



**Submission by Carers NSW to the House of Representatives Inquiry
into Better Support for Carers**

July 2008

Copyright Carers NSW Inc.
3 July 2008
Carers NSW Po Box 20156 World Square NSW 2002
www.carersnsw.asn.au
Ph: 02 9280 4744

Contents

Executive summary and actions needed	3
1. Submission content	5
2. Profile of carers in NSW	5
2.1 About Carers NSW	5
2.2 Who are carers?	6
2.3 What carers do	6?
2.4 Key statistics on caring in NSW	6
2.5 Demographic context in NSW	7
2.6 Carer support policy context in NSW	8
3. Carer recognition	9
3.1 Support for carer legislation	9
3.2 Carers as partners in care	10
4. Practical support for carers	13
4.1 Introduction	13
4.2 Financial support	14
4.3 National Companion Card and National Carer Card	16
4.4 Housing issues for carers	18
4.5 Supported accommodation	19
4.6 Service systems and service delivery	22
5. Specific population groups	24
5.1 Young carers	24
5.2 Aboriginal and Islander carers	29
References	33

*“Many people in this country are interested in this Inquiry, and await the outcomes with anticipation. I hope we are not disappointed”
(NSW Carer, to the Inquiry, 2008).*

Executive summary

Carers NSW, in its role as the peak organisation representing informal carers across NSW, aims to ensure that carers are recognised as an integral part of community care. With one in eight people in NSW taking on a caring responsibility, Carers NSW strongly believes support for carers is a beneficial investment for all the Australian Governments.

Carers NSW provides this submission to assist the Australian Government to identify the diversity of caring experiences and needs, and to use the available evidence to adequately support strategies and programs that enable carers to maintain their caring role now and into the future, when that role is their choice.

Carers NSW supports the extensive submission to the Inquiry by Carers Australia. The Carers NSW submission provides a focus on key issues for carers in NSW, namely carer recognition and carer support. In addition a focus on the carer population groups of Young Carers and Aboriginal and Islander Carers have been included as a focus of this submission because of their specific carer support requirements.

Actions needed

Carers NSW has recommended the following actions to the Australian Government to reduce the financial, social, physical and emotional disadvantages of carers, the families and the people for whom they care.

1. The Australian Government implements National Carer Legislation
2. The Australian Government implements a National Carer Strategy or Acton Plan
3. The Australian Government implements mechanisms to ensure that carers are recognised as partners in health and community care, across hospitals and community health, disability, aged care, residential care, mental health and community care service systems
4. The Australian Government increases the Carer Payment to the income equivalent of the federal minimum wage
5. The Australian Government implements income reform to provide financial security for all carers, including the benefits of a Carers Superannuation Scheme
6. The Australian Government introduces a National Companion Card Scheme including a streamlined administrative system
7. The Australian Government implements a National Carer Card

8. The Australian Government funds supported accommodation models that are appropriate for the individual; facilitates community involvement and involves inclusive practices amongst the individual, family, staff and service provider

9. The Australian Government reviews service systems and structures and identifies ways in which services, particularly respite, can better meet carer's individual needs

10. The Australian Government increases funding to the national young carer program to provide:

- increased specific respite services for young carers as well as better access to mainstream respite services
- increased financial support for young carers, including easier access to the Carer Payment and Carer Allowance, and incentives for young carers to remain in education or employment opportunities
- increased awareness and training programs to schools and school teachers about young carers and the supports they require to remain in school
- improved awareness and training to community care service providers about young carers and their needs, in order for services to have a better understanding about how to support young carers, particularly in regional and rural areas
- increased young carers social participation programs to provide young carers with linkages to support each other in their caring role
- additional funding to provide case management and service coordination to meet the ongoing and individual needs of young carers

11. The Australian Government develops and implements a National Aboriginal and Islander Carer Framework as a component of the Council of Australian Government's Indigenous reform priority

12. The Australian Government provides funding to conduct evidence-based research to inform national Aboriginal and Islander carer policy and service development

I provide this submission to the members of the Inquiry into Better Support for Carers on behalf of Carers NSW for consideration. Carers NSW would also like to acknowledge the information provided to us for the submission by many carers across and New South Wales, key partners, friends and stakeholders.

With thanks for the opportunity



Elena Karakas
CEO
Carers NSW

1. Submission content

The content of this submission relies on collective evidence of carers' identified issues and needs within a state, national and international context.

This submission complements the Carers Australia submission that addresses nationally recognised carer issues. This submission will have a NSW state focus but will also acknowledge and identify federal issues where appropriate, in recognition that carers access services and supports within NSW that can be state and, or, federally funded. The aim is not to identify all carer issues that have been raised with Carers NSW through research, but rather to identify, describe and provide recommendations to key issues that carers in NSW experience.

This submission is informed by recent research undertaken by Carers NSW, Carers Australia and the national Network of Carers Associations, and research from relevant national and international sources. Carers in NSW were also interviewed by phone to identify specific individual issues for carers, as well as written content carers provided to Carers NSW.

Carers NSW believes this Inquiry is one of the most important opportunities to ensure carers will be adequately supported now and in the future. Consulting with carers about this submission is paramount to providing a realistic and reflective account of carers' experiences in order to better support carers in NSW.

Carers NSW consultation process for the inquiry included:

- A mailout to our carer members and carer support groups informing them of the Inquiry and providing suggestions for carers to write letters of their own. This included both adult carers and young carers (those aged 25 years and under).
- Carer support groups and service providers were encouraged to hold focus groups with carers to identify specific needs of carer population groups and provide submissions based on the feedback from the focus groups.
- Phone interviews were held with carers to gain insight into specific individual issues.

A Young Carer Survey (18-25 years) conducted over May-June 2008 by Carers NSW also provided information for this submission.

Whilst the Carers NSW submission provides evidence of collective issues, the issues carers themselves have provided direct to the Inquiry through letters will give the Inquiry committee a deep insight into the individual circumstance of carers in NSW. This information complements the collective issues Carers NSW raises in this submission.

A collective submission from the Strategic Carer Action Network (SCAN) convened by Carers NSW was also provided to the Inquiry.

2. Profile of carers in NSW

2.1 About Carers NSW

Carers NSW is an association for relatives and friends who are caring for people with a disability, mental health problem, chronic condition or who are frail aged. It is the peak organisation for carers in New South Wales and the only state wide organisation that has carers as its primary focus.

Carers NSW is part of a national Network of Carers Associations and works collaboratively to lead change and action for carers. The core work of Carers NSW is to:

- be the voice for carers in NSW
- undertake research, policy development and advocacy
- provide carer services and programs
- provide education and training for carers and services providers.

Our vision is that all carers in NSW are recognised, valued and supported by their communities and by governments.

2.2 Who are carers?

Carers are usually family members or friends who provide support to children or adults who have a disability, mental illness/disorder, chronic condition or who are frail aged. Carers can be parents, partners, brothers, sisters, sons, daughters, friends or children of any age. Carers may care for a few hours a week or every day. Carers are unpaid. They may receive incomes from a range of sources including government pensions and benefits.

A primary carer is someone who takes on the main caring responsibilities of a care recipient. Australian Bureau of Statistics (ABS, 2005) defines a primary carer as a person who provides the most informal assistance on an ongoing basis, to another person who is restricted by one or more core activities in the areas of communication, mobility and self care. A secondary carer provides informal care in a supporting role where either another family member or formal services provide the majority of care (Carers Association of South Australia Inc, 2001).

2.3 What carers do

Each caring situation is unique. Some carers assist the person they support with all their activities of daily living while others provide intermittent support. Their caring tasks can range from administering medication and dressing wounds to personal care tasks such as showering, assisting with mobility, or supervision of daily activities. Carers also provide emotional support day in and day out to some of the most vulnerable, isolated members of our community and they often act as case managers; navigating service systems and organising appointments. Caring is the invisible work which enables people requiring support and care to live in the community, maintaining a good quality of life.

Carers are pivotal to both the community care and public health systems. In regard to the health system, some carers provide care for short, intensive periods of time following discharge from hospital. Others provide care intermittently for someone between hospital visits. There are carers who provide full-time care for many years to people requiring ongoing medical treatment and community support. Many carers care full-time, for the lifetime of the care recipient, for people with severe multiple disabilities. Carers are also anxious about what will happen to the person for whom they care after their own death, or they can no longer care.

2.4 Key statistics on caring in NSW

According to statistics on carers from the Australian Bureau of Statistics (ABS, 2004), in 2003:

- Approximately one-third of all carers in Australia live in NSW

- There were 748,000 carers in NSW (11% of the population), 20 per cent of whom were primary carers
- 40 per cent of primary carers cared for a partner, 29 per cent for a child, 32 per cent for other (eg sibling, parent)
- Women aged 45-54 years were the largest single group of carers
- 45 per cent of primary carers provided 40 hours or more care per week on average
- 78 per cent of primary carers lived with the person they supported
- 75 per cent of carers were of workforce age although 45 per cent were not in the workforce
- The median gross personal income for a primary carer was \$224, other carers \$365 and non-carers \$435
- 55 per cent of primary carers relied on a government allowance or pension as their principal source of income.

A report by the National Centre for Social and Economic Modelling (NATSEM, 2004) projects Australia faces a significant carer shortfall:

- It is estimated that by 2031 the number of older people likely to need assistance because of severe or profound disability is likely to increase by 160 per cent whereas the number of people likely to provide care will only increase by 57 per cent.
- The physical, mental and emotional health and wellbeing of most carers was poor because of their caring responsibilities. As a result of caring over half of carers suffered a decline in physical health and two thirds felt their mental and emotional health had been affected by providing care.

The largest survey of carers' health and wellbeing was released in October 2007. The survey undertaken by Deakin University, Australian Unity and Carers Australia found the following:

- Carers have the lowest level of wellbeing of any group surveyed using the Personal Wellbeing Index measuring tool
- Sole parent carers had the lowest wellbeing of any carer population group
- The wellbeing of carers decreases linearly as the number of hours spent caring increases
- Carers are more likely than is normal to be experiencing chronic pain
- Carers are likely to have an injury and this is associated with reduced wellbeing
- Carers have an average rating on the depression scale that is classified as moderate depression, and over one third are classified as having severe or extremely severe depression (Deakin University and Carers Australia, 2007).

2.5 Demographic context in NSW

The population of New South Wales is similar to the Australian population. It is both diverse and ageing. The effects of this on the economy, on health and community care systems, disability and aged care services, as well as families and individuals will be pronounced. An understanding of the demographic shifts is evidence of the need for increased support for both the formal and informal care sectors. Evidence shows that:

- In NSW, by 2044, the proportion of the population aged over 65 is projected to have doubled from 13.7 per cent in 2005 to 24.8 per cent in 2044 (NSW Treasury, 2006).
- In addition to an ageing population, technological advancements are contributing to longevity of life for people with a disability (AIHW, 2000). While age standardised rates of 'severe' disability have remained consistent since 1981 (AIHW, 2005), there is likely to be

an increase in the number of people with a disability requiring assistance as a result of ageing.

- Population ageing in Australia is a consequence of a steadily falling birth rate, increasing rates of lifetime childlessness and increasing average life spans. As a result, younger people will form a smaller proportion of the population in the future and older people a larger proportion.
- Changes to household structures, such as an increase in lone person households and one parent families with dependent children will also impact on caring roles. For example there may be an increased reliance on young people as carers.
- The population is becoming more culturally diverse. In 2006, 23.8 per cent of the NSW population was born overseas (ABS, 2006).

These demographic changes indicate the breadth of diversity that all governments need to consider in the development and delivery of appropriate formal and informal supports in the community.

2.6 Carer support policy context in NSW

Over the last two years the NSW Government has had a strong focus on a whole of government approach to improving services for people with disabilities, mental illness, chronic conditions and their carers.

A number of NSW Government plans to improve coordination and delivery of services include:

- *NSW Carers Action Plan 2007-2012*, highlighting the NSW Government's commitment to carers
- *Stronger Together*, the ten year plan for disability services
- *NSW: A New Direction for Mental Health*, the five year commitment to mental health services
- *Better Together*, the whole of government plan providing the overarching framework, and
- *A New Direction for NSW*, the NSW State Plan providing priorities for better health and community services including services for people with chronic conditions and their carers.

Carers NSW welcomed the NSW Government's strong focus on improving and increasing services for some of the state's most vulnerable people.

Despite these announcements to better support people with disabilities, mental illness, chronic conditions and their carers, unmet need remains considerably high. In addition future trends demonstrate that the need for these services will increase dramatically over the coming years. This will place growing demand on the Australian and NSW Governments to meet this need.

With key policy trends in the aged care, disability, mental health and health sectors moving towards shorter hospital stays, reduced or delayed admission to high cost residential accommodation or hospital, systemic substitution of high cost services and their replacement with care and support in the home (for example palliative care, aged care packages) and increased provision of care in the community, it is evident support for informal carers must be adequately addressed (Network of Carers Associations, unpublished, 2007).

3. Carer recognition

3.1 Support for carer legislation

The *NSW Carers Action Plan 2007-2012* includes a number of strategies, to increase the respect and recognition of carers, reach out to family members who may not see themselves as carers (or 'hidden' carers), improve services to carers and the people they care for, encourage agencies to view carers as partners in care and support carers to combine work and caring. Carers NSW recommends that this action plan should be supported by a legislative framework.

Legislative recognition of carers has been enacted in other states and territories in support of the formal recognition of carers as individuals. For example, the South Australian, Western Australian and the Northern Territory governments have all developed 'Carer Recognition Acts'. The Carer Recognition Act formally acknowledges that carers have legal rights in their own right, and not just in relation to the person for whom they care (Government of South Australia, 2005).

The Queensland Carers (Recognition) Bill 2008 was recently introduced into Queensland Parliament and aims to provide greater recognition for carers. It also includes a charter that would require the government to consider the impact of its decisions on carers.

The importance of legislation regarding carers is acknowledged in South Australia's Carer Recognition Act. The objects of the Act include:

- a) to recognise and support carers and their role in the community
- b) to provide for the reporting by organisations of the action taken to reflect the principles of the Carers Charter in the provision of services relevant to carers and the persons they care for.

Similarly, Western Australia's Carers Recognition Act was developed in 2004. The Act is the overarching legislation that aims to change the culture of service providers to ensure the impact of carers is considered when services are assessed, planned, delivered and reviewed (Department of Communities, Western Australia, 2007).

In NSW, formal recognition of the vital role of carers has been acknowledged in the recent changes to the NSW Mental Health Act (2007). The Act includes rights for nominated carers to have information regarding the patients treatment and be involved in health care planning. The changes to the Act recognise the integral relationship between the carer and care recipient in regard to health care needs. The changes demonstrate the acknowledgement by NSW Government of the importance of the care relationship.

Carers NSW supports national carer legislation and policy advocated by Carers Australia on behalf of the state and territory Carers Associations. Carers NSW believes national overarching legislation is important to recognise, protect and provide equal opportunity to carers across Australia. The key to effective national carer legislation will be to ensure its compatibility to state and territory legislation so that one does not negate the other.

Internationally, several countries have recognised the need to support carers, and have enacted carer support legislation and introduced national carer frameworks. For example, the United Kingdom and New Zealand have introduced legislation to provide family carers with

the right to flexible working hours and practices, and both these countries have introduced relevant legislation or a national carer strategy.

Australia is lagging behind in national carer legislation and a national carer strategy or action plan. The Australian Human Rights and Equal Opportunity Commission has made extensive recommendations in its 2007 report – *It's About Time: men, women, work and family*, to introduce a Family Responsibilities and Carer's Rights Act, and extended carer leave and flexible working practices for carers (HREOC, 2007). Carers Australia has similarly advocated for national carer legislation, a national carer framework and carer friendly work practices (Carers Australia, 2007 and 2008).

Carers Australia and the Network of Carers Associations was disappointed that the Australian Government's recently released National Employment Standards did not adopt recommendations for appropriate carer leave and flexible work practices. The new standards that provide for paternal leave and early childcare provisions ignore needs of other carer responsibilities in 'working families' in Australia.

Carers NSW believes that development of national carer legislation by the Australian Government is one way to ensure carer rights and individual needs are acknowledged at all levels of government and across all sectors.

Action needed

The Australian Government commits to the development of National Carer Legislation

The Australian Government commits to the development of a National Carer Strategy or Action Plan

3.2 Carers as partners in care

The ageing of the Australian population is a demographic reality. According to the Productivity Commission (2005) the effects over the next 40 years will be pronounced. One quarter of the population will be aged 65 years or more by 2044-45, roughly double the present proportion of the population in that age cohort. The proportion of the people 85 years and older will increase even more, from 1.5 to five per cent over this period.

One of the implications of an ageing population is that there will be many more Australians requiring assistance because of disability (Giles et al, 2003). An important disability trend is the survival of many people with early onset disability into old age. According to the Australian Institute of Health and Welfare (AIHW, 2000), this influences not only the longevity of the caring relationship, but also patterns of service use in health and community care.

The Australian health and community care systems increasingly rely upon family, friends and neighbours who provide unpaid care and support to children and/or adults who have a disability, mental illness/disorder, chronic condition or who are frail aged. Seventy-four per cent of the assistance required by Australian's due to disability or illness is provided by informal carers. Every year carers provide over 1.2 billion hours of support (Access Economics, 2005).

According to the Productivity Commission (2005), the current care mix, between formal and informal care, is likely to remain similar over the next 10 to 15 years. The most likely scenario therefore is that carers will continue to provide substantial support to the health and community care systems over the next 15 years given government policy and the wishes of members of the community to be cared for at home.

The *NSW State Health Plan*, together with the *NSW Carers Action Plan 2007-2012* have placed a strong emphasis on 'carers as partners in care', identifying the integral role that carers and families play in supporting people with health needs who use formal services at home in the community. The *NSW Carers Action Plan 2007-2012* places specific emphasis on the acknowledgement that improving the quality of life and health and wellbeing of carers directly benefits the recipients of care (NSW Health, 2007).

The notion of carers as partners in care is increasingly acknowledged in international literature (Performance Improvement Advisor, 2004, p58):

Family members that care for patients at home can provide valuable information and feedback to health care professionals. Educating and training caregivers can increase compliance with discharge plans and prevent readmissions. During hospitalisations, caregivers can act as quality monitors, alerting staff to potential costly problems before they happen.

That carers are a vital part of the health care support team is well acknowledged in hospital settings with regard to carers of children with chronic conditions or disabilities for example (Wilson, L and Harnett, E, 2005). This fact is less acknowledged within other areas of the hospital system and then often only in relation to discharge planning. International research indicates that carer inclusion benefits patient quality of care (Droes, R, 2000; Kelly, M and Newstead, L, 2004) and can reduce readmission rates (Bridge, J and Barbe, R, 2004).

The recently released UK 10-year Carers Strategy, *Carers at the heart of 21st century families and communities: a caring system on your side, a life of your own*, also places significant emphasis on 'carers as partners in care'. The UK strategy proposes supports to ensure carers will be respected as expert care partners and will have access to the integrated and personalised services they need to support them in their caring role. A number of these supports are similar to those in the *NSW Carers Action Plan 2007-2012* including timely provision of information to carers, and appropriate education and training for both carers and paid workers.

There is a need for health professionals to understand the vital role of carers, what carers do and the impact caring can have. The complexity of the hospital and community service systems means that there can be a lack of understanding about carers and awareness of the toll that caring can take. It can also lead to misunderstanding about the availability of support to carers. Carers' involvement is generally based on a deep and abiding personal commitment. Carers do not have the same resources, pay or training as health service providers and therefore should not be tasked with the same responsibilities.

Carers have provided information that they often feel their knowledge and experience of the care recipient is not sufficiently acknowledged or used in health and care planning (Carers NSW, 2005). The role of the carer as a provider of information about a care recipient to

health care providers must be acknowledged and used so health care providers gain the most relevant information about a patient's care needs.

There is a need for inclusion of the carer, as appropriate, throughout the patient journey. The pressure within hospitals is toward clinical and technical health delivery which can mean that carers are viewed as extraneous to the process, although the non-hospital and health care for the patient will often be provided by the family.

Carers frequently do not receive the information, education and training that they need. At every level of the health system carers need to be identified and supported whether it is at the birth of a child, diagnosis of a condition, the end of life, or at any stage throughout.

Specific needs such as the need for patient and carer to have access to adequate and appropriate information and communication mechanisms are vital for informed decision making. For people who do not have the capacity to understand and make an informed decision about their own health care needs, carers often take on this responsibility on an informal basis as advocates and substitute decision makers. Where the patient has capacity to make an informed decision, the carer is often an important contributor to assist in information dissemination and communication between patient and health care provider.

Carers also state that the need for a smooth transition between acute and community care is vital. Assumptions are too frequently made about a family member's ability and willingness to care. Carers often feel that the system moves too fast, especially in the first 36 hours after discharge. There is a gap between assessment and provision of services which causes stress to carers. Referrals can be made but services may not be available. This reflects a continued focus in strategic direction and budget allocation on acute rather than community care. Patients may not be linked back into the community adequately after discharge. Continuity of care can be improved through greater coordination across community care, acute care and residential care and between health, ageing, disability and other key sectors.

Carers often have their own needs that are different or additional to that of the care recipient. The individual needs of the carer must be acknowledged and addressed to ensure adequate supports are in place when a patient leaves the hospital system to be cared for at home. This could include health worker training that addresses carer needs and contributions within the health care team; and discharge protocols that include and respect carer views and ensure follow-up supports are in place.

More broadly, the interface between the various sectors, health, disability, ageing and between community, residential and acute care needs to be better coordinated and developed into models of integrated care (Carers NSW, 2005).

Carers are often forced to accept considerable responsibilities in relation to the provision of care and support, yet provided with few rights or supports themselves. It is necessary to ensure that carers' significant contribution to the wellbeing, treatment, and recovery of people is appropriately recognised, respected, valued, and supported (Carers QLD, 2008).

Evidence about the physical impact on carers was released by the WA Independent Living Centre (2006). Over 1,600 carers responded to a survey to measure the physical impact of caring on carers in Western Australia; measure the training, information, equipment, and

assistance carers receive; and identify which carers are at higher risk of injury and the need for training.

The data revealed that for many carers providing care was demanding and had a significant impact on their health. Over 40 per cent of carers said they had been physically hurt or injured as a result of providing care, and 55 per cent had never received information or training on injury avoidance.

The data also indicated that of the assistance they received to provide care:

- only 11 per cent of carers got assistance on a regular basis
- almost half (47 per cent) had assistance 'sometimes'
- 40 per cent said they never received assistance with caring.

These results indicate that many carers do not receive any assistance to care for the person or persons they looked after, and older carers were more likely than younger carers to be getting no assistance with caring. There was no coordinated system of providing information or training in a manner that is timely, relevant and responsive to carers needs and there is no process whereby information and training is updated and reviewed as care needs change (WA Independent Living Centre, 2006).

Recognition of carers should include:

- support and participation to act with or for the service user
- carers have their own requirements for information, education, communication and support
- carers have access to support for their own issues which may arise from providing care; and to exercise choice in the provision of care to another (Carers QLD, 2008).

Action needed

The Australian Government implements mechanisms to ensure that carers are recognised as partners in health and community care, across hospitals and community health, disability, aged care, residential care, mental health and community care service systems

4. Practical support for carers

4.1 Introduction

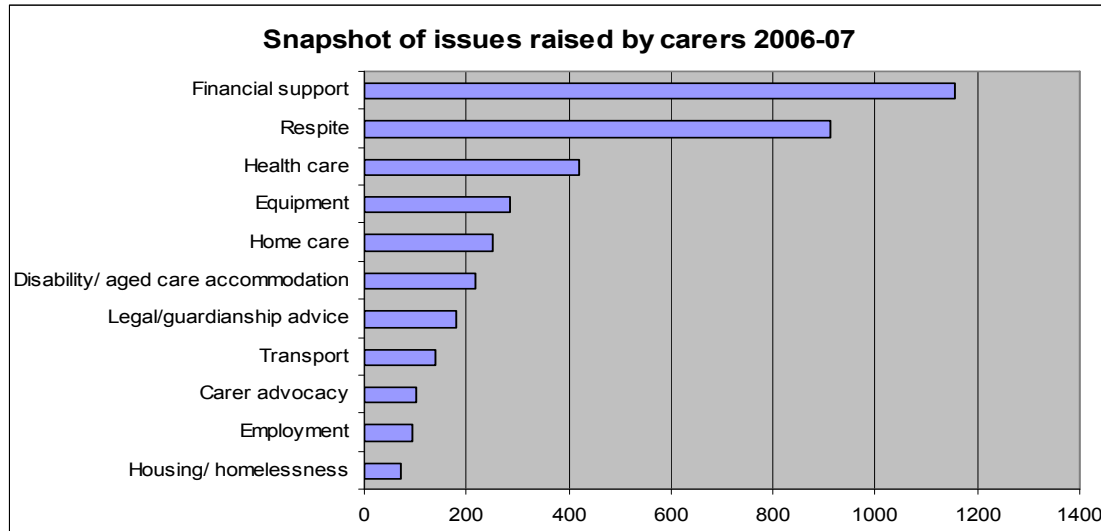
A key aspect of current social policy development is an understanding of carers and how to best support them now and in the future. The need to focus on a coordinated approach to policy development and program enhancement for carers is crucial to retain and sustain an adequate number of carers, and meet the increasing need for informal carers given the current community care focus of governments.

The NSW Department of Ageing, Disability and Home Care's (DADHC) *Stronger Together* initiative recognises the need for increased support to formal services such as accommodation, respite and case management, and has committed to increased funding of \$1.3 billion over five years. The initiative also recognises the growing diversity of the

population and has committed to assisting diverse groups by providing appropriate information about services, and training workers in cultural competence.

Carers NSW collects regular information regarding carers support needs. A snapshot of the 12 months to July 2007 (Figure 1) shows some of the highest priority services that carers need.¹

Figure 1. Carers identified needs



Source: Carers NSW data (unpublished) 2006-07

Figure 1 illustrates the range of services that carers require. Respite and financial support are recorded as the most common issues raised by carers (AIHW 2006, Carers NSW, 2007, FaHCSIA, 2008). The table shows carers also have significant need for assistance such as equipment, legal and guardianship advice, transport, employment, disability and aged care accommodation, home care services, health care services, advocacy services, and housing assistance. Carers also raised issues in relation to their cultural background (including Culturally and Linguistically Diverse and Aboriginal and Islander carers) and the barriers they face because of this additional need.

4.2 Financial support

Caring comes for many at a high personal cost, which in turn, can affect the public health system and government more broadly. There is now a wealth of Australian and international evidence to demonstrate the high financial, health and quality of life costs associated with caring. Many of these costs could be prevented by more effective and innovative support options for carers.

For example, the 2007 Australian Unity Wellbeing Index (AUWI) survey of carers indicated carers had the lowest wellbeing of any population group surveyed over six years since the index commenced. Other research by Professor Bob Cummins, the key AUWI researcher, indicates that a \$15,000 increase in income for people with incomes under \$15,000 can improve their wellbeing index by nearly two percentage points (Australian Centre on Quality of Life, 2007).

¹ Note: Figure 1 does not include general inquiries from carers or referrals made. It includes only the data on issues raised: ie gaps in services, inability to access services, high cost of services or complaints about services.

Carers assist people to remain living in the community for longer and therefore make substantial savings to government on premature admission to costly residential care or supported accommodation options.

The value of work undertaken by unpaid carers and savings to government is high, according to recent estimates by research bodies such as the Australian Institute of Health and Welfare, Access Economics and the National Centre for Social and Economic Modelling. The replacement value of informal carers (ie the cost of replacing all informal carers with paid care workers) is estimated at \$30.5 billion (Access Economics, 2005). This would equate to nearly \$10 billion for New South Wales.

Phone interviews conducted by Carers NSW in June 2008 support the data in Figure 1 above that financial support is the most important support carers need. Better financial support in terms of actual dollars was the most frequent response when asking carers the best practical measures to better support them as carers.

Case Studies

1. A carer left his full time job to care for his wife with a disability. He was assessed as ineligible for Carer Payment at the start of his caring role and consequently used all his superannuation over the years to support himself and his wife. Now years later, superannuation has run out. They now survive on the Disability Support Pension and Carer Payment and are unable to afford even basic necessities. For example, they were unable to repair their car and now the carer relies solely on public transport.

2. A carer left work after 40 years in full time employment to take up a full time carer's role for her ill father. She was deemed ineligible for Carer Payment because she is paying off a block of land – an asset. The carer now relies on superannuation for living expenses, however this will not last forever. The carer says she has chosen to care for her father at home saving the government money by not placing him in high cost residential care, yet she is receiving nothing in return.

Direct financial costs associated with caring include inflated bills for utilities (eg arising from increased need to heat and cool the family home), equipment, modifications for access to the home, transport and for medication and pharmaceuticals. There are also immediate and long-term costs associated with limited access to employment and education. If a single person on an average wage were to give up work in order to become a full time care their weekly income would drop from \$1,030 to around \$294. Those carers who manage to balance caring and working are likely to work fewer hours than non-carers. The annual personal cost of caring (only taking into account lost income) is estimated to be \$9,300 for primary carers and \$2,600 for other carers (Lymer et al, 2006).

These factors combined lead to a significant level of financial stress for carers, placing them at 'high risk' of poverty. Sole parent carer research commissioned by Carers Australia found that just under half of the sampled carers had to go without food or medication for their children at some time due to poverty. It also reported that three in four carers 'never' have money left at the end of each week for savings. Consequently they have no ability to deal with financial emergencies (StollzNow, 2005). The research also indicated that emotional, physical and financial hardships are a way of life, rather than an occasional disturbing episode, and 34 per cent of sole parent carers have at some time felt like relinquishing their

child. Of these, 77 per cent had felt like relinquishing their child within the 12 months period prior to the research. The researchers stated that qualitative discussions revealed this was considered an absolute last step when the carer can no longer cope (StollzNow, 2005).

Whilst income support and allowances such as the utilities allowance (the federal utilities allowance was only extended to carers in 2008, and some states and territories have also extended utilities allowance to carers) are acknowledged, personal evidence from carers demonstrates the provision of income support and allowances simply does not meet escalating cost of living, and falls short of covering the additional costs associated with supporting a person with a disability, chronic condition, or frail aged person. Increase in financial support is essential to remove carers and the people they care for out of crisis financial situations and to enable even a basic standard of living to be achieved.

Action needed

The Australian Government increases the Carer Payment to meet the income equivalent of the federal minimum wage

The findings from the Federal Senate Community Affairs Committee Inquiry into Living Costs for Older People identifies the role of the carer amongst older Australians, and the need to relieve the pressure of increasingly difficult costs in people's every day lives. The report recognised that although older Australians take on significant caring responsibilities that benefit the Australian community, these activities are insufficiently recognised and supported in government policies. One of the major findings was that a significant number of older single people were dependent upon government income support. It is likely that as carers age they too will continue to be dependent on government income to support themselves, regardless of whether their caring role continues as they age or ceases (Standing Committee on Community Affairs, 2008).

A number of recommendations were proposed by the committee including encouraging people to contribute further to superannuation funds. Carers Australia in its 2008-09 federal budget submission proposed the introduction of a carers superannuation fund, in recognition that carers who are unable to work will have access to limited or no superannuation later in their lives. The Australian Government has announced the Henry Inquiry which will look at Australia's future tax system. Carers Australia and the Network of Carers Associations will place a strong emphasis on the need of carers in regard to income support, including superannuation.

Action needed

The Australian Government implements income reform to provide financial security for all carers, including the benefits of a Carers Superannuation Scheme

4.3 National Companion Card and National Carer Card

4.3.1 National Companion Card

A number of states and territories have taken steps to enable people with a disability and their carers to better access social and recreation opportunities and facilities. Western

Australia, Victoria, Tasmania and Queensland have implemented a Companion Card Scheme, which enables people with a disability who need a companion to access social and other opportunities the right to use services and facilities without having to pay for the cost of the companion that must accompany them. The NSW Government will introduce a similar Companion Card scheme in early 2009.

The Companion Card supports antidiscrimination legislation in regards to fair ticketing rights, and provides significant opportunities for the intended recipient, the person with a disability to access services and facilities affordably when they need a companion to enable these opportunities.

With a number of states and territories implementing the Companion Card Scheme there has been some discussion about development of a National Companion Card, allowing a streamlined administrative process for the development and use of the card. People with disability and their companion will have the opportunity to use the card in different states and territories, for example if they go on holidays or move interstate.

Action needed

The Australian Government introduces a National Companion Card Scheme including a streamlined administrative system

4.3.2 National Carer Card

The Queensland Government is in the process of developing and implementing a Carer Business Discount Card, in recognition of the need to provide carers with financial benefits and recognition of their contribution to the people they care for and the wider community. The scheme has been identified as a need in the Queensland Government's *Carer Action Plan 2006-2010*.

Carers NSW has collected evidence of the need for a similar scheme for carers in NSW. In a survey undertaken by Carers NSW (2004), carers were asked what practical measures could be taken to improve recognition. One third of respondents answered financial assistance, of which one in four specified a carer card that offers discounts, another form of identification or free travel and access to events. Carers NSW recognises the need for a similar card to be introduced to support recognition and financial support to carers, providing opportunity to participate further in the community.

The Australian Government introduced the National Seniors Card to recognise the contribution that seniors have made, and continue to make, to the Australian community. The Seniors Card entitles older Australians to a range of benefits provided by commercial and retail businesses. The Seniors Card is issued by every state and territory government around Australia.

Western Australia has the oldest Seniors Card Scheme in Australia. It is estimated that in 2008 holders of the card will receive \$150 million savings in state government fees and services alone. The WA Communities Minister Sue Ellery indicated that each holder of a WA Senior's Card can save up to \$1,500 a year just through the government fees and services (WA Government, 2008).

Carers NSW supports the development of a national carer card enable national recognition and financial support to carers across Australia. In consideration of the recent discussion by governments to develop a National Companion Card, it would be timely for the Australian Government to consider a national carer card using the Western Australian Seniors Card and Queensland Business Discount Card models to develop a national carer card to recognise the financial disadvantages of many carers and to provide additional financial support.

Action needed

The Australian Government implements a National Carer Card

4.4 Housing issues

Carers NSW welcomes and supports the identification of housing needs for carers in the *NSW Carers Action Plan 2007-2012*. Research undertaken by Carers NSW complements and supports the strategies identified, particularly those strategies which relate to the appropriateness of housing to meet the diversity of carers and care recipients; provision of support services in addition to social housing; and identification of a number of diverse groups including homeless people, older people, people with a disability, young people, families with children, isolated carers, hidden carers, Aboriginal and Islander, and Culturally and Linguistically Diverse populations, and unemployed or low income families.

ABS (2004) figures show that in NSW 78 per cent of primary carers live with the person for whom they care.

Anecdotal evidence from Carers NSW shows carers have specific needs in regard to housing, separate to the needs of the person for whom they care. Carers identified financial disadvantage and the flow on effect of access to housing, as well as difficulties in accessing appropriate housing in relation to type, location and cultural sensitivity, as the main issues carers are concerned about in relation to housing.

Financial issues underlie many of the housing issues carers identify. Difficulty in meeting mortgage payments and private rental payments are key issues. Carers that have had to give up work for their caring role may find meeting mortgage payments impossible to repay, find them selves in further financial difficulty because they have to sell their home and use the money for private rental. Over the long term this places carers in further financial crisis as any savings they had will be depleted over time.

For carers on limited income the costs of home modifications and maintenance needed for the carer to assist the care recipient can be prohibitive and pose a danger to the carer who may be forced to undertake caring tasks without proper modifications, eg accessible bath or ramps.

Carers needs also need to be considered in regard to appropriateness of social housing. Appropriateness includes such things as access to transport, services and employment for the carer. It can also include things such as living in a home with appropriate facilities. The following case study highlights this point:

Case study

A carer moved in with her mother whose health was deteriorating in order to better support her. She was unable after several attempts to get the NSW Department of Housing to relocate them to a two bedroom house and accordingly had to share a one bedroom home with her mother.

The appropriateness of housing can impact on a carers quality of life, and the health and wellbeing of both the carer and care recipient. Housing policy development needs to consider the housing needs of the carer in addition to the needs of those they support.

4.5 Supported Accommodation

4.5.1 Introduction

A significant stress for carers is finding appropriate accommodation for the person they care when this is needed. Finding appropriate models of accommodation is critical for many carers of people with a disability, chronic illness or older person. Knowing that there are suitable places where a family member can live is important for the entire family. People with disabilities and their carers should also have choices about where they live at various life stages.

It is clear, both from available literature and from reports by carers and people with disabilities that there is not enough accommodation support available to reduce the pressure on carers. This includes both services that assist people to live at home, and other supported accommodation options.

The 2005 Productivity Commission Report on Government Services provides some information on people using accommodation support services. It shows that, in NSW:

- Around three per cent of the potential population of people with disabilities currently access accommodation support services² (this is slightly lower than the national average)
- Around 60 per cent of these service users have profound limitations, 35 per cent severe and five per cent moderate to no limitations
- The proportion of people living in outer regional and remote areas that access accommodation support services is lower in NSW than the national average.

These figures demonstrate that family carers are currently providing the vast majority of accommodation support for people with severe and profound disabilities in NSW. Carers are under-supported by essential formal respite, accommodation and other services for which there is significant demand.

4.5.2 Key considerations for supported accommodation models

There are several key components of all models of supported accommodation that are most important for carers and their family members with disability. These include a range of available service models, appropriate and safe accommodation, improved community involvement, reliable and inclusive staff and appropriate support throughout the continuity of care, and above all, choice.

² Funded under the CSTDA, excludes psychiatric services.

- **Information and support for families**

Carers NSW contends that families and carers of people with disabilities need a range of supports throughout the caring relationship. They can be provided either by formal services or by family and friends. A comprehensive support framework for family carers should contain the following aspects:

- Timely, accessible and relevant information that is culturally and linguistically appropriate and targeted to people who it will reach
- Emotional support to assist carers dealing with a range of changing emotions including guilt, fear, frustration, isolation, loss, anger, depression and anxiety
- Education and training to equip carers with practical skills for management of the disability or condition, communication and coping skills
- Effective and sufficient respite to give the carers substantial breaks from caring responsibilities
- Financial assistance.

For support and services to be effective they must be available at the time when the family needs them. For many people trying to access supported accommodation (and other services such as respite and home care assistance) this does not occur.

Highlighting the urgent need for additional resources and improved options for supported accommodation were the carers contributing to this submission in their 50's and 60's and still supporting a son or daughter in their 30's because they have not been able to find any supported accommodation. They do not have any indication of how much longer they will need to continue their active caring role. One carer of two sons is currently facing this frustration as she is unable to access services prior to a crisis occurring.

Case study

Mary provides care for her two sons, Troy and Mick. Troy is in his 30's and has Autism and Stickler Syndrome. He lives in a group home that he and his family are very satisfied with. He entered the home when the family was in crisis. Mick is in his 20's and has the same condition and similar support needs, however he is unable to gain access to supported accommodation of any sort because, as Mary was told, he is not "homeless or abused" (ie there is no crisis currently).

- **Appropriate and safe accommodation**

Appropriateness and safety of services is often the primary concern for carers. Some responses from the 2004 Carers News survey highlight this important factor. To demonstrate the need for appropriate services and the need for a choice of services, below are some of the suggestions made by carers about what they felt was necessary:

- "A place for younger people to go other than nursing homes"
- "More premises or residences for people who need one on one residential care"
- "Residential care for my severely disabled daughter if not earlier at least when she's 18"
- "Supported accommodation with right amount of individual support"
- "Housing for the mentally ill with supervision" (Carers NSW, 2004).

Another source of stress for carers and people with disabilities is inappropriate placement of younger people in nursing homes and other aged care residential facilities. One carer contributing to this submission was distressed that her 64-year-old husband (and younger

people) with Multiple Sclerosis had been placed in a nursing home because his care needs were too high for community care and there was no supported accommodation for younger people available.

... they get put in with dementia and dying elderly people and it's absolutely terrible. There are no other options available". Jill, who is the wife and carer of 64-year-old Dennis hopes that one day there will be a separate living area from the nursing home - where her husband now lives - for younger people with high support needs. She is unaware of any such services in her area.

Supported accommodation should be available to people of all ages including flexible options for people who still wish to live independently or with their partner but have complex health care or high support needs.

Part of having appropriate and safe supported accommodation options is ensuring there are enough services for people with high support needs. A report by the Australian Housing and Urban Research Institute in 2002 found that people with high support needs were at the highest risk of being institutionalised (AHURI, 2002).

- **Facilitating community involvement**

Carers have identified many different services that are important to promote community participation for the person they support. The key services, in addition to personal and home care support, that were identified by carers were single or a combination of transport, recreation, social support, employment, therapy and day programs, depending on the individual care situation. As one carer said in her telephone interview *"bricks and mortar aren't the issue – support services are the crucial issue"*.

Community education is also vital to the successful participation of people with disabilities living in supported accommodation in their local community. This is significant for all groups of people with disabilities including those with mental illness and challenging behaviours to reduce stigma and social isolation. Many people with disabilities grow up being involved in the local community and it would be unnatural for them to move into supported accommodation and find that they became isolated.

- **Service providers, staff and family inclusion**

A study carried out in Victoria in 2002 assessed some available literature on models of supported accommodation. It reported that there are many factors that influence the integration of people with disabilities into the community and cited Australian research by Ralph and Usher (1997) that "merely closing the institutions and transferring clients and staff into community-based settings will not ensure successful integration. Staff need new skills, new values and new goals if they are to succeed".

According to this report families were previously discouraged from visiting people with disabilities in institutional settings, as it would disrupt their care patterns. It is therefore important that consideration is made in future planning of supported accommodation to include families and carers in the daily lives of people with disabilities living in supported accommodation. In addition it is a requirement of the NSW Disability Services Act (1993) that support for people with disabilities includes valuing the importance of their relationships with friends and family.

Carers NSW often receives reports that families are not involved enough or encouraged by service providers to be part of the care process after their family member leaves their care at home. One in 10 respondents to the Carers News survey in 2004 felt that greater inclusion by health professionals and service providers in all areas of the care situation would be a practical way that carers could be recognised. It is important to many carers that staff understand the ongoing needs of family support once a person requiring care has moved out of the family home.

The most effective models of supported accommodation are those that allow flexibility in the delivery of care services to cater for the different lifestyles and needs of people with disabilities and their families and carers. For supported accommodation to be effective family or carer involvement must be incorporated in the provision of support.

- **The continuity of care**

Every person's care needs change throughout different stages of their life. For some this will be associated with the ageing process and for others it will depend on their disability or condition. For instance a carer of a boy with Asperger's and ADHD commented that when his son is ready to move into supported accommodation the type that he requires will depend on his condition at that time and how he is interacting with other people. There must therefore be different levels of support and different models of accommodation available for people at different life stages.

Integration and linking of services is fundamental to addressing changing care needs. A person's support needs can increase and decrease during their lifetime and various different support services should be available when needed. For many a case manager or key worker will be needed to ensure the care needs and social needs of a person are met. These relationships should be established while a person with disability is still living with their primary family carer.

Action needed

The Australian Government funds supported accommodation models that are appropriate for the individual; facilitates community involvement and involves inclusive practices amongst the individual, family, staff and service provider

4.6 Service systems and service delivery

Consumers of various services should be able to move fairly seamlessly between the different services they need. It is often the carer that will be coordinating services for both themselves and the person they care for. Greater coordination between the health, disability and aged care sectors will overcome some of the 'interface' issues that cause problems for carers in their caring role. The problems include:

- a fragmented and confusingly complex system of services
- the need to renegotiate services as needs change
- multiple assessments, where the same questions are answered over and over again
- delays in having assessments or getting services or equipment
- assessments with no outcome in terms of access to services
- certain carers or people requiring care 'falling through the gaps' between sectors

- services which are inappropriate to the needs of the care situation
- additional stress on carers due to the frustration of finding appropriate support, or finding the appropriate access pathway to get the support they need (Carers NSW, 2006).

Interviews with carers provided an insight into specific service access and delivery issues that carers experience. Several carers during phone interviews were frustrated with the knowledge that services were not able to provide them with services to meet individual needs. They felt that money provided to different services should not be allocated for particular types of service, but rather be used to provide the carer with what they are asking for. The following case study illustrates the issues raised by carers.

Case Studies

Rhonda cares for her 22-year-old son who has an intellectual disability, some challenging behaviours and moderate to high support needs. He attends an employment program that keeps him occupied during the day. However Rhonda is finding that as he gets older he wants to go out and do things but relies on his parents to take him. This is not suitable for the parents and does not allow him to have choices that other people his age in the community have. The recreation group that used to take him out was de-funded but this is the type of service he needs to keep active in the community once he has transitioned to supported accommodation.

A carer aged over 65 years caring for an adult daughter with a disability was assessed as eligible for a service providing domestic assistance. However when carer rang services she was told there was 'no funding' to provide her service. Carer has been on a waiting list for over a year. Carer had also been assessed as eligible for respite. Respite was available, and she requested the respite money be used instead for domestic assistance because this is what she needed, but was told this was not possible because the funding was allocated to respite only.

A carer has been on a state funded package, and then was offered an EACH package because the care recipient was assessed as requiring a higher level of care. Carer then received more hours of personal care for the care recipient, yet the number of hours allocated to respite had been reduced. Carer was dissatisfied with this outcome as the respite had been the service she most needed.

Carers were concerned about the level of paperwork and phone calls that had to be made to find out about, and apply for services. This was particularly the case for a number of carers who cared for a child that had recently turned 16 years of age. Services had been cut and therefore the carer had to fill in numerous forms and apply for new packages because of the care recipients age, regardless of the fact that care needs had not changed. Hopefully this situation will change from 1 July 2009 with the implementation of the initiatives from the Carer Payment (Child) review.

Carers also commented that the amount of forms is confusing, time consuming and costly as many forms need to be signed off by a GP or specialist. Most of the information being asked in the forms is very similar, and there should be a streamlined process where information is kept in a central administration system that can be accessed by other government departments.

In addition carers felt confused as to which services are funded by which level of government, and which government department. Carers are also not informed about which services they are eligible for, and find it difficult to find this information themselves because the system is fragmented.

Case Study

Jen is 31 years old. She now suffers hypoxic brain damage following an acute asthma attack six years ago. Gloria, her mother is her primary carer, and receives a care package to assist support Jen's care at home. The care package provides paid attendant care. (Gloria, has asked that Carers NSW documents her care situation in our submission because carer issues 'need to be addressed at top level'.)

Jen's family has received only three days respite over the past 18 months. This is because of the limited respite places available for complex care requirements. The family was previously able to access appropriate respite care at an ACT respite centre, but can no longer access this because of state/territory funding barriers.

Jen has just returned from respite at a NSW centre, with severe congestion that required additional care from her mother and paid care attendants to resolve. Gloria feels confident that this situation would not have occurred if the ACT respite centre, familiar with Jen's situation, could have provided this respite.

Gloria would like the government to provide two weeks respite care every year for carers caring for somebody who requires complex care should that provides them with an adequate break from what is a 24/7 care situation.

Carers felt a central point of access for all information would provide them with the best access to the most appropriate support for themselves and the person they care for.

Action needed

The Australian Government reviews service systems and structures and identifies ways in which services, particularly respite, can better meet carer's individual needs

5. Specific population groups

5.1 Young carers

5.1.1 Who are young carers?

A young carer is a child or young person 25 years or under who provides support for a family member who has a long term disability, mental illness, other illness, drug or alcohol problem. Young carers usually have more responsibilities than other young people their age. The person they care for may be a parent, sibling, their own child, other relative or friend.

5.1.2 How many young carers are there in Australia?

The ABS (2004) states there are approximately 347,700 young carers (5.2% of all people under 25) in Australia who provide support for a family member who has a disability, mental illness or other long term illness. There are 101,600 young carers aged less than 15 years (representing 0.5% of all people under 15 years of age).

In NSW it is estimated there are currently 90,200 young carers (ABS, 2004). Carers NSW supports young carers as young as seven years old. There are currently 1,502 young carers on the Carers NSW young carer database.

5.1.3 What do young carers do?

Young carers may undertake tasks ranging from cooking, cleaning, being responsible for finances, minding siblings and supporting the person with an illness or disability. Supporting the individual may involve personal care such as showering, emotional support, or medical support such as administering medication.

While each caring situation is different, the experiences and challenges of young carers and their families can be similar. Young carers often say that the emotional side of caring is the most difficult challenge. They can feel sad, confused and frustrated, as well as worry about the person they care for.

5.1.4 Young carers in NSW Carers Action Plan 2007-2012

In 2007 the NSW Department of Health launched the *NSW Carers Action Plan 2007-2012*. The Action Plan outlines a whole of government commitment to recognising and supporting carers over the next five years. It includes strategies to increase the respect and recognition of carers, reach out to family members who may not see themselves as carers, improve services to carers and the people they care for, encourage agencies to view carers as partners in care and support carers to combine work and caring. The Action Plan specifically refers to identifying and supporting 'hidden' carers'. Young carers have been identified within this group. The plan identified both the need to support young carers directly, as well as supporting parents who need care in their parenting role to reduce inappropriate levels of caring by young carers.

5.1.5 Supports for young carers in NSW

The Young Carer Project at Carers NSW, funded by the NSW Department Of Ageing, Disability and Home Care (DADHC) and the Australian Government Department of Families, Housing Community Services and Indigenous Affairs (FaHCSIA), was created to make a positive difference to the lives of young carers (aged 25 years and under) and their families.

The young carer state-wide project has been created to:

- promote the issues and needs of young carers through state wide community awareness programs
- develop a young carer support network in partnership with relevant agencies, services and schools
- coordinate a variety of young carer activities in the short-term
- support referrals to local services who can assist young carers and their families
- provide telephone support, information and referral for young carers and their families
- develop and distribute other appropriate resources
- review and evaluate existing young carer support activities.

The project undertakes the following activities to achieve its objectives: state-wide camps, quarterly newsletter, telephone group counselling, face-to-face counselling, telephone support/information/referrals, interactive young carer website, development of regional networks and community awareness and education.

In 2005 FaHCSIA launched a range of initiatives to respond to young carers educational, emotional, social, information and respite needs. The initiatives included:

- up to five hours a week of 'in home' respite to enable 'at risk' young carers to complete secondary school
- two weeks of respite each year to enable young carers 'at risk' to undertake activities such as studying for exams, training or recreation
- young carer information, advice and referral services including a telephone hotline, age-appropriate information and a website.

Injecting significant funds to increase respite availability to young carers who had been excluded from education, and funding to state and territory Carers Associations has gone some way to further young carers and their families. However, there continues to be a level of unmet need and lack of appropriate supports for young carers.

5.1.2 Key issues for young carers

Demographic changes in household structure places young people in a more likely position to take on a caring role. The percentage of one parent families with dependent children increased from 20.7 per cent to 21.6 per cent of all families with dependent children from 2000 to 2005. This trend increases the likelihood of young people taking on significant caring roles within families as no-one else is available (ABS, 2005 and 2006).

A number of research projects have been undertaken in both the UK and Australia, acknowledging young carers have a distinct caring profile and are a vulnerable group with specific needs in their caring role. In 2001 Carers Australia published a research report about young carers, which revealed:

- Young carers often fulfil the role of the carer because there is no one else to do it.
- Being a young carer can result in reduced life choices and future opportunities. Approximately 60 per cent of young primary carers between 15-25 years are unemployed or not in the labour force, compared to 38 per cent for the general population in this age group.
- Being a young carer can impact negatively on the young carer's health and well being. Many young carers have feelings of constant sadness, guilt, anger, fear and worry which can contribute to impaired psychosocial development.
- Being a young carer can impact negatively on their participation in school, work or other community activities. Only four per cent of young primary carers between 15-25 years are still at school, compared to 23 per cent for the general population in this age group. Social impacts, including limited time to participate in social and leisure opportunities, reduced opportunities to develop friendships and relationships, reduced time to attend school or complete homework can impact negatively on the young carer's participation in school, work or other community activities.

It is also important to note that whilst research has identified many negative impacts of caring on young carers, being a young carer can also have a positive impact on their lives. Many young carers experience pride in their role and the contribution they make to their family; the development of caring skills which could be used in future employment; maturity of the young carer due to the responsibility of their caring role; and development of close bonds between the young carer and the person they care for.

5.1.3 Needs of young carers

One of the most significant issues for young carers is their participation in school and other learning institutions. Young carers report difficulty in attending school and completing homework due to the demands of their caring role. In addition cost of school fees, books and extra curricula activities can be prohibitive to participation at school for some young carers facing financial hardship.

Case Study

Because my brother/family have always come first I have missed out on a lot. I love my brother and would do anything for him. But now as he is needing me less and less (though he will always need support), I am worried about my future. Soon I am going to have to put my needs first and am terrified that when I do it will cause my family to fall apart, because they are so dependent on me. Also I feel that I don't have the social skills that I need and I don't have any qualifications/references to get a job. I have no support or friends and worry about how I will cope in the world. (I have been completely isolated since I left school, not have any contact with anyone outside my family.) I have no idea how I am going to put my needs first because it means turning my back on my brother (and family).

I would like to see the government continue to support Young Carers so they have a chance of being a kid/teenager and the opportunity to finish school and pursue their dreams. And to help ease the financial pressure on families caring for someone. I would like to see a greater awareness and understanding of Young Carers and what we do (Letter from young carer).

The Australian Government's Young Carers 'at risk' Respite program mentioned above is one initiative that has been implemented to assist young carers to remain in education through provision of respite to allow attendance at school, time to do homework, and study for exams. Whilst the initiative is welcome, and addresses some level of unmet need, respite continues to be a key issue for young carers. Young carers identify that respite services need to be available when needed and in a form that meets the needs of the young carers and their family. Availability of, and access to specific respite services for young carers as well as better access to mainstream respite services will assist in the provision of respite for the individual needs of young carers.

In addition to respite there are other factors that limit access to education for young carers that also need to be addressed.

Access to education opportunities is also restricted by eligibility of the Carer Payment and Carer Allowance. The Adult Disability Assessment Tool (ADAT) used to assess eligibility of Carer Payment and Carer Allowance does not reflect the needs of young carers. The ADAT limits eligible carers to 20 hours per week of work or study. This limitation is prohibitive, particularly for young carers who are trying to juggle employment and their caring role, or for those who are completing primary, secondary or tertiary studies. This impacts on their future life choices as it does not encourage young people to seek further education or employment opportunities. Access to adequate income support for young carers and their families is essential in ensuring young carers have the opportunity and financial access to education.

There also needs to be a greater awareness of young carers within the school system, community care sector and general community. Young carers need to be identified as a specific group of carers at risk. Schools need to be better informed about and more supportive of young carers. Awareness training to school teachers is needed to assist school

staff to identify young carers and support them to remain at school. Young carers identify needs such as flexibility in completing some school work at home rather than class attendance, and having someone to talk to about their caring situation (Institute of Child Protection Studies, ACU National, 2006).

Schools need to be more proactive in identifying and supporting young carers. Primary and Secondary school teacher information kits have been sent out by Carers Australia in attempt to raise awareness in schools about young carer identification, needs and issues. However, additional follow-up is required by the states in terms of implementing information and recommendations. Carers NSW would like to see participation of young carers in education, training and employment at rates approaching that of their peers who do not have caring responsibilities.

Young carers identify that there is little understanding from service providers and in the community about the role of a young carer and therefore what their support needs are. There needs to be a greater awareness of young carers and an understanding of the extent of the responsibilities they have. A survey of young carers conducted in the ACT (Moore, 2005) suggested that young carers and their families were not receiving supports because services did not respond to their need, they weren't of quality, they were not accessible and they were not well publicised. This meant that many families did not know what they were entitled to or how to access supports.

Young carers identify the need for both widespread programs and services specifically targeted to young carers and their families, as well as identification of young carers and their families as a key target group for all mainstream services. It is particularly important for mainstream services in rural and regional areas to acknowledge young carers and provide appropriate support due to the fact that there may be limited services specific for young carers in regional and rural areas.

Case Study

For me, the camps held by Carers NSW have helped me a lot. They've given me the biggest insight into the world of caring and disabilities and provided me with, not with relief, but with comfort in knowing that there are people out there in similar situations. The young adult carers that I have met are amazing and are truly an inspiration. I believe that these camps provide us with opportunities to do things that we never get a chance to do. Sometimes these are very normal, day to day activities that everyone takes for granted, such as going to the beach or the movies. I will never forget the look in my other 9 year old brother's eyes when we showed him the beach for the very first time, around when he was 5 years old. Being taken to the movies, or even to a park, it's just the little things, that he hardly gets a chance at doing.

The government should provide more funding into these types of activities. Giving young carers a chance to have a break, sit back, and be normal, before returning back to their demanding lives (letter from young carer).

The demand of the caring role also limits young carers access to social and recreational opportunities. Appropriate respite and support is needed for young carers to access social opportunities, as well as an increase in the availability of specific social and recreational opportunities that assist young carers to connect with each other, for example more peer

support activities so young carers can meet or connect with other young carers to support each other and talk about their caring role.

Action needed

The Australian Government increases funding to the national young carer program to provide:

- increased specific respite services for young carers as well as better access to mainstream respite services
- increased financial support for young carers, including easier access to the Carer Payment and Carer Allowance, and incentives for young carers to remain in education or employment opportunities
- increased awareness and training programs to schools and school teachers about young carers and the supports they require to remain in school
- improved awareness and training to community care service providers about young carers and their needs, in order for services to have a better understanding about how to support young carers, particularly in regional and rural areas
- increased young carers social participation programs to provide young carers with linkages to support each other in their caring role
- additional funding to provide case management and service coordination to meet the ongoing and individual needs of young carers

5.2 Aboriginal and Islander carers

5.2.1 About Aboriginal and Islander carers

Aboriginal and Islander³ data from the 2006 Census indicated that the prevalence of disability among Aboriginal and Islander people is higher at all ages. The median age for males needing assistance was 41 years, and for females, 49 years. In comparison, the median ages for non-Aboriginal and Islander males and females who needed assistance were 61 years and 75 years respectively. The prevalence of need for assistance with core activities increased noticeably from about 35 years of age onwards for both Aboriginal and Islander men and women (ABS, 2008). This is consistent with the patterns for chronic long-term health conditions such as heart/circulatory diseases and diabetes, which show onset some 10 years earlier in this population group than in the non-Aboriginal and Islander population.

NSW has the largest population of Aboriginal people of any state or territory in Australia. 138,506 people in NSW identify as Aboriginal or Islanders, representing 2.1 per cent of the total population of NSW (ABS, 2006). Based on overall carer populations in NSW, Carers NSW estimates there are approximately 15,000 Aboriginal carers in NSW. The majority of Aboriginal carers live in major and regional cities.

Another important factor from the data is that Aboriginal and Islander people who needed assistance were less likely to be partnered than were those not needing assistance. It is likely that a family or community member would be required to become their carer.

³ Carers NSW is using the terms 'Aboriginal' or 'Aboriginal and Islander' in this submission, rather than 'Indigenous' or 'Aboriginal and Torres Strait Islander' unless cited from other documents, as this is the preferred terminology for Aboriginal people in NSW.

The 2006 Census also revealed new data about Aboriginal and Islander carers that has significant policy and service implications for all governments. Data indicated:

- The median age of Indigenous carers was 37 years, 12 years less than the median age of non-Indigenous carers (49 years)
- Nearly two-fifths of Indigenous carers were male
- Around 2,100 Indigenous carers needed help with core activities themselves, of whom more than two-thirds (68%) were under 55 years of age
- Indigenous carers were between one-and-a-half and three times as likely as other carers to need assistance with core activities, similar to the overall Indigenous to non-Indigenous rate ratios for those needing assistance (ABS, 2008).

5.2.2 The impact of caring

Carers Australia coordinated an Indigenous Carers and Communities Health project in 2007, which was funded by the Commonwealth Department of Health and Ageing. Research undertaken for this project indicated that:

Little consistent information about the number of Indigenous carers in Australia and specific Indigenous carers programs exist. This may reflect that the construct of caring in Indigenous communities is one that includes caring for somebody with a disability, chronic condition, mental illness or who is frail as a community responsibility, and that programs are delivered to communities rather than services or programs to individual Indigenous carers. Indigenous carers are likely to be caring for more than one person (Carers Australia, 2007a).

Culturally, people with disabilities or mental illness often have low status in their communities, and carers providing their care have a similar low status. As the Aboriginal and Islander population are the most disadvantaged in the nation, this low status in their own communities increases their social exclusion and disadvantage even further.

Within Aboriginal and Islander communities, there is often little knowledge about the assistance available to carers and the impact caring can have on emotional and physical wellbeing. Aboriginal and Islander carers are usually supporting more than one family member and often have health problems themselves. This lack of clear data and information indicates a critical need for further research into Aboriginal and Islander carers overall, who they are, their caring circumstances and the kinds of support needed to assist them.

The negative impact of caring responsibilities on an individual's health is another negative factor in the health of Aboriginal carers. Commonly, when caring for a parent or older person the Aboriginal carer would be identified and selected by older family members, and they would have responsibility for everyday physical and emotional care while other family member takes care of finances. Finances are often saved for funeral expenses and not shared with the carer. This lack of finance adds further to the social exclusion and disadvantage Aboriginal and Islander carers can face.

5.2.3 Carers NSW Aboriginal advocacy and programs

Carers NSW is committed to providing information, support and referral to Aboriginal and Islander carers. A specific Aboriginal Policy and Development Officer position has been in place for 10 years, predominantly funded by the NSW Department of Ageing, Disability and

Home Care. The position works with Aboriginal services and non Aboriginal services to raise awareness about Aboriginal carers and their needs, and provides support to Aboriginal carers through Carers NSW Koori Yarning project. Because of her knowledge of the home and community care sectors, and her extensive experience with Aboriginal carers and communities, this staff member is also the Chair, NSW Aboriginal Community Care Gathering Committee.

In 2004, Carers NSW appointed an Aboriginal Carer Support Officer to provide direct telephone and advocacy support to Aboriginal carers.

Carers NSW has also been funded by NSW Department of Ageing, Disability and Home Care to deliver 'The Planning for the Future Project' which includes a specific Aboriginal service offering a culturally sensitive, respectful and flexible family-centred case management service, which aims to prevent or alleviate the stress that can build up in families with older parent carers caring for a son or daughter with a disability because of their caring responsibilities.

During the course of Carers NSW's development work with Aboriginal carers and service providers, it has become obvious that Aboriginal carers face greater difficulties in accessing community services than the general population of carers. This is, in part, due to the lack of understanding by service providers of the barriers which Aboriginal carers face.

Some of the diverse needs of Aboriginal carers identified in a conference report by the NSW Aboriginal Community Care Gathering Committee (2006) included:

- The NSW Department of Ageing, Disability and Home Care estimates 74 per cent of clients live in rural, isolated and regional areas. It can be estimated that the same percentage or higher of carers live in similar areas.
- Very few indigenous people identify as carers, however many have significant care responsibilities.
- Often there are multiple caring roles. This can include one person caring for a number of family members, and also a number of family members that share caring responsibilities.
- Aboriginal and Torres Strait Islander carers have difficulty with and mistrust of linking into mainstream services (NSW Health, 2007).

5.2.4 Needs of Aboriginal and Islander carers

In 2007 Carers Australia held the first national Indigenous Carer Forum. Carers NSW, along with Aboriginal elders and Aboriginal health worker representatives from each state and territory, participated. Information learned at this forum derives from findings of the Aboriginal and Islander projects and programs undertaken by the Network of Carers Associations and comments from Aboriginal elders and workers.

For carers, this included:

- Indigenous people are *more* likely to be women and *less* likely to see themselves as carers because caring *for their own* is what they do
- an individual carer is also likely to be caring for several people across generations
- carers need to be at the centre when dealing with carer issues
- Indigenous carers and their issues are a priority for the Network and for governments at all levels. Yet Indigenous carers do not necessarily access services

For services, this included:

- the cultural background of Indigenous carers must be recognised and supported, including their kinship relationships
- acceptance of diversity in culture and lifestyle is critical as is understanding how cultural backgrounds affect how people interact
- partnerships, trust and good relationships make projects work
- governments and funding bodies must understand that effective change in the lives of Indigenous carers can only happen when a long term planning, funding and service delivery agenda is negotiated with community representatives and stakeholders (Carers Australia, 2008).

This forum also revealed the access barriers faced by some Aboriginal and Islander carers to the Federal Government's carer support payments—the Carer Payment and Carer Allowance—also called 'looking after money'. Each has stringent eligibility criteria, with the former including an asset test. While some Aboriginal and Islanders carers would be eligible for these benefits very few in remote areas receive them. This is because of the difficult interaction between many Aboriginal and Islander people and communities and Centrelink caused by language barriers, lack of necessary documentation, and the concept of caring. And, many Aboriginal and Islander carers are unaware that these payments exist or that they may be eligible for them (Carers Australia, 2008). This situation is also likely to exist for some Aboriginal and Islander carers in NSW.

Carers NSW participated recently in a workshop series across the New England region in NSW to identify the needs of Aboriginal carers who met the criteria for Carer Disability Respite funding. Aboriginal carers were invited from larger community and also from smaller outlying communities. Delphi Mentors undertook the consultation process for Kamilaroi Aged and Disability Service. Issues raised by Aboriginal carers included:

- improved access to Centrelink carer payments
- improved access to home modification and yard maintenance programs
- improved access to and appropriate housing for people with mental illness
- respite definitions must be explained
- improved access to culturally appropriate respite, including emergency respite
- improved access to aged care with an easier process
- ongoing carer support groups, flexible, with professional support
- case management for carers
- equipment program to be more accessible
- address and reduce carer isolation through retreats, Koori Carer Yarning Camps and carer support groups
- flexible funded programs
- improved medical transport, and access to this for the care recipient as well as the accompanying carer
- need for Aboriginal carer advocates

Carers NSW believes that the Australian Government and State and Territory Governments must recognise the extreme disadvantage many Aboriginal and Islander carers and they people they care for experience. This disadvantage is social, physical and financial. The Council of Australian Government's Indigenous reform priority should include the

identification and implementation of strategies to address the particular needs of Aboriginal and Islander carers.

As Aboriginal and Islander carers also are more likely to have chronic conditions and poor health outcomes programs to support Aboriginal and Islander carers must include a carer health and wellbeing component. Carers Australia continues to recommend that the Australian Government introduce a national carer health and wellbeing program. This should also include Aboriginal and Islander carers.

A 2007 study by the Centre for Health Services Development indicated that lack of research about Aboriginal and Islander carer support programs. This was also identified by a literature review undertaken by Carers Australia in 2007.

Action needed

The Australian Government develop and implement a National Aboriginal and Islander Carer Framework as a component of the Council of Australian Government's Indigenous reform

The Australian Government provides funding to conduct evidence-based research to inform national Aboriginal and Islander carer policy and service development

References

ABS (2004) Survey of Disability, Ageing and Carers (SDAC) Summary of Findings, Australian Bureau of Statistics, Canberra

ABS (2005) Australian Social Trends 4102.0, Australian Bureau of Statistics, Canberra

ABS (2006) Census of Population and Housing, Australian Bureau of Statistics, Canberra

ABS (2008). The health and welfare of Australia's Aboriginal and Torres Strait Islander Peoples, 2008, Canberra

Access Economics (2003) The Dementia Epidemic: Economic Impact and Positive Solutions for Australia, Prepared for Alzheimer's Australia, Canberra

Access Economics (2005) The Economic Value of Informal Care, Access Economics Report for Carers Australia, Canberra

Australian Centre on Quality of Life (2007) 'The Wellbeing of Australians – Changing conditions to make life better', Survey 18, Report 18, Part A & B, Deakin University, Melbourne

Australian Government Department of Families, Housing, Community Services and Indigenous Affairs (2008) A new Approach – Report of the Carer Payment (child) Review Taskforce November 2007, Canberra

Australian Government Department of Health and Aged Care (2005) Home and Community Care Minimum Data Set 2003-2004 Annual Bulletin, Ageing and Aged Care Division, Canberra

Australian Human Rights and Equal Opportunity Commission (2007) *It's About Time: women, men, work and family*, Human Rights and Equal Opportunity Commission, Sydney

Australian Institute of Health and Welfare (2000) *Disability and Ageing Australian Population: Patterns and Implications*, Australian Institute of Health and Welfare, Canberra

Australian Institute of Health and Welfare (2003) *Australia's Welfare*, Australian Institute of Health and Welfare, Australian Government, Canberra

Australian Institute of Health and Welfare (2005) *Australia's Welfare*, Australian Institute of Health and Welfare, Canberra

Australian Institute of Health and Welfare (2006) *Disability Updates: children with disabilities*, Canberra

Australian Institute of Health and Welfare (2007) 'Current and future demand for specialist disability services', Australian Institute of Health and Welfare, Canberra

Bridge C et al (2002) 'Housing and care for younger and older adults with disabilities', Australian Housing and Urban Research Institute', Sydney.

Bridge, J, and Barbe, R, 2004, Reducing hospital readmission in depression and schizophrenia: current evidence, *Current Opinion in Psychiatry*, 17 (6): 505-511

Carers Association of South Australia Inc (2001) 'Children as Carers Report: An Overview of Literature and Projects of Children as Carers', Carers Association of South Australia, Unley, South Australia

Carers Australia (2006). *2nd National Young Carers Summit 2006 Report*, Canberra

Carers Australia (2007) *Federal Budget Submission*, Carers Australia, Canberra

Carers Australia (2007a) *Hand in Hand Indigenous Carers and Communities Discussion Paper*, Carers Australia, Canberra

Carers Australia (2008) *Submission to the Discussion Paper on National Employment Standards*, Carers Australia, Canberra

Carers NSW, (2004) *Carers News Survey 2004*, Carers NSW, Sydney

Carers NSW (2005) *Carers and the Health System Issues Paper*, Carers NSW, Sydney

Carers NSW (2005a) *Models of Supported Accommodation Paper*, Carers NSW Sydney

Carers NSW (2006) *Respite Reconsidered: A discussion of key issues and future directions for carer respite*, Summary Paper, Carers NSW, Sydney

Carers NSW (2006) *Carer Support Framework: a Position Paper*, Carers NSW, Sydney (unpublished)

Carers NSW (2007) *Issues Paper: Carers and Housing Issues*, Draft document, Carers NSW, Sydney

Carers NSW and Down Syndrome NSW (2007) 'Making it work: The theory and practice of partnering with carers from CALD backgrounds', in *Partnerships for better health outcomes: Carers and professionals working together: Conference Proceedings*, Carers NSW, Sydney

Carers QLD (2008) Submission to the Health Quality and Complaints Commission, Code of Health right and responsibilities, Carers QLD, Brisbane

Centre for Health Services Development (CHSD) (2007) Carers Information Needs, Literature Review, August 2007, University of Wollongong, Wollongong

Deakin University and Carers Australia (2007) Australian Unity Wellbeing Index, Survey 17.1, Report 17.1, October 2007, Melbourne

Delphi Mentors (2008) New England Aboriginal Carer Consultation Report, Delphi Mentors Consultants, NSW

Droes, RM, Breebart, E, Ettema, TP, Van Tilburg, W and Mellenbergh, GJ, 2000, Effect of integrated family support versus day care only on behaviour mood of patients with dementia, International Psychogeriatrics, 12, 1

Government of South Australia (2005) Carers Recognition Act 2005 and what it means, Government of South Australia, accessed at http://www.carerssa.asn.au/pdf_files/CarersRecognitionAct.pdf, viewed on 19 November, 2007

Giles et al, 2003, Disability in older Australians: projections for 2006-2031, MJA, Vol 179 August

Independent Living Centre of WA (Inc) (2006) Family Carers and the Physical Impact of Caring – Injury and Prevention, Research Report, Perth

Institute of Child Protection Studies, Australian Catholic University and Carers Australia (2006) Reading, writing and responsibility, Young carers and education, Canberra

Kelly, M and Newstead, L (2004) Family Intervention in routine practice: it is possible! Journal of Psychiatric and Mental Health Nursing, 2004, 11, 64-72

Moore, T (2005) More than words: supporting young carer and their families, Canberra, Youth Coalition of the ACT

Network of Carers Associations (2007) Draft position paper on Carers and Employment (unpublished document), Network of Carers Associations

NSW Aboriginal Community Care Gathering Committee (2006) 'Leading the Way in Community Care Conference Report', NSW Council of Social Service (NCOSS), Sydney

NSW Government (2007) Better Together: A new direction to make NSW Government services work better for people with disability and their families 2007 – 2011, NSW Department of Ageing, Disability and Home Care, Sydney

NSW Government (2006) Stronger Together: A new direction for disability services in NSW 2006-2016, Department of Ageing, Disability and Home Care, Sydney

NSW Government (2006) NSW State Plan: A New Direction for NSW, NSW Premier's Department, Sydney

NSW Health (2006) NSW: A new direction for mental health, NSW Department of Health, Sydney

NSW Health (2007) 'Aboriginal information and support needs assessment for families and carers'. Aboriginal Families and Carers Training (AFACT) Stage One, Sydney

NSW Health (2007) NSW Carers Action Plan 2007-2012, NSW Department of Health, Sydney

NSW Treasury (2006) NSW Long-Term Fiscal Pressures Report, Budget Paper No. 6, NSW Government

Pagnini (2005) Carer Life Course Framework: an evidence-based approach to effective carer education and support, Carers NSW, Sydney

Percival and Kelly (2004) 'Who's going to care?' Informal care and an ageing population, report prepared for Carers Australia by the National Centre for Social and Economic Modelling, Canberra

Productivity Commission (2005) Economic Implications of an Ageing Australia, Australian Government, Canberra

Productivity Commission (2006) Report on Government Services, Australian Government, Canberra

Senate Standing Committee on Community Affairs (2008) 'A decent quality of life: inquiry into the cost of living pressures on older Australians', Parliament of Australia, Canberra

Stollznow Research (2005) Market Research Report: A crisis in caring, or a system that works? For Carers Australia, Canberra

UK Department of Health (2008), Carers at the heart of the 21st century; a caring system on your side, a life of your own, London

Western Australia Department of Communities (2004), Carers Resources on-line homepage Carers Recognition Act 2004 homepage, Western Australia Department of Communities, accessed at http://www.community.wa.gov.au/DFC/Communities/Carers/Carers_Recognition_Act_2004.htm, viewed on 19 November, 2007

Western Australia Government (2008) Media Statement, accessed at <http://www.mediastatements.wa.gov.au/Pages/CurrentMinistersSearch.aspx?ItemId=130386&minister=Ellery&admin=Carpenter>, viewed on 1 July 2008

Wilson, L and Harnett, E, 2005, Parents as Carers: The Development of a Family Resource Centre at The Children's Hospital at Westmead, Conference Proceedings, Shifting Paradigms in Health Care: Leading Practice in Carer Support, Carers NSW and NSW Health, Sydney