both formal and informal sources. The degree to which use of personal care services by clients with a primary carer represents primarily substitution or supplementation of informal care cannot be ascertained from the data.

The greatest difference between the groups was associated with the use of social support services (75% of clients without a carer versus 49% of those with a carer). Age stratification reveals that the difference between the two groups with respect to the proportion using social support services is only apparent at ages 75 years and over (Table A7). Among clients aged 75 to 84 years, 75% of those without a carer used social support services compared to 50% of clients with a carer. The corresponding proportions of clients aged 85 years or over are 82% and 46%.

Approximately half of the clients in each group used food services, with slightly higher utilisation among clients without a carer (54% versus 47%). The proportion of clients who used food services appears to increase with age: 46%of clients aged 65–74 years without a carer and 39%of those with a carer used food services, with the respective proportions rising to 62% and 53% of clients aged 85 years or over (Table A7). Similarly, proportionately more clients without a carer used transport services. However, the proportion of clients who used transport services does not tend to increase with increasing age: 43% of clients aged 65–74 years without a carer versus 34% of those with a carer use transport services, falling to 41% and 28% respectively of clients aged 85 years or over (Table A7).

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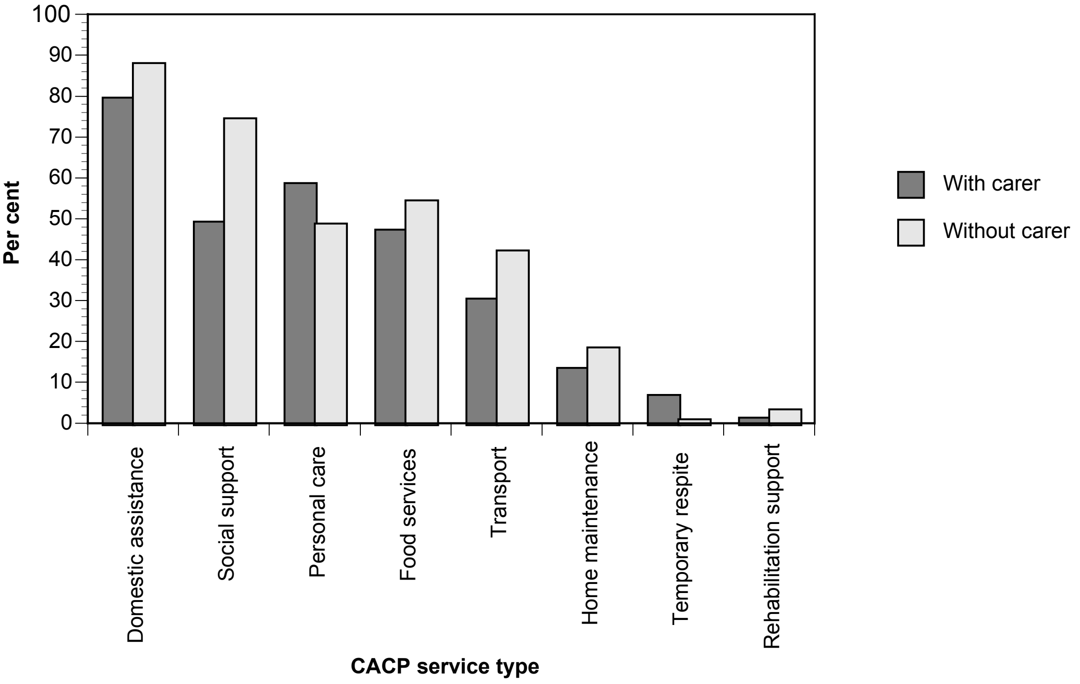
[9] Although the CACP Census guidelines stipulated that temporary respite care is by definition a service for package recipients with a primary carer, CACP recipients who used temporary respite may have been recorded as being without carer because the carer was unavailable during the census period.



Source: Appendix Table A7.

Figure 5.1: Community Aged Care Packages clients, percentage of clients aged 65 or over by service type and carer availability, September–October 2002

In summary, apart from personal care and respite services, a higher proportion of clients without a carer used each CACP service type than clients with a primary carer. The most striking difference between the with- and without-carer groups is seen in the use of social support and transport services. Lincoln Gerontology Centre has noted that Aged Care Assessment Team clients living alone at home are more likely to be recommended for low-level than high-level care and suggest that many such recommendations are based on the psychosocial needs of these clients (LGC 2002:55).

These results underscore the important contribution of carers to the social and physical wellbeing of their care recipients. They also demonstrate that older people with a severe level of restriction in daily activities call on formal services for personal and domestic assistance, even when they have a primary carer. This at least partly reflects the fact that primary carers of older persons are likely to be an older co-resident spouse or partner, or an ex-household family member with other family responsibilities.

A report on the 2002 census of EACH clients—EACH clients have been assessed as needing the equivalent of high-level residential care—noted that 'many EACH package recipients are able to remain at home only because a carer provides regular assistance with physical tasks' (AIHW 2004b). At the time of the census, EACH was a pilot program of around 290 care packages. Approximately 90% of EACH clients at the time had a primary carer and almost one in three of all clients had a diagnosis of dementia. Dementia in an EACH care recipient was associated with more extensive needs. However, the association between dementia and use of EACH services was found to vary according to the availability of a primary carer, as evident in the CACP census data. For example, among EACH care recipients with a carer, the average number of hours of assistance was similar for those with and without dementia (17.3 and 17.7 hours respectively). Yet for care recipients without a carer, those with dementia received more care on average (26.0 hours) than those without dementia (18.6 hours) (AIHW 2004b).

Improved CSTDA and HACC data collections will help to determine whether these patterns of service utilisation hold for the wider household population with severe or profound restriction.

5.3 Carer support programs

Formal services available to people through the HACC program, Veterans' Home Care, CACP, EACH, the CSTDA and other government aged care and disability programs help to reduce the load on carers. Services that directly assist carers, such as respite care, counselling, and care planning and coordination services are also offered through these programs. Growth in the community care sector has seen an expansion of programs that specifically offer assistance to carers in the form of respite care, counselling and education, and information services (Box 5.1) and financial support (Box 5.2). State and Territory health and disability programs complement Australian Government initiatives that recognise and support carers. The support and acknowledgment of carers of frail elderly people is one of the key principles of a proposed national framework for the care of older Australians (AHMAC 2003).

Respite care was a key component of the Staying at Home measures announced in the 1998–99 federal Budget and continues to be an important area of service provision. The 1998 ABS survey revealed that just on 36% (160,000) of primary carers did not have a fall-back carer and a further 8% (36,300) did not know if a fall-back carer was available (AIHW 2000: Table 16.7). However, an estimated 87% of primary carers (388,900 people) at that time had never made use of respite care services and 11% indicated that they needed respite but had not received it (AIHW 2000:145). It is anticipated that more carers are now able to make greater use of formal respite care through developments in the National Respite for Carers Program.

Box 5.1: Australian Government carer support programs

Commonwealth Carelink Centres

A network of Commonwealth Carelink Centres was established in 2001 to provide an information service to help put older Australians, people with a disability, and their carers in touch with a range of community, aged care and disability services. Carers can access the network by telephoning Freecall™ 1800 052 222 or by visiting one of over 60 shopfronts throughout Australia, by visiting one of over 90 access points in 54 regions, or through the Commonwealth Carelink website, www.commcarelink.health.gov.au.

National Respite for Carers Program

The aim of the National Respite for Carers Program is to contribute to the support and maintenance of caring relationships between carers and their dependent family members or friends by facilitating access to information, respite care and other support appropriate to their individual needs and circumstances, and those of the persons for whom they care.

The National Respite for Carers Program is an Australian Government-only funded program. It was established as a 1996–97 Budget initiative and built on the existing Commonwealth Respite for Carers Program. Funding for the National Respite for Carers Program has increased more than five–fold from $19 million in 1996–97 to an estimated total of $104.9 million in 2004-05 (figures supplied by the Department of Health and Ageing).

The National Respite for Carers Program consists of the following components:

- *Commonwealth Carer Respite Centres*

There is a national network of 61 Commonwealth Carer Respite Centres (89 outlets in all) to assist carers obtain short-term or emergency respite. These Centres have a pool of funds that can be used to purchase or subsidise respite care. Centres encourage services to develop more flexible approaches to respite care as well as linking carers to appropriate respite care services, including residential respite. They are reached through a regionally diverted Freecall number, 1800 059 059.

- *Commonwealth Carer Resource Centres*

These Centres provide information, support and advice to carers on a range of issues. They are auspiced by Carers Associations in each state and territory and by Carers Australia for the national Commonwealth Carer Resource Centre. They are located in each capital city and are reached through a state-wide Freecall number, 1800 242 636.

- *Respite services*

There are 432 community-based respite services providing respite in a variety of settings, including in-home, day centre, host family, residential overnight cottage-style accommodation and in aged care homes.

- *National Carer Counselling Program*

Carers Australia is being funded to manage this 2002 Budget initiative and implement the program through Commonwealth Carer Resource Centres. The aim is to address issues specific to carers such as carer stress, grief and loss, coping skills and transition issues. Counselling is provided on a sessional basis by qualified counsellors.

- *National Dementia Projects*

The National Respite for Carers Program provides funding to the National Dementia Behaviour Advisory Service, the Carer Education and Workplace Training Project, and the Early Stage Dementia and Respite Project.

The National Dementia Behaviour Advisory Service provides a telephone advisory service, 1300 366 448, staffed by clinicians for carers and respite workers concerned about the behaviours of people with psychological and behavioural symptoms of dementia. The Carer Education and Workplace Training

(continued)

Box 5.1 (continued): Australian Government carer support programs

Project provides coordinated national accredited training for carers and respite workers caring for people with dementia and challenging behaviours. The Early Stage Dementia and Respite Project provides a nationally coordinated support and respite service for people in the early stages of dementia and their carers delivered through Alzheimer's Associations.

- *Carer Information and Support Program*

This program provides carers with information and practical advice about services that can help them in their caring role. Commonwealth Carer Resource Centres in each State and Territory and a national Commonwealth Carer Resource Centre receive funding through the Carer Information and Support Program to distribute carer information products.

Residential respite care

Residential respite provides short-term care in aged care homes for people who are in temporary need of residential care. Some $81 million was provided in 2002–03 to subsidise the cost of using about one million bed days for respite stays in aged care homes (see AIHW 2004c for additional statistics on residential respite care provision in 2002–03). Residential respite may be used on a planned or emergency basis to help with carer stress, illness, breaks away from homes or the unavailability of the carer for any reason.

As at 31 December 2002, Carer Payment provided income support to 71,210 carers (Centrelink unpublished data). Fewer older carers than carers aged less than 65 years receive Carer Payment because the payment compensates carers for lost earnings while providing full-time care (Table 5.2). Of the 74,229 persons who received assistance from a carer supported by Carer Payment or Carer Allowance, 72% were aged 45 years or over, and 37% were aged 65 years or over (Table 5.4).

Box 5.2 Financial support for carers

Carer Payment

Carer Payment (Adult and Child) is an income-support benefit payable to people who, because of their caring responsibilities, are unable to engage in a substantial level of paid work but are not eligible for other income support payments such as the Age Pension. It is set at the same rate as the Age Pension, and is subject to the same income and asset tests. Because Carer Payment is for people who are unable to work because of their caring responsibilities, the vast majority of people receiving the Payment are aged between 25 and 64 years (see tables 5.2 and 5.4 for the distribution of Carer Payment in 2001–02).

Carer Allowance

Carer Allowance (Adult and Child) is currently payable to co-resident carers who provide full-time care on a daily basis for up to two people who need substantial amounts of care because of a disability, severe medical condition or age-related frailty. As of 1 September 2004, eligibility for Carer Allowance extends to carers who are not co-resident if they provide a minimum of 20 hours per week of personal care assistance to a person who is in need of personal care.

Carer Allowance can be paid to carers in receipt of a government pension or benefit, including Carer Payment. It is not income-or asset-tested, but eligibility is determined according to an assessment of the care recipient's care needs. The level of Carer Allowance, adjusted on 1 January each year, is designed to help meet additional costs involved in caring for a person with a disability (see tables 5.3 and 5.4 for the distribution of Carer Allowance in 2001–02).

Table 5.2: Carer Payment: carers by age and sex, 31 December 2002

	Males	Females	Persons	Males	Females	Persons
Age	**Number**			**Per cent**		
Carer looking after person(s) aged under 65						
<24	823	1,316	2,139	1.8	2.9	4.6
25–34	1,825	2,927	4,752	4.0	6.3	10.3
35–44	3,445	6,167	9,612	7.5	13.4	20.8
45–54	4,659	9,890	14,549	10.1	21.5	31.6
55–64	6,922	7,496	14,418	15.0	16.3	31.3
<65	*17,674*	*27,796*	*45,470*	*38.3*	*60.3*	*98.6*
65–74	297	267	564	0.6	0.6	1.2
75+	11	58	69	0.0	0.1	0.1
65+	*308*	*325*	*633*	*0.7*	*0.7*	*1.4*
Total	**17,982**	**28,121**	**46,103**	**39.0**	**61.0**	**100.0**
Carer looking after person(s) aged 65 and over						
<24	196	305	501	0.7	1.2	1.9
25–34	611	879	1,490	2.3	3.3	5.7
35–44	1,836	2,763	4,599	7.0	10.5	17.5
45–54	2,862	6,338	9,200	10.9	24.1	34.9
55–64	2,662	6,752	9,414	10.1	25.6	35.7
<65	*8,167*	*17,037*	*25,204*	*31.0*	*64.7*	*95.7*
65–74	369	568	937	1.4	2.2	3.6
75+	81	111	192	0.3	0.4	0.7
65+	*450*	*679*	*1,129*	*1.7*	*2.6*	*4.3*
Total	**8,617**	**17,716**	**26,333**	**32.7**	**67.3**	**100.0**

Source: Centrelink unpublished data.

Table 5.3: Carer Allowance: carers by age and sex, 31 December 2002

	Males	**Females**	**Persons**	**Males**	**Females**	**Persons**
Age	**Number**			**Per cent**		
Carer looking after person(s) aged under 65						
<24	903	3,493	4,396	0.4	1.7	2.1
25–34	2,871	38,252	41,123	1.4	18.5	19.9
35–44	6,511	74,554	81,065	3.2	36.1	39.2
45–54	6,982	37,758	44,740	3.4	18.3	21.7
55–64	8,900	16,984	25,884	4.3	8.2	12.5
<65	*26,167*	*171,041*	*197,208*	*12.7*	*82.8*	*95.5*
65–74	3,562	3,733	7,295	1.7	1.8	3.5
75–84	466	1,299	1,765	0.2	0.6	0.9
85+	47	233	280	0.0	0.1	0.1
65+	*4,075*	*5,265*	*9,340*	*2.0*	*2.5*	*4.5*
Total	**30,242**	**176,306**	**206,548**	**14.6**	**85.4**	**100.0**
Carer looking after person(s) aged 65 and over						
<24	194	308	502	0.2	0.3	0.5
25–34	631	1,086	1,717	0.7	1.2	1.9
35–44	1,998	4,018	6,016	2.2	4.4	6.6
45–54	3,497	9,381	12,878	3.8	10.2	14.0
55–64	3,653	15,382	19,035	4.0	16.8	20.7
<65	*9,973*	*30,175*	*40,148*	*10.9*	*32.9*	*43.7*
65–74	8,104	18,297	26,401	8.8	19.9	28.8
75–84	9,612	12,525	22,137	10.5	13.6	24.1
85+	1,836	1,264	3,100	2.0	1.4	3.4
65+	*19,552*	*32,086*	*51,638*	*21.3*	*35.0*	*56.3*
Total	**29,525**	**62,261**	**91,786**	**32.2**	**67.8**	**100.0**

Source: Centrelink unpublished data.

Table 5.4: Care recipients of carers receiving Carer Payment and/or Carer Allowance, by age and sex of care recipient, 31 December 2002

	Carer Payment				Carer Allowance			
Age	Males	Females	Persons		Males	Females	Persons	
	Per cent care recipients			Number	Per cent care recipients			Number
0–14	1.3	0.9	2.2	1,639	27.2	14.0	41.3	132,938
15–24	4.3	3.2	7.5	5,567	5.9	3.4	9.3	29,989
25–34	3.9	3.9	7.8	5,787	1.5	1.3	2.8	9,126
35–44	5.0	5.3	10.3	7,647	1.9	1.7	3.7	11,869
45–54	7.4	7.7	15.2	11,251	3.0	2.4	5.4	17,392
55–64	11.2	8.9	20.1	14,890	5.2	3.4	8.6	27,871
65–74	4.8	5.7	10.5	7,795	5.3	4.4	9.6	30,997
75–84	4.3	11.4	15.7	11,622	6.6	6.3	13.0	41,789
85+	2.6	8.2	10.8	8,031	2.3	4.0	6.3	20,284
Total	**44.7**	**55.3**	**100.0**		**59.0**	**41.0**	**100.0**	
Total Number	**33,194**	**41,035**		**74,229**	**190,101**	**132,154**		**322,255**

Source: Centrelink unpublished data.

Aged Care Assessment Team guidelines have long required formal aged care assessment to consider the needs of carers when making recommendations. Carers are an official target group for HACC services and recent developments in the CSTDA national data collection also indicate that the key role of carers is well recognised in the delivery of assessment and care services throughout Australia.

Care coordination and case management, often viewed as primarily a service to care recipients, carries direct benefits for carers, particularly carers of people with impaired decision-making capability. Primary carers have been likened to 'bridges', connecting their care recipients to health and community care networks (Edelbrock et al 2003; Schneider et al. 2003; Jette et al. 1995). Case management, such as that available through CACPs, EACH and HACC Community Options (or 'Linkages' in Victoria), can relieve carers from the time-consuming detail of investigating alternative services, assessment procedures, eligibility criteria and fees, and liaison with service providers to establish and manage services at home. As an example of the value of case management to carers as well as care recipients, this particular feature of formal services is highly valued by carers who are participating in pilot dementia-care programs funded through the Australian Government Aged Care Innovative Pool.[10]

The 2003 Review of Community Care has focused attention on the complexity of the community care system due to multiple assessment points, multiple funding programs and a vast array of services, each with its own set of rules and procedures (DoHA 2004). Case management is a necessary rather than optional form of support for the 'bridging' role of primary carers, especially while the Review of Community Care remains a work in progress.

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[10] The AIHW is conducting a national evaluation of Aged Care Innovative Pool dementia pilot programs.

5.4 Discussion

This chapter has examined the role of formal services in supplementing and substituting for informal care, albeit with a relatively narrow focus of older care-recipients. Population ageing will lead to higher uptake of formal services to complement the assistance given by carers and offer more specialised assistance that many carers are not equipped to provide. Tailored packages enable people without a primary carer to remain in the community, which might be otherwise impossible. Data on CACP recipients in 2002 reveal that clients with a primary carer include a higher proportion of very old people (85 years or over) and a higher rate of diagnosed dementia than clients without a primary carer. It is intuitively appealing to observe that a highly dependent person stands a better chance of remaining at home if there is a primary carer.

It does not necessarily follow that having a primary carer reduces a person's need for all types of formal assistance. The relationship between use of formal services and carer availability is inextricably linked with the care recipient's level of disability. Naturally, individual preferences and habits of a lifetime feature in the equation.

This chapter has cited several studies of older populations which suggest that, for a given level of disability, a care recipient with a primary carer is likely to be less reliant on formal assistance of a non-professional nature than a person without a primary carer but is likely to use professional services at a higher rate. Theories of substitution and supplementation are supported by this model in which carers and formal service providers work together to provide an appropriate level of care.

Jette et al. (1995) undertook a six-year cohort study to characterise patterns of substitution and supplementation between formal and informal care in the United States. The study led to a proposal that the degree of supplementation or substitution between informal care and formal services depends on an underlying care continuum. The continuum starts with mainly informal care, progresses to mixed informal and formal care and, in some cases, finishes with full formal (institutional) care. Consistent with this model, cross-sectional data show varying degrees of mixed modes of assistance corresponding to individuals at different points on the care continuum. Supplementation is likely to occur when special needs arise that cannot be adequately met by a primary carer (e.g. wound dressing and medication review). Further along the continuum formal care increasingly substitutes for the care given by a primary carer (e.g. high-level personal care and residential respite care).

Cross-sectional service utilisation profiles of the with-carer and without-carer groups in the 2002 CACP Census are similar, which likely reflects efficient targeting in the Aged Care Assessment Program. High proportions of both groups used most types of assistance associated with daily activities during the census week. Lower proportions of clients using home maintenance services and rehabilitation support reflect the fact that these needs arise more sporadically and would ideally be measured over a longer timeframe. The picture that emerges is that older people with severe restrictions require assistance with domestic duties and 50% or more will seek formal assistance in the areas of personal care, social support, and food services. At least one-third of such people require transport assistance. These observations hold irrespective of carer availability, although a slightly higher proportion of CACP clients without a carer used most services concerned with the instrumental activities of daily living (meal preparation, transport, domestic duties etc.). Similar service utilisation profiles possibly reflect the homogeneity of this client population, and the fact that most carers of older people are themselves an older person or an ex-household family member. Older CACP clients without a primary carer appear more likely than clients with a carer to use social support services. Social support services are aimed at increasing social contact for clients, thus the observed difference possibly relates to the high likelihood that CACP clients without a carer live alone.

Demand for personal care services, including home nursing, will increase in line with increasing numbers of people with a severe or profound restriction living in the community. Unless the data examined here more strongly reflect patterns of supply than demand, they suggest that demand for formal assistance with domestic work is likely to be ongoing and consistently high, irrespective of trends in informal care. Previously it has been found that demand for formal assistance in the instrumental activities of daily living, e.g. meal preparation and domestic duties, among community-dwelling older people with severe disability appears to be higher among certain population groups (Mawby et al. 1996). These include the 'old old', those aged 80 or over, people with higher levels of non-core activity restriction, and people with severe disability who live alone. Mawby and colleagues also reported that use of personal care services is highly correlated with restriction in the core activities of daily living, age and recent hospitalisation.

Observations in relation to CACP clients may not generalise to younger people with a disability or indeed to the wider disability population—including frail, older people—serviced by HACC. Ongoing data developments hold a promise of more broad-based analysis of the interaction between informal care and use of formal services.

Tennstedt, Crawford & McKinlay (1993) in the United States have observed that, controlling for disability, higher levels of unpaid informal assistance are associated with lower use of non-professional community services such as domestic assistance, shopping, transport and home maintenance. The Sydney Older Persons Study provides evidence of the relationship between the availability of informal care and use of formal services in an Australian community (Edelbrock et al. 2003). This latter study investigated the availability of informal network support and use of formal services among 537 community-dwelling older people in inner metropolitan Sydney. The results of a regression analysis on these data indicate that among individuals of equal disease and disability, those without access to unpaid informal assistance made greater use of formal services for help with the instrumental activities of daily living, e.g. meals, transport, domestic help and home maintenance, shopping, laundry and day care, while care recipients with a primary carer accessed professional services (e.g. nursing and medical care, allied health therapy) at a higher rate. The researchers concluded that carers act as a 'bridge' to medical and other professional services, in terms of identifying need, managing referral processes, and facilitating timely contact between care recipient and professionals. At the same time, carers are seen to reduce the care recipient's reliance on formal services for domestic assistance and community access.

The ABS projects that many more 'old old' people, and very old women in particular, will be living alone in the years ahead. Effective community care in this demographic climate implies increasing demand for formal assistance, to compensate for a lack of informal care when a primary carer is not available and to supplement informal care provided by older primary carers, ex-household primary carers, and secondary carers. Chapter 1 showed that, in 1998, over one-third of primary carers with an older care recipient did not live with the care recipient. Thus, as the Australian population ages, formal services will need to respond to the different needs of two distinct groups of primary carers: older, co-resident spouse carers and working carers. A broader range of data than was available for this report is needed to explore trends in the use of formal services by people of all ages with co-resident and non-co-resident carers.

6 Conclusion

Both in Australia and overseas, there has been considerable attention to the role of informal care in the future sustainability of community care systems (examples of recent work in Australia include AIHW 2003 and NATSEM 2004). Yet uncertainty remains because of the myriad of psychosocial factors which influence whether, and under what circumstances, an individual will accept primary responsibility for the welfare of a family member or friend with a severe level of disability. Many such factors cannot be reliably quantified in mathematical and statistical models; the results of most analytical exercises need to be qualified by our limited understanding of substitution and supplementation between informal care and formal services. This report aims to characterise informal care in Australia to enable the reader to form an impression of which factors might play the greater role in shaping informal care over the next decade. Such an appreciation provides a basis for assessing the validity of alternative projection models for informing public policy.

The effects of population ageing, changing patterns of family formation, and work and family balance, particularly as perceived and experienced by women, the traditional primary carers, are central to the international commentary on informal care. A number of overseas studies have been reviewed and are discussed here by way of providing a context for the findings of this report.

Some observers of change in the United States have proposed that the ageing of the population will bring with it a larger proportion of the population with health and personal care needs and that this is occurring at the same time as the traditional supply of paid and unpaid caregivers is shrinking (NHPF 2002). While these trends are evident in the Australian context, researchers have pointed to characteristics of the Australian situation that may support the continuing availability of carers. Although fertility rates are currently declining, the decline in the number of children per family will not occur until the baby boomers replace their parents at the top of the population pyramid. In Australia, the post-Second World War 'baby boom' was notably later and longer than in many other developed countries, thus delaying this decline in family size.

Rowland (1991) has suggested that the post-war marriage boom resulted in an increase in potential family support. Over time, however, marriage rates have declined while divorce rates have increased (ABS 1999b) and these factors may offset this additional family support. Litwin (1997) contends that informal support structures are becoming more fragile and cautions against the 'back-to-the family' policy of long-term care provision. Others have also questioned whether past patterns of informal care can withstand the stresses of contemporary life and the changing nature of 'family' (see for example the discussion in RIS 1998).

While the number of people remaining single is increasing, Howe and Schofield (1996) argue that this is mainly in the generation who are the children of the baby-boomers. Among the oldest generation, improving life expectancies for men reduces the proportion of people at these ages who are widowed. Indeed, Rowland proposes that caring outcomes as affected by marriage should be examined using cohort analysis.

Shaw and Haskey (1999) and Shaw (2000) have proposed that a rise in the proportion of older women with partners will occur in the United Kingdom in the future because the proportions of women ever marrying are higher for cohorts currently aged 40–65 years than for older cohorts and because improved male life expectancies will result in fewer widows.

Australian projections to 2006 derived by McDonald (in AIHW 1997) indicate an increase in the number of older people living as couples in households. McDonald (1997) points out that, while married couples may be surviving longer together, it is possible that both will require care at the same time. Although there is no evidence that disability-free life expectancy is increasing in Australia, disability-free life expectancy is increasing in line with average life expectancy (Mathers 1996). This would suggest that couples surviving longer together have more years in which they are able to provide assistance to each other.

Concern has been expressed about the impact that increased female labour force participation will have on carer availability (e.g. Schofield & Bloch 1998). Chappell (1990) has argued that there is little evidence that this increased workforce participation has resulted in reduced care for older people in the United States, an argument supported by the research of Aytac and Waite (1995). Howe and Schofield (1996) maintain that changes in labour force participation patterns will not be so large as to threaten the availability of carers in the future, and that increased flexibility of work arrangements will allow carers to work and continue their caring role. Since the time of Howe and Schofield's paper, however, older women's labour force participation has risen beyond projected participation rates. Between 1988 and 2001 Australian female labour force participation rates rose from 33% to 49% for women aged 55–59 years, while that for women aged 60–64 years increased from 16% to 25% (AIHW 2002). Howe and Schofield further argue that family changes will not impact negatively on the supply of carers, as future cohorts of women will, on the whole, have completed child-rearing responsibilities before they may need to care for their ageing parents. Millward (1999) contests that there is evidence of many carers having dual caring responsibilities or other responsibilities in addition to caring.

This report contributes to the debate, firstly by describing the main players and context of informal care in Australia and, secondly, by attempting to quantify the relative impact of certain factors on informal care over the next decade. There is a strong focus on primary carers—those people who provide the most ongoing assistance with the core activities of daily living to a person with a disability. The ABS collects detailed data on primary carers and the work they perform in its 5-yearly Survey of Disability, Ageing and Carers. Although primary carers numbered 450,900 out of an estimated 2.3 million carers at the time of the 1998 survey, these numbers do not translate proportionately in terms of nature, duration and intensity of the care that is provided. The vast majority of primary carers provide assistance to one or more individuals with a severe or profound restriction in self-care, mobility or communication.

Relative to approximately one million persons with a severe or profound restriction in 1998, the number of primary carers does not imply that over half a million people did not receive informal care in 1998. Around 20% of primary carers provide ongoing assistance to more than one person and many people receive assistance from their care networks without identifying a primary carer.

Chapter 1 summarised the results of the most recent ABS survey, which revealed that caring for a person with a severe or profound restriction was a predominantly female occupation in 1998. Women comprised 70% of primary carers, according to the survey definition. Primary carers of young people were mostly mothers, those caring for middle-aged people were mostly partners or spouses, and primary carers of people aged 65 or over were a mix of adult offspring and spouses or partners. However, at ages 75 years and over a primary carer in 1998 was just as likely to be male as female (Figure 1.1). In 1998, 64% of male primary carers were spouses or partners of their care recipient, whereas female primary carers were more evenly represented among spouses or partners (34%), parents (27%) and children (26%) of care recipients (Table 1.3). Overall, spouses and partners accounted for 43% of primary carers in 1998. Most primary carers (79%) lived with their care recipient, while carers of older people (65 years or over) were less likely to be co-resident (62%) (Table 1.1). Most ex-household carers of older people are daughters and daughters-in-law with other family responsibilities. Changes to women's predisposition to care and trends in the formation of spouse and partner relationships are likely to have a profound impact on the level of informal care.

Chapter 2 described the nature of caring work in terms of intensity, duration and the disabling conditions that care recipients report as causing the most problems. Over 50% of primary carers in 1998 reported spending 20 or more hours per week in the caring role and over one-third reported spending 40 or more hours per week on caring activities (Table 2.4). Over 60% of primary carers aged 15 or over usually assisted their main care recipient with self-care (dressing, bathing, feeding, using the toilet and managing incontinence) and 74% reported that they usually assisted with mobility (lifting, transferring, and moving around in and outside the home). These results underscore the important contribution of primary carers to the welfare of older Australians and people with a disability.

Chapter 3 examined the changing context of community living with a focus on dimensions that might influence future levels of informal care. Primary carers in 1998 most often cited family obligation and duty to care as motivating factors for accepting their caring role.

Chapter 4 described four scenarios of informal care to 2013. A 'baseline propensity to care' scenario assumes that population projections with respect to age, sex, labour force participation category and living arrangement drive changes in the number of primary carers over the next decade. In this scenario, the proportion of people in each age group by sex, labour force participation category and living arrangement who are primary carers is held at the 1998 level. Three other three scenarios separately assess the impact of some commonly held assumptions: that in the future, relatively fewer women will reduce paid employment to take on a caring role; that higher average life expectancy could mean a higher proportion of supportive co-resident relationships at older ages; that there will be an overall decreased propensity to care as a result of high rates of relationship breakdown bringing an altered community sense of duty to care. More specifically, the chapter examines the relative impact on future numbers of primary carers of:

(a) projected demographic changes (focusing on changes in the age and sex structure of the population and patterns of living arrangement) and projected trends in labour force participation throughout the projection period which combine to drive change in the size of the primary carer pool in the absence of any underlying change in propensity to care among population groups by age, sex, living arrangement and labour force participation category. This is the 'baseline propensity to care' scenario, which applies 1998 carer rates;

(b) a decrease, arbitrarily set at 20%, in the proportion of women aged 25–59 years who are willing to reduce paid employment to take on a primary carer role (this proportion was 7% in 1998) that might result from higher labour force participation among older working-aged women;

(c) an increase, arbitrarily set at 20%, in spouse or partner carers aged 60 years or over that might result from converging male and female life expectancies; and

(d) an arbitrary 20% decline in the proportion of primary carers by age and sex.

The objective was not to forecast the number of primary carers to 2013, but to isolate the impact of changes that have been hypothesised in the informal care literature and assess them relative to each other. Compared to the situation in 1998 and considering just these scenarios, it appears that only an across-the-board decreased propensity to care will have a marked impact on the ratio of primary carers to the 'at risk' population over the next decade. In the social context of informal care in the 21st century, such a scenario is not entirely unrealistic. Overall decline in the propensity to care could occur through a complex interplay of altered patterns in interpersonal relationships, family formation, living arrangements, labour force participation and life expectancy affecting multiple generations.

There is a sense that higher rates of relationship breakdown could prove a significant factor in the future of informal care. While these trends signal lower caring potential, this report does not intend to imply that the reduction will equate to a 20% decline in age- and sex-specific proportions of primary carers. A figure of 20% was used consistently to compare the same magnitude of effect on the trajectories listed above, and the sensitivity of the outcome of each scenario was verified using alternative rates of 10% and 30%.

Chapter 5 presented an overview of patterns of substitution and supplementation of formal and informal care among CACP recipients in 2002. Package recipients with a primary carer were more likely to have a diagnosis of dementia as recipients without a carer, highlighting the important role of primary carers in helping vulnerable older people to remain in the community. Package recipients with a carer were about as likely as recipients without a carer to receive help with personal care and domestic activities from formal services. Marked differences in service utilisation between the with- and without-carer groups of package recipients are evident only in the areas of social support and transport. These data highlight the importance of formal community services in supplementing the work of family carers and in providing a substitute to those people with have limited access to care from family and friends. Further investment in data development is required to more fully explore the relationship between formal and informal care across all age and disability groups.

Chapter 5 also described the key national carer support programs that are intended to help sustain carers in their caring role: financial support, respite care, and programs for the delivery of carer information and education services. Delivered effectively, these programs decrease the costs to carers, increase the benefits of the caring experience and in so doing, help to maintain the balance of care.

Primary carers are just one, albeit significant, component of informal care in Australia. Many care recipients receive assistance from members of a care network without identifying a primary carer as such. This at least partly explains the 'gap' between the number of primary carers and the number of people with severe or profound restriction in core daily activities who were living in households in 1998. Approximately 11% of primary carers in 1998 were a friend or relative, other than immediate family, of their care recipient; however, it cannot be assumed that people from these groups will step in to compensate for any future reduction in care provision by the immediate family. More distant relatives, friends and neighbours are not generally involved in providing support of the type and intensity given by a spouse or offspring carer (RIS 1998). Further, if the dependency levels of individuals living in the community without a primary carer were to increase substantially over time, then a care ratio of the 1998 proportion could represent an entirely different scenario from the baseline presented in this report. While the difference in the projected number of people in need of assistance and the projected number of primary carers does not necessarily define unmet need for informal care, any widening of that gap or any change in the dependency levels of people who do not have access to a primary carer should be closely monitored.

In applying analytical methods to the question of the future of informal care, one should recognise that the level of informal care provision represented by primary carers in 1998 is a quantitative measure of society's response to prevailing needs at a point in time. Disability-related need in the community reflects not only the total population of people with severe or profound restrictions, but also the provision of care accommodation and the preferred living arrangements of those in need of assistance. To suppose that a proportionate response based on 1998 primary carer numbers would prevail throughout a period in which there will be a dramatic increase in the older population is highly questionable. In this respect, a scenario based on 1998 carer rates by age, sex, labour force category and living arrangement category is no more likely than any of the other scenarios considered here. It is used only as a baseline against which to compare the effect of the other scenarios, relative to each other.

Assuming that 1998 age- and sex-specific disability rates prevail, the number of people aged 10 years or over with severe and profound core activity restriction will rise to just over 1.4 million by 2013 (Table 3.1). Older people, 65 years and over, will account for approximately 67% of projected growth between 2003 and 2013 in the population with a severe and profound restriction and a further 30% growth in this population will occur in the 45–64 years age group (Table 3.1). Significantly, the number of people aged 85 years or over with a severe or profound activity restriction is projected to grow by over 50% (96,400 people) between 2003 and 2013.

In 1998, approximately 29% of people aged 65 years or over with a severe or profound restriction lived in some form of cared accommodation excluding hospitals (ABS 1999a: Table 8). Critical factors that are likely to determine whether growth in the number of primary carers keeps pace with growth in the population at risk of needing assistance include:

- how the household population with a severe or profound restriction grows in proportion to the total number of people with this level of disability i.e. the level of provision of permanent cared accommodation and the preferred living arrangements of people in this population group; and
- the willingness and capacity of people to care for very old and highly impaired family members.

The discussion in Chapter 3 on motivation to provide care highlights the critical factor of sense of duty to care that comes from family belonging and interpersonal relationship. On the surface, there is reason to be optimistic that future numbers of primary carers and carers in general will represent a proportionate response to increasing numbers of people with severe disabilities living in the community. Close attention should be paid to meeting the needs of primary carers, especially the projected growing number of older carers and carers with multiple caring roles.

As the population ages steady growth in the number of primary carers who do not live with their care recipient can be expected because of growth in the number of older people in need of assistance for whom traditionally, there has been a higher proportion of ex-household carers. Crucial issues for these carers, who are more likely than co-resident carers to be female, younger and have other family responsibilities, include their ability to combine paid employment with the caring role, extra costs that are associated with caring, and the impact of competing demands on their psychological and emotional wellbeing. The ability to continue to provide adequate care for a son or daughter with a disability, or an ageing partner, will be a source of anxiety for a growing number of older, mainly co-resident, carers.

Awareness of, and confidence in, the system of assessment, referral and service delivery is critical if care recipients and their carers are to receive timely and appropriate support, particularly as care recipient needs, hence carer support needs, are rarely static. Effective ongoing communication of this type of information to people who may have become isolated for any number of reasons including disability, age, cultural background, social or financial disadvantage, or the circumstances that can be associated with full-time provision of care, presents a major challenge.

Recalling that the achievement of policy objectives in aged and community care depend on ‘the extent to which the relationship between the carer and the person cared for can be sustained without unacceptable costs to either’ (DHFS 1996), the challenge over the next ten years will be to implement a framework for community care that facilitates early intervention for carers and care recipients who are in need of formal support and to continue to develop support mechanisms that are responsive to the needs of individuals.