



Australian Government

Australian Institute of
Health and Welfare

Submission No. 1033

(Inq into better support for carers)

ACC 28/7/08

*Better information and statistics
for better health and wellbeing*

The Secretary
House Standing Committee on Family, Community, Housing and Youth
House of Representatives
Parliament House
Canberra ACT 2600

Submission to Inquiry into Better Support for Carers

Dear Mr Catchpole,

The Australian Institute of Health and Welfare (AIHW) welcomes the invitation to make a submission to the Inquiry into Better Support for Carers. Please find enclosed a copy of the Institute's submission which addresses the following terms of reference:

- The role and contribution of carers in society and how this should be recognised
- Practical measures required to better support carers
- Specific needs of particular groups of carers

Yours sincerely,

Dr Penny Allbon
Director
Australian Institute of Health and Welfare
18th July 2008

Key point summary: practical measures to better support carers

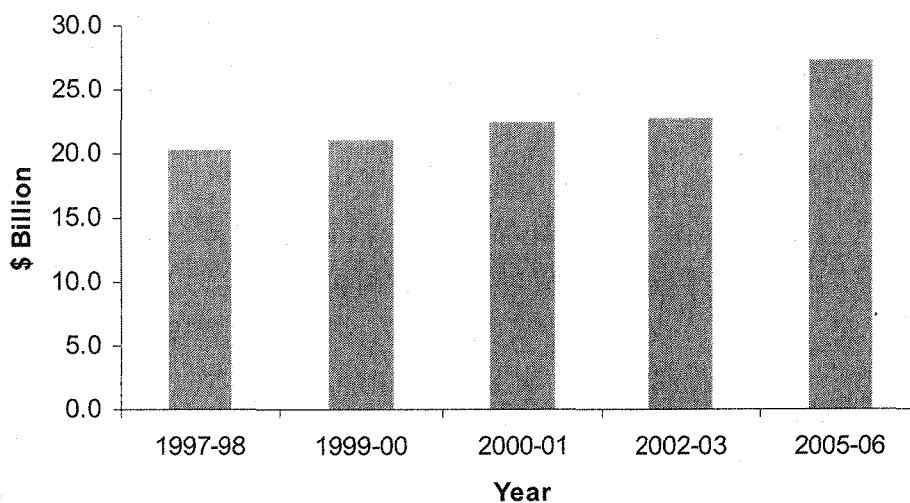
1. Many carer support mechanisms are based on narrow concepts or definitions of 'primary carer' that may not adequately describe the range of circumstances and needs of people who are primary carers.
 - The ABS primary carer definition is a fundamental and robust element of statistical information on carers. It has, however, been shown to have limitations for the purpose of representing the diverse circumstances and needs of some groups of carers. It potentially excludes, for example, primary carers of people with mental illness, particularly episodic mental illness, and high intensity palliative care for periods of three or four months.
 - In the contexts of policy development and service access a number of groups of carers can be usefully identified: primary carers who receive income support payments from Centrelink; primary carers who meet the eligibility requirements for government income support but who do not seek or receive that support; people who do not meet the income/assets test or personal care criteria for Carer Payment but who are nevertheless a primary carer; carers other than primary carers. These are not necessarily mutually exclusive groups.
2. Services for care recipients also assist carers. In other words, supporting carers involves providing services to address a carer's own needs but also ensuring that the wider service 'system' works for carers in relation to the people they assist. This can involve access to and coordination across service sectors: medical and nursing care, allied health care, specialist disability services, and aids and equipment services.
3. Comprehensive, socially inclusive, respite can be particularly beneficial for very long term carers and older carers who may have become disconnected from wider society as a result of the caring role. Such models of respite care have existed for some time and their benefits have been well demonstrated.
4. Access to case management that operates across program boundaries has demonstrated benefits for very old carers, very long-term carers and carers looking after people with high and complex needs.
5. Access to counselling, support and information is important for carers when they reach critical transition points: commencing or increasing caregiving (possibly involving decisions about paid employment) or ending care through death or institutionalisation. Some carers may need help to re-engage with their community after a long period of caregiving.

Introduction

Family and friends are the main source of ongoing support for people with a disability living in the community. Carers contribute to the quality of life of the people with disabilities by providing direct assistance with activities of daily living, helping them to access essential services such as health care, and assisting them to remain connected to their families and communities.

Although this care is unpaid, largely provided within families, it is possible to place an economic value on this activity. The AIHW has imputed the economic value of unpaid care for people with disabilities (including those who need assistance because of old age) at \$27.4 billion in 2005-06 (Figure 1). Other estimates are in the range \$4.9 billion to \$30.5 billion, depending on the method used (Access Economics cited in Edwards et al. 2008). By comparison, expenditure on welfare service provision in 2005-06 is estimated at \$31.4 billion, including \$2.5 billion in income support for carers (e.g. Carer Payment, Carer Allowance and Carer Bonus).

Figure 1: Economic value of informal care provided by the household sector, constant prices 1997-98 to 2005-06



Notes

1. The imputed economic value is derived from AIHW welfare expenditure databases. Calculations follow the method described in AIHW (2007): Box 7.2 with the portion of expenditure relating to unpaid child care excluded.
2. Imputed value is expressed in 2005-06 dollars. Price deflators are the GFCE-Other Chain price index: 0.765 (1997-98); 0.810 (1999-00); 0.839 (2000-01); 0.899 (2002-03); 1.000 (2005-06).

Source: Australia's welfare 1999, 2001, 2003, 2005, 2007.

There is an increasing number of people in the community who need assistance with daily living. Greater numbers of older people is just one, albeit major, demand factor. Other contributing factors include the improving life expectancy of people with an early-onset disability, service system interactions that impact on people with disability at major points of transition in their lives, and disability related to the prevalence of chronic health problems among relatively young people.

1 Term of reference: recognising carers (who to recognise?)

The deinstitutionalisation of health and welfare services that started in the 1980s has given added significance to the role and contribution of carers in Australia. AIHW analyses have shown, for example, that if 1981 patterns of use of institutional care had been maintained until 1996, then an additional 80,700 people would have been living in health and welfare institutions in 1996, or 38% more than actually were according to the 1996 Census (AIHW 2001: 12). Significant changes have occurred in aged care, disability services and the mental health sector. Changes in hospital practice brought about by new technology and increasing use of same-day procedures and efficiency drives to reduce average length of stay through developments at the acute and sub-acute care interface, have also contributed to increased demands on carers.

An overview of available information on care recipients and carers provides a context for a discussion of better support for carers but raises a basic yet crucial question: for planning and support purposes, who are regarded as carers?

Care recipients

In 2003, 2.3 million people with a disability, living in households, needed assistance with everyday activities (ABS 2004). The following findings from AIHW (2007) are based on the 2003 Australian Bureau of Statistics (ABS) Survey of Disability, Ageing and Carers, the best existing national source of detailed information on recipients of informal care.

- Almost 1.8 million people aged 15 years or over received assistance from family and friends because of disability (AIHW 2007: Table 3.7). This number excludes children with disability, making the total number of care recipients even higher.
- The vast majority (around 1.7 million people) had a 'main' provider of assistance, i.e. one person who provided the bulk of care and supervision with or without support from other carers or formal services.
- 1.2 million people who received care from family and/or friends had a co-resident main provider of assistance; around 1.1 million received assistance from persons outside their own household. Thus, many care recipients receive support from a 'care network', which often includes a main provider and others who provide secondary or back-up support.
- Just under half of care recipients (781,000 people) had a severe disability, that is, they were profoundly or severely limited in the core activities of daily living, self-care, mobility and/or communication. Most of this group (756,000) had a main informal provider of assistance. Many of these people would not be able to live in the community without ongoing, high-level, often 24-hour support. Care

AIHW submission to the 2008 Inquiry into Better Support for Carers recipients can also have episodic and therefore highly unpredictable need for intensive support (see type and intensity of care, below).

Who is a carer (how do we count carers)?

The AIHW places most confidence in estimates of carer numbers from the ABS Survey of Disability, Ageing and Carers (SDAC). According to the 2003 SDAC 2.6 million carers provided unpaid assistance to someone with a disability – this number refers to **total carers** (ABS 2004). Identifying and counting people who are carers can quickly become a matter of definition and methodology:

- Among these 2.6 million carers, 474,600 were identified by the ABS survey as **primary carers** – the main informal providers of assistance to a person or persons who needed ongoing help with core activities.
- The ABS survey identified an additional number of carers who did not receive a follow-up to establish their primary carer status. If 20% of these carers are included the number of primary carers increases to around 484,600 (see further explanation in Hales 2007).
- Even this number of primary carers (484,600) is significantly smaller than the 1.7 million people identified by the SDAC as having a 'main informal provider of assistance'. And it is also much smaller than the 756,000 of those people who had severe disability and a main provider of assistance (AIHW 2007: Table 3.7). These disparities are not adequately explained by the number of carers with more than one care recipient.
- The 2006 Census produced a count of 1.6 million total carers, a number based on a single question to the household reference person (carer data from the Census suffer from other limitations – see part 5 below).
- Other counts of carers can be derived from persons in receipt of Carer Payment and/or Carer Allowance (see below).

Further issues of definition and recognition

Although the SDAC is the best available source of detailed information about primary carers at a national level, the SDAC definition of primary carer may not produce a picture of the full extent of high-end caring activity. In addition to being the main provider of assistance, the SDAC requires that the person has been or expects to be providing assistance with the core activities of daily living (self care, mobility, communication) for a period of at least 6 months. This definition has been shown to be too narrow for the purpose of representing the diverse circumstances and needs of primary carers (Schofield et al. 1997, 1998). It potentially excludes, for example, primary carers of people with mental illness, particularly episodic mental illness, and high intensity palliative care for periods of three or four months.

ABS estimates of total carers and primary carers are substantially higher than the number of carers who receive Carer Payment or Carer Allowance (111,419 and 382,490 respectively as at 31 December 2006; AIHW 2007).

- Not all carers are eligible to receive carer support payments paid by Centrelink.
- Not all people who are carers consider themselves a carer or want to be labelled as a carer (see below for further discussion).

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- Levels of awareness of Carer Payment and Carer Allowance affect the uptake of these forms of support (Edwards et al. 2008; Hales et al. 2006).
- Older carers in receipt of Age Pension are not required to transfer to Carer Payment for income support.

Added complexity comes from the link between caring roles and intimate relationships (AIHW 2004; Hales 2007). A proportion of carers do not see themselves as a carer – they identify primarily or exclusively as a wife, husband, mother, father, son, daughter, sibling or friend even though their role extends well beyond what most people expect of these relationships (Schofield et al. 1998). We note that the SDAC is better than the Census at picking up carers who do not self-identify as carers.

Implications

Depending on purpose, carers can be usefully grouped into several co-existing broad categories:

- primary carers who receive income support payments from Centrelink
- primary carers who meet the eligibility requirements for government income support but who do not seek or receive that support
- people who do not meet the income/assets test or personal care criteria for Carer Payment but who are nevertheless a primary carer
- carers other than primary carers.

There is inconsistency across programs and portfolios in what constitutes a primary carer and the levels and types of informal care that are recognised as helping people to remain living in the community.

Ways of recognising the role and contribution of carers that link recognition to receipt of Carer Payment or Carer Allowance will not reach carers who do not receive these benefits, including many primary carers.

2 Term of reference: The role and contribution of carers

According to the SDAC, primary carers in 2003 comprised

- 42% spouses/partners of the care recipient
- 26% sons and daughters
- 23% parents
- 9% other relatives/friends.

Almost three quarters (71%) of primary carers were women. Men are better represented among total carers (50%), than among primary carers (ABS 2004).

Three quarters of primary carers were of working age (31% aged 15–44 years plus 45% aged 45–64 years) and one quarter were 65 years or over (ABS 2004).

- Primary carers aged up to 45 years are predominantly parents, mostly mothers, providing assistance to a child with a disability, but offspring and partners are also well represented in this group of primary carers.
- In the 45–64 years age group spouses and partners account for the highest proportion of primary carers, slightly ahead of sons and daughters caring for a parent/s.
- Spouses/partners are the overwhelming majority of older primary carers (65+) and at much older ages (75+), there are roughly equal numbers of men and women (AIHW 2004).

Primary carers are a mix of people for whom assisting a person with a disability is additional to other family responsibilities and, for some, paid employment, and others who are mainly occupied in the provision of care to one person.

Parents and spouses/partners make up the vast majority of primary carers of people aged under 65 years, in roughly equal number (AIHW 2005: Table 5.22). Not surprisingly, most (85%) of these carers are aged between 25 and 64 years (only 8% are aged over 65 years but many of these older carers are very long term carers). Most carers of people under 65 years of age are co-resident carers. Primary carers of older people (65+) are concentrated in the mature and older age groups: around 40% are themselves 65 years or over; close to 50% are aged 45–64 years, divided almost equally between what are conventionally considered the mature working age group (45–54) and pre- and early-retirement ages (55–64) (AIHW 2007). More than half of mature-age primary carers who provide assistance to an older person do not live with that person. For this group care provision can involve lengthy travelling times and the management of two households.

Starting and stopping caregiving

Responses to questions on what motivates people to become a carer reveal that caregiving is a response to need for assistance, driven by intrinsic motivation but possibly responsive to external signals that value the contribution (AIHW 2004; Hales 2007). The emergence of need and the caregiving response can be gradual or sudden, giving rise to different patterns of starting, stopping and duration of care. AIHW work has not specifically addressed this area but has highlighted some pertinent issues:

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- A multi-national study of the empirical relationships between caregiving and paid employment found that the association between employment and caregiving depends on the level of support available from community services. In countries with strong community care systems, changes to hours of employment to accommodate increased caregiving were more likely to be temporary than in countries with less formal supports (Spiess & Schneider 2003).
- Millward's (1998) study of caregiving in Australia highlighted the importance of choice (i.e. alternatives) to people making decisions to provide unpaid care, with consequences for positive caregiving outcomes.
- In the light of this evidence, it seems likely that with appropriate formal and informal supports a working carer may be able to return to work after a relatively short break. Being able to access services that work together from the start can strongly influence decisions about longer term arrangements.
- The literature on caregiving suggests that people caring for a parent tend to give priority to their spouse and children where those relationships are adversely impacted by their role as a carer (Piercy 1998).
- The end of a primary carer role marks a major life transition that can be accompanied by significant grief and anxiety especially when intensive caregiving has extended over many years.
- It is not uncommon for carers to delay seeking help until they reach a crisis in care, at which point it may be difficult to intervene to help maintain the caregiving relationship (Hales et al. 2006).

Type and intensity of care

Across the range of core activities, health care and non-core activities, carers provide the bulk of care to people with disabilities living in the community (Figure 2). The assistance provided can include emotional support; companionship; supervision, including prevention of injury and self-harm; financial assistance; transportation and community access; liaison with formal care providers including health and disability services; physical assistance with personal care, mobility and communication. The importance of health and allied health services in supporting care recipients and carers is highlighted by the number of people with a disability who need and receive health care – almost 1 million – and the proportion who receive help from carers to access health care (62%; ABS 2004). A key aspect of support for carers relates to their role in interacting with medical and allied health professionals, hospital staff, mental health services, aged care and disability services, and others.

Carer support involves good communication between service providers, care recipient and carer and between service providers. There is evidence of the effectiveness of case management that operates across program boundaries. This is of particular value to very old carers, very long-term carers, carers looking after people with high and complex needs and people caring for a frail older parent who live some distance away. Some carers find it difficult to navigate the complex service system, either through a lack of time/energy or inability for self advocacy. Carers in this situation say they need an active liaison point between themselves and their care recipient and the multiple service providers who support them (Hales et al. 2006). This type of case management exists in the disability services sector and has been trialled and demonstrated to be effective in high-level dementia care.

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Health care aside, in any one area of assistance depicted in Figure 2, between 76% and 94% of people with a disability, living in households, who needed assistance received assistance from informal providers. It follows that the provision of care usually involves assisting in multiple areas of daily living.

Other indicators of caring demands include:

- 48% of primary carers spend at least 40 hours per week in providing care
- 60% of primary carers in 2003 had been a carer for 5 or more years (ABS 2004).

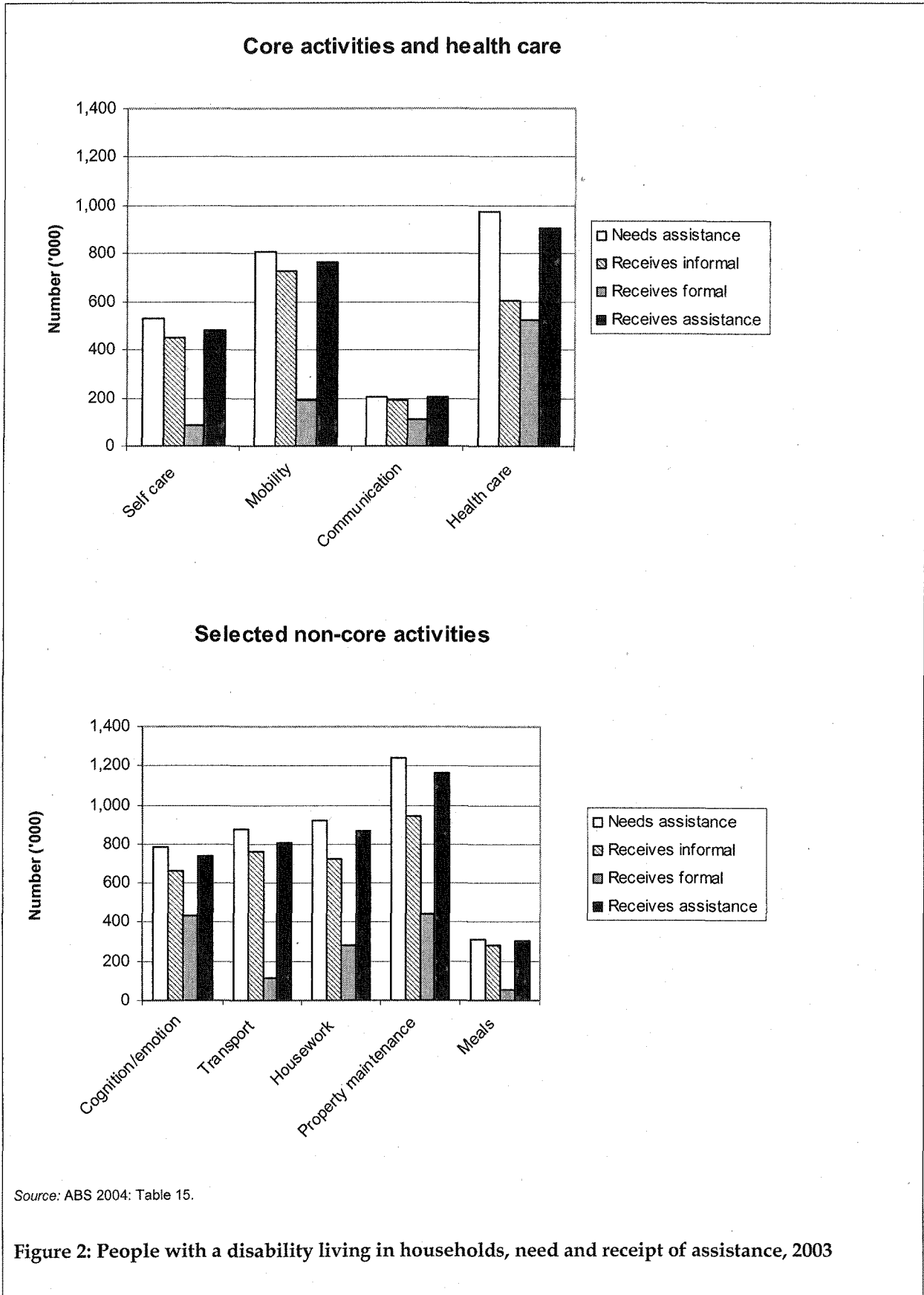
This information comes from the SDAC and therefore reflects the SDAC definition of 'primary carer'. The profile might not reflect the activity of specific groups of primary carers. Consider care recipients who have an ongoing need for assistance but who need high level support intermittently and unpredictably and people whose needs are not necessarily in the areas of self-care and mobility:

- a mainly stable condition requiring long-term intensive support e.g. person with mild to moderate intellectual disability or acquired brain injury
- steadily increasing care needs with occasional and unpredictable acute episodes, e.g. person of any age with a chronic health condition who experiences sudden acute episodes
- mainly low level support needs in core activities but high emotional and cognitive support needs, unpredictable episodes requiring intensive care and support and at risk of a serious long term downturn, e.g. person in early to middle state of Alzheimer's disease and people with mental health disorders

Such groups of care recipients may not have severe core activity limitation (or indeed any level of core activity limitation) and their carers do not necessarily fit the SDAC and similar definitions of primary carer. In this way statistical definitions such as used in the SDAC may influence the visibility of certain groups of carers in policy and service access contexts. And there is evidence that this is indeed the case: carers of people with psychiatric conditions report that the fluctuating and different nature of support needs associated with psychiatric disability leads to their exclusion from mainstream support services that are more geared to the needs of people with intellectual or physical disability (AIHW 2002: 181).

Implications

There may be gaps in the provision of support to carers who do not fit a conventional model of a full-time carer providing assistance to a person with self-care, mobility and/or communication limitation. Falling into this category are carers who provide ongoing low to moderate level assistance with frequent bouts of high intensity assistance, for example carers of people with mental illness.



Impact of the caring role

The financial and social impacts of providing unpaid care are well documented (see for example, ABS 2004; AIHW 2000, 2004, 2007b; Hales et al. 2006; Schofield et al. 1998). These include:

- Reduced labour force participation with consequent effects on long-term financial security.
- Difficulty in returning to work after a period of caring.
- Financial costs associated with the provision of care; difficulty in meeting living expenses.
- Social isolation.
- Strained family relationships (although some carers report strengthened relationships).
- Reduced physical and emotional wellbeing, including frequent feelings of anxiety and depression associated with caregiving.
- Paid employment can protect carers from becoming engulfed in the caring role and help them to maintain vital social contact, yet can be hard to sustain when the caring demands are high.

For carers who are not in the labour force, particularly the very long-term and older carers, the risk of losing contact with friends is high. Caring for a person who is housebound or not holding a drivers license can limit a carer's social participation. The end of a long period of caregiving may be especially difficult for those carers who become socially isolated because of the caring role.

The design of respite care services is a critical aspect of support for many carers. Flexible respite care can cater to the varied needs of both carers and care recipients: not just 'minding' but providing both parties with opportunities for social participation, help with transport etc. Comprehensive, socially inclusive, respite can be particularly beneficial for very long term carers and older carers who may have become disconnected from mainstream society as a result of the caring role. Such models of respite care have existed for some time and their benefits have been well demonstrated (some innovative respite trials are described in Hales et al. 2006).

Two-thirds of primary carers in 2003 were not satisfied with their role and almost one third attributed frequent worry and feelings of depression to being a carer; carers attribute dissatisfaction to a variety of factors, with financial assistance and improved or more support rating highly among the types of carer support most desired (Hales 2007).

The impact of a caring role is a very individual experience. Different carers have different needs – services to support carers need a degree of flexibility because there is no one size to fit all (refer to term of reference number 3, below).

Carers do not necessarily stop providing assistance when the person enters a care facility; rather than a cessation of the caregiving relationship, the relationship changes. Carers who do stop caring may need continued support during the transition period. There may be strong feelings of loss and grief, exacerbated by the difficulties often associated with relinquishing the carer role and having to adjusting to a new set of circumstances (Ryan 2002). It is important that carers do not see stopping caregiving as a personal failure.

3 Term of reference: special groups of carers

For certain groups of carers the caring role can carry an extra burden which influences their need for support. These groups include older carers, young carers, Indigenous carers, carers from culturally and linguistically diverse (CALD) backgrounds, carers in rural areas, and carers of dementia sufferers. Only limited information is available about some of these groups.

Older carers (aged 65 or over)

While older people, defined as 65 years or over, are often recipients of informal care, a substantial number of older people are themselves carers.

- Some 18% of all carers in 2003 (452,300 people) and 24% of all primary carers (113,100) were aged 65 or over. Overall, 19% of older Australians were carers, and 5% were primary carers (AIHW 2007c).
- Men make up over half (54%) of all older carers. Though women still form the larger proportion (58%) of older primary carers, the gender breakdown of primary carers in the older age groups is markedly different by comparison with younger groups of carers. The support needs of older male carers can be easily 'lost' in an analysis of aggregate data (AIHW 2007c).
- Caring for a spouse or partner is the most common situation of older carers (83%). The proportion of spouse carers is higher among men (92%) than women (76%). Older women tend to have a more diverse set of caring responsibilities with 8% caring for a son or daughter, and 5% caring for their parents (AIHW 2007c).
- The needs of older carers derive, among other things, from their potentially high burden of care as:
 - In 2003 one-third (33%) of older primary carers had spent more than 10 years in the caring role. An additional 23% had spent between 5 and 9 years in the caring role (AIHW 2007c).
 - Despite acting as a carer for someone else, a large proportion of older carers (59% or 66,400) in 2003 themselves had a disability, and around 13% (15,100) had a severe disability (AIHW 2007c).
 - Older carers can be engaged in intensive caregiving. In 2003, 79% of older carers were assisting people with continuous rather than episodic care needs (AIHW 2007c). Eighty-four per cent of primary carers of older people assist with mobility, e.g. bed transfers, lifting, and weight bearing, and 55% assist with personal care (bathing, dressing, eating, managing incontinence) (AIHW 2007a). Since many primary carers of older people are themselves older people, this highlights that many older carers face heavy demands on their physical strength and mobility.
- Primary carers of a spouse or partner are the least likely of all primary carers to seek help (Hales 2007). The implication of a high proportion of spouse carers among older carers is that older carers are at particularly high risk of not seeking and receiving support when it is needed.

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- A key concern of older carers of adult children was about who would provide care when they no longer can. Many wish to see alternative arrangements made for the future of the care recipient (AIHW 2003).
- People in this age-group (and indeed those aged 50 to 64) can also be heavily involved in care of grandchildren, particularly where their own adult children are unable to do so as a result of ill-health, disability, substance abuse and related issues. While not directly within the scope of this inquiry, the dual role responsibilities for this group of 'grandparent carers' are rarely recognised.

Young carers (aged to 24 years)

Young carers are a group about whom relatively little information is currently available. Nevertheless, many young people are carers.

- In 2003, around 300,900 people aged less than 25 years, or 4.5% of this age group, were carers (AIHW 2007a). Though most young carers were aged 15-24 years, almost one-quarter (23%) were aged 10-14 years. The gender balance among young carers was almost equal, with males accounting for 52% (AIHW 2007a).
- Some 5% of young carers are primary carers. If unconfirmed primary carers are included, the proportion increases to 8%. The majority (74%) of young people identified as primary carers in 2003 were aged 20-24 years (AIHW 2007a).
- Young carers were most likely to be caring for a parent (63%) (AIHW 2007a).

Taking on a caring role may significantly affect the life of a young person and the literature identifies several key issues.

- Young carers may experience a more limited social life, lower educational achievement and increased stress compared with their non-caregiving peers (Gays 2000; Mukherjee et al. 2002). The negative impact on education can carry consequences for career development in an increasingly competitive employment climate (AIHW 2000).
- The mental health of young carers may also be affected by social isolation and the stress of extra responsibilities (Gays 2000).
- The impact of being a younger carer can vary depending on the type of disability or health condition of the care recipient. Caring for a parent with a physical disability may take a physical toll on a young carer. A variety of physical ailments such as muscle strain, fatigue and exhaustion have been reported (Gays 2000). Young people living with a parent with mental illness may experience greater social isolation as a result of the stigma attached to mental illness, as well as the stress of coping with the parent's condition (AIHW 2007a).
- Living in a one-parent family can increase the caring responsibilities for young carers because they are less likely to have a fall-back carer. This results in a more limited support base compared to young carers in couple families (AIHW 2007a).

Aboriginal and Torres Strait Islander carers

Although SDAC 2003 includes little information on Aboriginal and Torres Strait Islander carers, the 2006 Census provides some information about this group. The following information is reported in ABS & AIHW (2008).

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- The 2006 Census identified 11,600 Indigenous male carers and 20,000 Indigenous female carers. These numbers probably underestimate the Indigenous carer population because approximately 11% of Aboriginal and Torres Strait Islander people aged 15 years and over in private dwellings did not answer the carer question. This compares to a 5% non-response rate among the non-Indigenous population.
- After adjusting for differences in the age structure of the Indigenous and non-Indigenous populations, Aboriginal and Torres Strait Islander people are more likely than non-Indigenous people to be carers.
- The median age of Indigenous carers was 37 years, which is 12 years younger than for non-Indigenous carers (49 years). The rate ratio of Indigenous to non-Indigenous carers was highest in the age group 15-34 years. This reflects younger parenting and the earlier onset of many chronic diseases in the Aboriginal and Torres Strait Islander population (AIHW 2008).
- Some 8% of younger Indigenous people (aged 15-24 years) were carers.
- In 2006 around 2,100 Indigenous carers needed help with core activities themselves. Of these carers, over two-thirds (68%) were under 55 years of age. Indigenous carers were between 1.5 and 3 times as likely as non-Indigenous carers to need assistance with core activities. This ratio is similar to the overall Indigenous to non-Indigenous rate ratios for those needing assistance.

Carers from culturally and linguistically diverse backgrounds

As the number of people from culturally and linguistically diverse (CALD) backgrounds is expected to increase at a faster rate than other segments of the older population (AIHW: Rowland & Karmel 2004), the number of carers of older people from a CALD background can be expected to increase accordingly. The CALD population is a heterogeneous group reflecting the wide variety of cultural groups in Australia, and their different immigrant histories and settlement patterns. However, a review of the literature indicates little research on issues and experiences unique to carers of older people from CALD backgrounds.

- Based on an analysis of the 1998 SDAC, approximately 23% of primary carers were born outside Australia, and approximately 14% of primary carers were born in non-English speaking countries. One in ten primary carers (43,500) in 1998 said that they used a language other than English to communicate with their main care recipient (AIHW 2004).
- Older people born in non-English speaking countries show a preference for care in the community over residential care (AIHW 2007a).
- The absence of culturally-specific programs which are sensitive to the migration and settlement patterns of older people can result in a loss of cultural identity. Language barriers impact on socialisation, psychological well-being as well as fundamental activities such food and fluid intake (Hales et al. 2006).
- A lack of culturally-specific programs can also increase the burden on carers as these carers will often delay seeking assistance due to their own reluctance or the care recipient's reluctance to use mainstream services. Bilingual support for care recipients can make it easier to introduce formal assistance (Hales et al. 2006). Respite care without bilingual support and accompaniment in the community

AIHW submission to the 2008 Inquiry into Better Support for Carers may be of little benefit to carers who do not have a good command of the English language.

- Some cultural groups have entrenched views on who should care for older family members which can lead to carer strain. Having care workers who understand these cultural issues can facilitate the process of accepting formal assistance (Hales et al. 2006)

Carers in rural areas

Census data indicates that in 2006 there were 517,137 carers living in rural Australia (regional and remote areas). Of these, 21,785 were Aboriginal and Torres Strait Islander people and 489,424 were non-Indigenous (unpublished ABS data). While little is known about the special needs of carers outside major metropolitan areas, as far back as 2000 the AIHW reported that primary carers living outside capital cities are less likely to receive help with the caring role than carers in capital cities (AIHW 2000: 145). More recently, Barrett's (2005) study of 76 carers in rural Western Australia found that the key issue is access to, rather than absence of, services. These carers said that the main obstacles to accessing services are travel time and distance, financial constraints and the physical management of the care recipient.

Access to specialist and allied health care can be a major problem for care recipients in rural Australia and their carers. Innovative approaches to service delivery have made inroads into solving problems associated with vast distances from specialist services (for example, see the results of outreach and telehealth trials for people with dementia and their carers in Hales et al. 2006).

Older Australians living in remote areas were under-represented in the Aged Care Assessment Program (ACAP) client group in 2004-05. Referrals to the program represented only 66% of the size that would be expected given the proportion of people in the ACAP target population who lived in remote parts of Australia (ACAP NDR 2006). The exact implications are unclear but this might signal significant unmet need for carer support in these areas.

Carers of people with dementia

The increasing number of older people with dementia means that there will also be an increasing demand for community and residential care (AIHW 2003). Having a carer plays a pivotal role in terms of whether people with dementia are able to remain in the community. Consequently, the physical and mental well-being of carers is a crucial factor in facilitating this.

- The SDAC indicates that there were 23,200 (+/-7,800) carers in 2003 who provided assistance to co-residents with dementia. Of these, 12,200 were primary carers; however, the true number of primary carers is thought to be much higher (AIHW 2006).
- Also according to the 2003 SDAC, men are strongly represented among co-resident carers of people with dementia (45%); however, co-resident primary carers are still more likely to be women (71%) (AIHW 2006).
- Much of the literature suggests that caring for someone with dementia is especially demanding. Behavioural problems have to be managed in addition to

AIHW submission to the 2008 Inquiry into Better Support for Carers physical care needs (AIHW 2006). Moreover, it can be a distressing experience to witness a once independent person become increasingly dependent in multiple life areas (Draper 2004).

- Dementia carers can experience high levels of carer strain and try to manage too long without sufficient support. Anxiety, insomnia, social isolation, anxiety and depression can all affect carers of dementia sufferers (AIHW 2006; Hales et al. 2006).
- The six most frequently stated needs of family members who were primary carers of people with dementia reported by Leong et al. (2001) included:
 - knowing that someone will provide care when the carer is unable to do so
 - a telephone hot-line
 - time away from caring duties
 - ways to deal with stress
 - time for physical rest
 - ways to deal with feelings of being trapped.
- A firm diagnosis of the care recipient's condition can often help to reduce carer burden (Bruce & Paterson 2000; Schofield et al. 1998).

4 Trends

The 2003 ABS estimate of 474,600 primary carers represents an increase of 5.2% on the 1998 estimate of 450,900 (ABS 1999, 2004). Because primary carer status was not determined for all carers, 474,600 is regarded as a minimum and uncertainty surrounds the ratio of primary carers to people with severe disability living in households. It is likely that the ratio was in the vicinity of 43 primary carers per 100 people in need of assistance, which is the same as in 1998 (Hales 2007). Statements of a slide in the provision of informal care are as yet unsubstantiated – the 2009 SDAC promises to shed much needed light on this issue. Available evidence suggests that any increased pressure on formal care services up to 2003 was the result of increasing numbers of people in need of assistance, both formal and informal, rather than a relative decrease in the number of carers.

The AIHW undertook a study in 2003 to assess the relative impacts of demographic and social factors that could affect the supply and demand for informal care over a decade (Jenkins et al. 2003). Analysis was based on data from the 1998 SDAC. Projections of the number of primary carers in 2013 were made by applying 1998 carer (primary carer) rates and taking into account projected future changes in the age and sex structure of the population, changing male and female labour force participation rates and changing living arrangements at older ages, over the projection period. These projection results were complemented by the addition of three hypothetical scenarios: (i) an overall decreasing propensity to care; (ii) a reduction in women's propensity to give up paid employment to provide care; and (iii) an increase in the proportion of spouse or partner carers aged 60 years or over.

The baseline model projected 492,700 primary carers in 2003 (compared with the 2003 SDAC estimate of 474,600, or 484,600 if we include an additional 10,000 out of 50,000 unconfirmed primary carers), rising to 573,900 by 2013. We caution against placing too much emphasis on small differences between estimated and projected numbers. A main finding of the hypothetical component of the projections was that even a 20% reduction over the period in the proportion of women who give up paid employment to become a primary carer is unlikely to substantially reduce primary carer numbers. A large cohort of baby boomer women will enter the 45–64 years age group during this period and this age group has been a traditional source of primary carers for spouses with a disability and ageing parents. Only an overall decreasing propensity to care was found to substantially impact on primary carer numbers during the projection period.

These scenarios were used to explore the impact of supply factors because much of the public discourse about informal care concentrates on supply issues. Yet, the SDAC data suggest that becoming a carer is demand (needs) driven and the data provide evidence of increased supply in response to higher levels of need (AIHW 2007: Table 3.7).

New information will come from the Department of Families, Housing, Community Services and Indigenous Affairs commissioned work on the future provision of informal care (modelling is being undertaken by Access Economics).

5 Gaps in the evidence

A number of different important data collections are available on carers including the SDAC, Census, and administrative databases. However, key issues concerning a quality evidence base in terms of carer numbers, profile, patterns of service use and needs, relate to the fact that the data currently available and accessible are limited, inconsistent and fragmentary.

Administrative data collections are restricted to coverage of program clients, and cannot be used to estimate the total number of carers. The SDAC indicates that many carers do not use services and do not receive payments.

Some limitations derive from problems of defining and identifying carers. In some collections, the definition of a carer can be particularly narrow in scope, a problem referred to earlier in relation to the SDAC definition of primary carer. The SDAC distinguishes between 'carers' and 'primary carers', with the detailed data collected only from primary carers. Only limited information is collected on non-resident carers. Under the SDAC interview protocol, carers under the age of 15 can not be classified as primary carers, and so are excluded from further data collection. The role of a primary carer needs to be ongoing, that is, for a minimum of six months. This excludes intermittent or short-term carers such as those caring for people with a mental illness or palliative carers.

The SDAC has limitations in regard to its sample size for analysis at state and territory level, remote areas, or for other small area analysis, as well as with regard to certain special groups as discussed in section 3. The AIHW is aware of and supports the proposed increase in the sample size of an additional 18,000 households for the 2009 survey. The AIHW is participating in the consultation on survey content, with the joint aims of promoting enhancements of questions (particularly in relation to unmet need) while maintaining continuity in data items that are critical to establishing key trends (e.g. the number of carers).

The 2006 Census of Population and Housing was the first time data on carers has been collected in the Census. While the Census provides additional scope to examine data on carers the relevant question did have a large non-response component.

Differences in how a carer is defined across different collections leads to differences in carer counts such as between the 2006 Census and the SDAC. Census data on carers is restricted to a single question completed by either each household member themselves or by a household member on behalf of other household members. The SDAC interviews care recipients which enables the survey to pick up people who would not necessarily self-identify as carers. Differences between the Census and the SDAC mean that carer numbers vary between the two collections. While web published data from the Census 2006 puts the number of carers over 15 at 1,606,177 (ABS Cat. No. 2068.0 - 2006 Census Tables) the SDAC estimates it at 2,455,400, a difference of almost 850,000 people.

The fragmentary nature of the data means that an integrated analysis and understanding of carer numbers, needs and patterns of service use is not readily achieved. The AIHW is currently preparing a scoping study into the feasibility and utility of a National Carers Data Repository as one way of addressing some of those issues raised here, thereby strengthening the evidence base. The concept of the NCDR involves two aspects – bringing key data sources together in one place (the repository), and analysing the data in more integrated ways to address important policy issues. The development of an integrated national approach to sharing and enabling access to existing data on carers is an important strategy for building knowledge about carer needs and how to support them.

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