



Carers NSW Budget Submission 2009-2010

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Section 1:

EXECUTIVE SUMMARY

Carers NSW, in its role as the peak organisation representing family carers across NSW, aims to ensure that carers are recognised as an integral part of the community, and aged and community care sectors. With one in eight people in NSW taking on a caring responsibility, Carers NSW strongly believes support for carers is a beneficial and cost effective investment for the NSW Government.

Carers NSW welcomes the opportunity to provide this submission for the NSW Government's consideration. This submission is provided to assist the NSW Government to acknowledge the diversity of caring experiences and support needs. Carers NSW uses the available evidence to inform support strategies and programs that enable carers to maintain their caring role now and into the future.

Carer recognition and carer support remain key issues for carers in NSW and are the focus of this submission. In addition, specific carer population groups such as young carers, Aboriginal carers, older parent carers, carers of people with a mental illness or disorder, and carers from culturally and linguistically diverse backgrounds have been highlighted because of their specific support requirements.

SUMMARY OF RECOMENDATIONS

To improve support to carers, Carers NSW recommends:

Strengthening the capacity for specific carer groups

1. That the NSW Government increases the number of Aboriginal Home and Community Care (HACC) Development Officers to facilitate and promote HACC access to Aboriginal people, especially in rural areas of NSW.
2. That the NSW Government implements specific strategies to provide adequate transport to Aboriginal carers, especially in rural areas of NSW.
3. That the NSW Government demonstrates its commitment to Aboriginal carers under the *NSW Carers Action Plan 2007-2012* to hold an Aboriginal Carers Roundtable.
4. That the NSW Government encourages and supports service providers and training organisations to develop culturally appropriate training in community services for Aboriginal people in order to increase the number of Aboriginal respite workers and the availability of respite for Aboriginal carers.
5. That the NSW Government increases Carers NSW capacity to carry out a comprehensive and long-term strategy for young carers in NSW to further develop service models for Aboriginal and culturally and linguistically diverse young carers, and young carers from rural and remote areas.
6. That the NSW Government, in partnership with Carers NSW, develops an additional project aimed at scoping NSW educational curricula to identify entry points for young carer identification and support policies by teachers, other education providers and student peers.
7. That the NSW Government strengthens CSTDA and Home and Community Care funded service provision to carers from culturally and linguistically diverse backgrounds, specifically through the provision of culturally appropriate respite.

8. That the NSW Government implements the use of culturally appropriate assessment tools in community and health services for carers from culturally and linguistically diverse backgrounds.
9. That the NSW Government provides further funding for bilingual community and health care workers and case managers in order to improve access to information and services for carers from culturally and linguistically diverse backgrounds.

Recognition of carers

10. That the NSW Government develops and enacts a NSW Carers Recognition Act to formally recognise and support carers and their role in the community.
11. That the NSW Government investigates options for developing a carer card in NSW that is based on the Seniors Card model as a tangible way of improving support to and recognition of carers in NSW.
12. That the NSW Government implements the NSW Carer Card to be administered by the NSW Department of Ageing, Disability and Home Care.

Enhancing social inclusion of carers

13. That the NSW Government supports and promotes the development of carer friendly and inclusive workplaces.
14. That the NSW Government continues to support carers' needs in social housing through the initiatives set out in the *NSW Carers Action Plan 2007-2012* as well as including carers as a specific client category in the *NSW Housing and Human Services Accord*.

Service delivery and support to carers

15. That the NSW Government increases funding of the Program of Appliances for Disabled People by an additional \$24.4 million in 2009-2010 as recommended by the NSW Council of Social Services and the Physical Disability Council of NSW.
16. That the NSW Government implements the 21 recommendations made in *The Program of Appliances for Disabled People* report by the NSW Legislative Council General Purpose Standing Committee No.2 released in December 2008.
17. That the NSW Government in line with *the NSW Carers Action Plan 2007-2012 Priority 2*, continues its commitment to older parent carers and extends funding for the Older Parent Carer – Support Coordination Program over the next three years to assist in sustainable planning for the future of adult children with disabilities and their parent carers.
18. That the NSW Government expands investment into the development of supported accommodation options and other forms of supported community housing packages for people with a disability who have ageing parent carers.
19. That the NSW Government expands the eligibility criteria of the Older Parent Carers – Support Coordination Program so that the younger cohort of aging carers (60 years and above) is included.
20. That the NSW Government ensures the expedient transition of young people from nursing homes to accommodation and care facilities that are compatible with their level of need for care and the social needs directly related to their life stage.
21. That the NSW Government, in line with the *NSW Carers Action Plan 2007-2012*, continues funding the Family and Carer Mental Health Program in order for carers of people with a mental illness to be recognised and supported.

22. That the NSW Government increases funding to the Family and Carer Mental Health Program to improve support to Aboriginal carers of people with mental illness, including additional funding for specific training for Aboriginal people, to increase the number of Aboriginal respite workers and the availability of respite for Aboriginal carers.

Section 2:

INTRODUCTION

The rapidly ageing population is a key feature of Australian public policy and it is projected to influence the future of caring in Australia. As a consequence there will be greater need for carers and many carers themselves will be ageing. Other trends such as fertility rates, workforce participation of women and changing family structures will likely impact the way caring by family and friends takes place in the future. Policies to reduce the institutionalisation of the frail aged, people with a mental illness or those who need care have resulted in more people being cared for by their families or friends in their homes.

According to the Productivity Commission (2005), the current care mix between residential and community care is likely to remain the same 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 Australian and State Governments policies and the wishes of individuals to be cared for at home.

The National Centre for Social and Economic Modelling (NATSEM) also identifies large projected increases in the ageing disabled population but a steady fall in the number of people available to care. They estimate there will be a 160 per cent increase in the number of people over 65 needing care by 2031. This compares with a 25 per cent projected increase for people less than 65 years (NATSEM 2004).

The key overall challenge for the NSW Government is to find appropriate ways of supporting family carers over the next 15 years and onwards in light of these trends, as well as reaching all carer populations with this support. An important aspect of this challenge will also be to ensure that alternative care is available for those without carers or where people are no longer available or willing to care. Meeting present and future demand for adequate housing and supported accommodation for people with a disability, mental illness, a chronic condition or frailty because of ageing requires a well planned and collaborative response from governments and community organisations.

2.1 Who are carers?

Carers are usually family members or friends who provide support to children or adults with a disability, mental illness or 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 an income from a range of sources including government pensions or benefits.

A primary carer is someone who takes on the main caring responsibilities of a care recipient. The Australian Bureau of Statistics (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 service provides the majority of care (Carers SA, 2001).

2.2 What carers do?

Each caring situation is unique. Some carers assist the person they care for with all their daily living activities while others provide intermittent support. Their caring tasks can range from administering medication and dressing wounds to personal care tasks such as showering 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 the service system and organising appointments. Caring is the invisible work which enables people requiring support and care to live in the community and maintain their 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. Other carers care full-time, for the lifetime of the care recipient, for people with severe and/or multiple disabilities. Thus carers are a valuable resource for governments and are essential for the effective operation of aged and community care and health systems in NSW.

2.3 About Carers NSW

Carers NSW is an association for relatives and friends who are caring for people with a disability, mental health illness, chronic condition or who are frail aged. It is the peak organisation for carers in New South Wales.

Carers NSW is part of the 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
- Build capacity in the aged and community sector.

Carers NSW's vision is that all carers in NSW are recognised, valued and supported by their communities and by government.

2.4 Key statistics on caring

According to the latest statistics on carers by the Australian Bureau of Statistics (ABS, 2008) in 2006:

- Approximately a third of all carers in Australia lived in NSW
- There were 748,600 carers in NSW (11.6 per cent of population), 20 per cent of these were primary carers
- Women aged 45-54 years were the largest single group of carers
- Women were more likely than men to be carers (17 per cent of women and 14 per cent of men). In addition, female carers were more likely to provide care on a full-time basis
- 52 per cent of female primary carers provided 40 or more hours of care a week, compared with around 39 per cent of male primary carers
- The largest number of Aboriginal carers in Australia lived in NSW. 148,200 people in NSW identified as Aboriginal or Islander, representing 2.1 per cent of total population of NSW, of these it is estimated 10, 600 are carers
- Of all carers with young children, almost half (47 per cent) were caring for a child (of any age) with a disability, including seven per cent who were caring both for a child and another person
- Carers in the 35-54 age group were over one-and-a-half times more likely than people of this age without caring responsibilities to live in low income households

- For 75 per cent of older carers the main source of personal income was a government pension or allowance
- 55 per cent of primary carers relied on a government allowance or pension as their principal source of income
- Two-thirds of carers have experienced a negative impact of caring such as frequently feeling weary or lacking in energy or frequently feeling worried or depressed
- The physical, mental and emotional health and wellbeing of most carers was poor because of their caring responsibilities. As a result of their 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 (NATSEM, 2004).

A report on women carers and economic consequences of caring was released in October 2008. The analysis of data undertaken by NATSEM for Commonwealth Financial Planning and Carers Australia (2008) found the following:

- Over half of female primary carers aged 30 to 64 years are not in the paid labour force compared to less than a third of other women in the same age group
- Of those women who do work, primary carers spend fewer hours in paid employment than do other women. Only one fifth of female primary carers are in full-time employment compared to nearly two-thirds of other women aged between 30 and 64 years of age
- The consequence of not being able to participate in paid work is that female primary carers earn considerably less income from wages and salaries over their working life compared to women with similar characteristics but without caring responsibilities (NATSEM, 2008).

2.5 Carers' health and wellbeing

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 groups surveyed using the personal Wellbeing Index measuring tool over the six years prior to the study
- Sole parent carers had the lowest wellbeing of any carer
- The wellbeing of carers decreases linearly as the number of hours spent caring increases
- Carers are more likely than is normal to be experience chronic pain
- Carers are likely to have an injury, which is associated with reduced wellbeing
- Carers have an average rating on the depression scale that is classified as moderate depression, and over one-third have severe or extremely severe depression.

Caring also poses a health risk. Research by the Independent Living Centre of Western Australia (2006) measuring the physical impact of caring on carers indicates that for many carers providing care is demanding and has a significant impact on their health. Research findings from 1,619 carers indicated:

- 43 per cent of carers said they had been physically hurt or injured as a result of providing care
- 63 per cent reported that caring had a medium to very large impact on their physical health
- 40 per cent described their current health as only 'fair' to 'poor'
- Carers reported a higher level of orthopaedic or spinal problems, cardiovascular problems and emotional and mental health problem now then before becoming a carer.

Caring is rarely chosen, but the majority of carers want to provide, or to contribute to the care of a family member or friend. The most frequently cited reasons for caring include a sense of family responsibility, a belief that they can provide a better quality of care, a perceived emotional obligation, or simply that there is no alternative available (ABS, 2004).

2.6 Carer support policy context in NSW

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

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

- *NSW Carers Action Plan 2007-2012*, the NSW Government's commitment to carers
- *Stronger Together*, the 10 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 for people with a disability and their families
- *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 welcomes the NSW Government's strong focus on improving and increasing services for some of the state's most vulnerable people, and consequently, family carers.

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

Section 3:

RECOMMENDATIONS TO THE NSW GOVERNMENT

3.1 STRENGTHENING THE CAPACITY FOR SPECIFIC CARER GROUPS

While carers as a population share many common issues, the diversity of carers and the people they care for varies significantly. Certain groups of carers may have additional and/or different needs which must be considered when providing support.

3.1.1 Aboriginal and Islander carers

NSW has the largest population of Aboriginal people of any state or territory in Australia. 148,200 people in NSW identify as Aboriginal, representing 2.1 per cent of the NSW population (ABS, 2008). There are approximately 10,600 Aboriginal carers in NSW (ABS, 2008).

Aboriginal and Islander data from the 2006 Census indicated that the prevalence of disability among Aboriginal and Islander people is higher at all ages than in the general population. The median age for males needing assistance was 41 years, and for females 49 years. 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.

Culturally, people with disabilities or mental illness often have a low status in their communities, and the 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 (Carers Australia, 2007).

3.1.1.1 Carers NSW Aboriginal support and advocacy programs

Carers NSW is committed to providing information, support and referrals 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 (DADHC). 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 a range of initiatives. The position has a key role as Chair of the NSW Aboriginal Community Care Gathering Committee.

An Aboriginal Carer Support Officer was appointed by Carers NSW in 2004 to provide direct telephone and advocacy support to Aboriginal carers. This position is funded by the Australian Government Department of Health and Ageing.

During the course of Carers NSW's development work with Aboriginal carers and service providers, it has become evident 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 people and Aboriginal carers face (NSW Aboriginal Community Care Gathering Committee, 2008).

The need for building effective partnerships with Aboriginal communities in order to improve health, social and emotional wellbeing of Aboriginal people and to reach and support their carers

is necessary. The recent *NSW Parliament Standing Committee on Social Issues Report on Overcoming Indigenous Disadvantage* (November 2008) in NSW and the Council of Australian Governments (COAG) Indigenous reform priorities identify the need to improve Aboriginal health outcomes.

The gravity of the current situation was evident at the health information day held in April 2008 by Babana Aboriginal Men's Group. Anecdotal evidence that emerged from this gathering showed that the majority of Aboriginal men attending the event had never had a Medicare card and had never had a health check-up. Yet a large majority (77 per cent) of the men experienced concerns over their health (Babana Aboriginal Men's Group, 2008).

Some of the diverse needs of Aboriginal carers identified in conference reports by the NSW Aboriginal Community Care Gathering Committee (2006 and 2008) included:

- DADHC estimates 74 per cent of Aboriginal clients live in rural, isolated or regional areas. It can be estimated that the same percentage or higher of carers live in similar areas
- Very few Aboriginal people identify as carers, however many have significant care responsibilities with multiple caring roles
- Even though culturally appropriate community care packages exist, the existing level of supply is not sufficient to meet demand
- Aboriginal carers have difficulty with and mistrust of linking into mainstream services
- Supporting the needs of Aboriginal carers should include the use of existing resources which target Aboriginal communities, delivered in a culturally appropriate way, and written in clear and pictorial formats that are accessible for people who may have limited literacy abilities
- Staff in mainstream services need to become more aware of cultural issues that impact on the carer support needs of Aboriginal carers
- The Gathering Committee has identified the need for improved support services to Aboriginal people through increased autonomy and development of service organisations, as well as transport, respite and general access to Home and Community Care (HACC) services and disability services (Gathering Committee, 2008).

Carers NSW believes that the current level of service provision to Aboriginal and Islander carers could be advanced by the following strategies:

- Enhancement of evidence based research to inform Aboriginal and Islander carer policy and service development
- As Aboriginal and Islander carers are also 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. This fits into broader COAG national priority of improvement in health outcomes for Aboriginal and Islander people
- Provision of training could be enhanced by relaxing the requirements for the community services work certificate at TAFE NSW. Carers NSW has successfully negotiated different criteria for a pilot program to facilitate entry into the certificate for community services with Meadowbank TAFE to allow a greater number of Aboriginal people to complete necessary minimum qualifications and obtain employment in the community respite services sector. This is expected to be rolled out in 2009.

Recommendations:

That the NSW Government increases the number of Aboriginal Home and Community Care (HACC) Development Officers to facilitate and promote HACC access to Aboriginal people, especially in rural areas of NSW.

That the NSW Government implements specific strategies to provide adequate transport to Aboriginal carers, especially in rural areas of NSW.

That the NSW Government demonstrates its commitment to Aboriginal carers under the NSW Carers Action Plan to hold an Aboriginal Carers Roundtable.

That the NSW Government encourages and supports service providers and training organisations to develop culturally appropriate training in community services for Aboriginal people in order to increase the number of Aboriginal respite workers and the availability of respite for Aboriginal carers.

3.1.2 Young carers

A young carer is someone 25 years of age and under who is the main provider of care and support for a parent, partner, child, relative or friend, who has a disability, is frail aged or who has a chronic mental or physical illness or alcohol or drug dependence.

Data reveals the profile of young carers (ABS, 1998):

- Most young carers live in NSW, Victoria and Queensland
- Between one-fifth and one-half of young carers live in rural or remote areas
- Young carers are usually representative of the general population in terms of cultural background
- More than one half of primary young carers are caring for a parent
- It is estimated that one in four young carers are providing care for a person with a mental illness.

In NSW there are estimated to be approximately 90,200 young carers aged under 25 according to the ABS data (2004), with an estimated 347,700 young carers in Australia (5.2 per cent of all people under 25). Most young carers provide emotional support and are also likely to assist with tasks such as mobility, provision of medication, housework and even intimate care tasks.

Young carers who live in one-parent families where the parent has a chronic illness or disability may have a greater caring role due to the unavailability of any other adult to share responsibilities. In 2003, 24 per cent of lone parents with a disability were being cared for by one of their children aged less than 25 years. In two parent families, this figure dropped to 17 per cent (ABS, 2004).

Many carers are hidden – they are unaware of available services or models of care or choose not to access government services. Young carers are often part of this group.

Of major concern is the impact caring can have on young carer participation and outcomes in secondary and tertiary education. Being late for school or missing it altogether, failure to complete homework and lack of concentration due to tiredness or concern at home can be detrimental for young carer education and development and also young carer opportunities.

Young carer and education data indicate that the responsibilities of caring limit young people's opportunities. Young carers tend to leave school earlier than their peers, and are less likely to be in the labour force or employed. For example, in 1998 only 4 per cent of primary young carers aged between 15-24 years were still in education, compared to 23 per cent of other young people (ABS, 1998).

Information that young carers provide to Carers NSW indicates that many continue to experience what they perceive as discrimination or unwillingness by some teachers to acknowledge the impact of their caring on their capacity to deliver assignments on time, or participate in school activities. Young carers have also informed Carers NSW about their reluctance to identify as young carers because of perceived bullying by student peers. The following extracts from a recent Carers NSW young carers electronic survey prior to the 2008 national BringIt Forum illustrates the challenges that young carers face, as one young carer wrote:

"If you go to the councillor she sometimes will give info out, that is how I found out about carers, but apart from that I don't think so, you need to go to the councillor to get it, which is silly because some people don't feel comfortable talking with her. they only have

info on carers associations though, no info on actually being a carer" (female student in year 11)

"I don't see the school counsellor, but i've spoken to people who have, and they feel they cant tell him anything because it isn't very confidential (even though it is his job to rely any really important information to parents or teachers)" (sic – from a 15 year old male student)

"I think that the students in schools should also get taught about young carers or illnesses to create more awareness so that there is less discrimination and misunderstanding... also a place somewhere in the school that you can go to be alone and cry, or just get away from everyone would be good, but it could be used by anyone that needed it, not just young carers, because there is no where to go in the school if you want to get away from prying eyes or just need some alone time" (female student in year 11)

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. For example, many young carers experience pride in their role and the contribution they make to their family; the development of caring skills could be used in future employment; maturity of the young carer due to the responsibility of their caring role; and the development of close bonds between the young carer and the person they care for.

Carers NSW receives funding from the NSW Government and the Australian Government to provide support to young carers in NSW and promote the issues and needs of young carers through limited policy development. However, there is a need to increase the focus on policy development and to build links across key agencies, including the NSW Department of Education and Training to build effective partnerships aimed at young carer identification and early intervention.

Carers NSW has identified several strategies to address the challenges of young carers' self-identification and streamline access to services by young carers:

- Carers NSW proposes that ultimately young carer camps be undertaken by a range of mainstream and other services. For example, running of the young carer camps could be a function of the Commonwealth Carer Respite and Carelink Centres and their auspices or undertaken by sport and recreation services. This would enable more young carers to participate in camps and would raise an awareness and identification of young carers in the wider community and build the capacity of mainstream services to respond and meet the needs of this carer group
- Further identification and assistance to young carers is necessary, particularly in rural and remote areas as well as young carers of Aboriginal and CALD backgrounds. Young carers from these groups face a double disadvantage because in other **cultures caring is often considered to be an intrinsic part of family life**. Geographical isolation and sometimes lack of community transport also mean lack of access to necessary services
- Identification of hidden young carers would be greatly improved by forming effective partnerships with the education sector and the NSW Department of Education and Training. Utilising student welfare programs in schools can be one effective way to encourage young carers to self-identify and access referral to existing services. This in turn would positively contribute to improved educational outcomes and better transition from secondary to tertiary education and/or employment
- Further development, refinement and distribution of resources and newsletter, brochures and fact sheets to meet the demand.

Furthermore, in order to improve identification of young carers through the education system and to streamline the provision of services to young carers in NSW, an integrated and consistent strategy is needed to enable Carers NSW, as well as service providers and educational institutions, to fulfil those needs.

Recommendations:

That the NSW Government increases Carers NSW capacity to carry out a comprehensive and long-term strategy for young carers in NSW to further develop service models for Aboriginal and culturally and linguistically diverse young carers, and young carers from rural and remote areas.

That the NSW Government, in partnership with Carers NSW, develops an additional project aimed at scoping NSW educational curricula to identify entry points for young carer identification and support policies by teachers, other education providers and student peers.

3.1.3 Carers NSW CALD Carers Program

Although research and data on carers from culturally and linguistically diverse backgrounds in NSW is limited, ABS (2006) data shows that 28 per cent of people in NSW are from culturally and linguistically diverse backgrounds.

While many issues are common for carers regardless of their cultural background or ethnicity, research undertaken by Carers NSW and Down Syndrome NSW (2007) identified additional issues and support needs of carers from culturally and linguistically diverse backgrounds. These include:

- Isolation of carers even though they belong to a tight knit community. There is often an assumption that people of specific cultural backgrounds rely on strong family ties. However, migration to Australia often means immediate and extended families, as well as close friends, are not there to offer support for carers
- Stigmatisation of people with disability or illness is common. This may inhibit carers from self-identifying as carers or recognise the need to access services and support
- Language and communication barriers between carers from culturally and linguistically diverse backgrounds and service providers are a common issue. Often carers cannot access appropriate translated information to assist them in their caring role. Carers need to be able to access bilingual staff as well translated material to assist them to access and use services appropriately
- Cultural concepts of disability, illness, ageing or caring are often different from mainstream Australian perceptions. Flexibility in service delivery is needed to ensure service delivery appropriately addresses the cultural needs of carers.

Recent research by the Nepean Multicultural Access Project funded by DADHC showed that the level of access and usage of Home and Community Services by people from CALD communities in NSW is only 8.6 per cent. This is significantly lower than the national benchmark of 19.1 per cent set by the Australian Department of Health and Ageing in 2004.

Cardona, Chalmers and Neilson (2006) have reported that there appears to be a gap in information strategies, for example, Commonwealth Carelink Centres and the dissemination of information about these strategies to carers in CALD communities. Contrary to previous beliefs, the recent Nepean study on CALD carers (2008) reports that CALD carers are willing to use services if they are aware of their existence.

Carers NSW has developed its CALD Carers Framework and Strategic Plan. The plan is designed to guide Carers NSW approach to CALD carers, with an emphasis on improving Carers NSW support and relationships with this group of carers. The bulk of our work with CALD communities is carried by one dedicated position which involves coordination, training, community development, representation and support for a host of CALD carers' projects and activities. The CALD Policy and Development Officer is also a member of various committees on CALD carers' issues in NSW.

From our experience in working with CALD communities and CALD carers and recently published research, it is evident that more needs to be done in order to appropriately address four areas of need in NSW:

- Recognition of their diversity and the need for services to address this diversity
- Bilingual community and health care workers and case workers in HACC and community sector to provide direct support and information
- Provision of culturally appropriate respite services
- The development of a culturally appropriate assessment tools (Sedger and Boyde, 2008).

Recommendations:

That the NSW Government strengthens CSTDA and Home and Community Care (HACC) funded service provision to carers from culturally and linguistically diverse backgrounds specifically through the provision of culturally appropriate respite.

That the NSW Government implements the use of culturally appropriate assessment tools in community and health services for carers from culturally and linguistically diverse backgrounds.

That the NSW Government provides further funding for bilingual community and health care workers and case managers in order to improve carers from culturally and linguistically diverse backgrounds access to information and services.

3.2 RECOGNITION OF CARERS IN NSW

In 2007 the NSW Department of Health launched the *NSW Carers Action Plan 2007-2012*. It outlines a whole of government policy commitment to recognising and supporting carers over this five year period. It includes strategies to increase the respect and recognition of carers, reach out to family members who may not see themselves as a carer, 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.

DADHC's *Stronger Together* initiative recognises the need for increased support for formal services such as accommodation, respite and case management, and DADHC has committed to increased funding of \$3.1 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 by Carers NSW about services and training workers in cultural competence.

Development of carer legislation and development of a carer card are two key recommendations by Carers NSW.

3.2.1 Carers Recognition Act

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, improve the 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.

This is particularly very important to young carers who often have intense caring responsibilities but lack recognition as carers in this caring role and also access to services.

The passing of the recent amendments to the Mental Health Act 2007 has brought about significant change for carers. The Act has **radically** changed mental health service delivery by recognising the crucial role carers have in supporting people with mental illness. This has allowed carers greater access to information and the right to be consulted in discharge planning.

Carers NSW welcomes the NSW Government's strong commitment to work to improve carers lives and proposes that the *NSW Carers Action Plan 2007-2012* should be supported by a legislative framework.

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

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

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

The Queensland Government will, in addition to its new legislation, establish a Carers Advisory Council to monitor the compliance with legislation and the Office for Carers within Disability Services Queensland.

Carers NSW believes a legislative document recognising carers should be introduced in NSW. A legislative document will underpin the *NSW Carers Action Plan 2007-2012*, which states specifically that it will '*commit government agencies to incorporating the needs of carers in the development of policies and programs*' (p 20).

Legislation is important to not only provide formal recognition of carers, but also ensures that the NSW Government and the aged and community sector is responsible for planning and delivery of services which are inclusive of carers. Furthermore, a carers recognition act validates the accompanying charter (or action plan) outlining government and other responsibilities firmly embedded in legislation.

In addition, as demonstrated by the Mental Health Act 2007, when a carer is formally acknowledged through legislation their rights as a carer are upheld by the system in a way that is not always achieved by the presence of the *NSW Carers Action Plan 2007-2012*. For example, Carers NSW has become aware that in spite of the presence of the Action Plan across NSW Health instances where carers are not acknowledged by health care professionals in hospitals are common. It is argued that the presence of legislation would close the gap and decrease these instances and improve the recognition of carers from the top down.

Carers NSW is also aware that a NSW Carers Recognition Act is what carers want. Preliminary data from the Carers NSW 2008 Carer Survey indicated that the implementation of a NSW Carers Recognition Act was the highest ranking requirement for the carer respondents with 88 per cent of carers surveyed identifying carer legislation as their top priority. This was closely followed by introduction of a NSW Carer Card (Carers NSW, 2008).

Recommendation:

That the NSW Government develops and enacts a NSW Carers Recognition Act to formally recognise and support carers and their role in the community.

3.2.2 NSW Carer Card

Improving financial outcomes for carers is one of the top priorities for Carers NSW. The proposal of a NSW Carer Card is one step that the NSW Government can take towards improving financial outcomes for carers and increasing their ability to participate in community life.

A number of states and territories have taken steps to enable people with a disability and their carers to better access social and recreational opportunities and facilities. NSW, Western Australia, Victoria, Tasmania and Queensland have implemented a Companion Card Scheme, which enables people with 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 who must accompany them.

In addition to the Companion Card and following on the *Queensland Government Carer Action Plan 2006-2010*, the Queensland Government introduced a Carer Business Discount Card in 2003 that provides carers with the opportunity to obtain discounts from participating businesses. This is a significant step in recognising carers contribution to the people they care for and to the wider community. The Carer Business Discount Card is available to Queensland carers who receive the Centrelink Carer Payment or Centrelink Carer Allowance and is valid for four years from the date of issue.

Similarly, in 2006 the Northern Territory Government introduced the NT Pensioner and Carer Concession Scheme which entitles carers who are in receipt of Centrelink Carer Allowance a broad range of concessions including bus travel, electricity, water and sewage rates, spectacles and motor vehicle registration.

In June 2006, Carers NSW proposed to the NSW Government that a carer card be offered to carers who are recipients of Carer Allowance and/or Carer Payment. It was recommended that the card be introduced to reflect the benefits offered by the NSW Seniors Card and that the administration of the carers card in NSW be modelled on the same framework used to administer the Seniors Card and overseen by the NSW Department of Ageing, Disability and Home Care.

Since the proposal of the carers card in 2006, Carers NSW has collected additional evidence for the need of a carer card scheme in NSW. For example, in the Carers NSW 2008 Carer Survey, one-third of respondents answered financial assistance and 34.3 per cent specified a carer card that offers discounts as a practical measure to better support their caring role (Carers NSW, 2008).

The introduction of the NSW Carer Card will serve three functions: meeting government and community obligations to carers and the people they support; decreasing financial stress on carers and encouraging full community involvement and participation of carers and the people they provide care for. An intended outcome of the carer card is improved recognition for carers and promoting their carer status both in the community and when dealing with health and other services.

Recommendations:

That the NSW Government investigates options for developing a carer card in NSW that is based on the Seniors Card model as a tangible way of improving support to and recognition of carers in NSW.

That the NSW Government implements the NSW Carer Card to be administered by the NSW Department of Ageing, Disability and Home Care.

3.3 ENHANCING SOCIAL INCLUSION OF CARERS

Carers NSW greatly supports the NSW Government's commitment to improving participation and representation of carers as stated in the *NSW Carers Action Plan 2007-2012* and the *NSW State Plan, A New Direction for NSW*, which both recognise carers as partners in care.

The extent and quality of carers involvement in society is determined by the level of support and services they receive as well as by the level of their participation in the workforce. The latter is of great significance as it affects carers' quality of life and impacts on their future. This is particularly true for certain groups of carers, such as women carers and sole parent carers. Similarly, having an access to appropriate and secure housing determines the level of carers' involvement in society and their ability to take advantage of life opportunities.

Carers NSW has identified the following key recommendations in this section: support for working carers and housing support for carers.

3.3.1 Carers and Employment: reducing barriers to opportunity

At some stage in their life the majority of people will either provide or receive care due to an illness, disability, frail age or injury. This includes many people with work responsibilities. Of primary carers in NSW only half participate in the workforce, suggesting that a caring role is a prohibitive factor in obtaining and retaining employment (ABS, 2004; NATSEM, 2008).

While changes to assist or support carers in the workforce have been introduced, such as extending the number of hours that can be spent in employment, training and volunteer work without affecting the Carer Payment and Carer Allowance, there are still significant issues identified by carers which inhibit their participation in the workforce (HREOC, 2007).

The majority of carers in Australia are women. Research undertaken by Carers Australia and Commonwealth Financial Planning in 2008 identified that women primary carers pay a high price in terms of their health and financial wellbeing for taking on a primary carer role, evident by shorter periods of good health over their working years, being less able to participate in paid employment and receiving lower income. They are also less able to invest towards retirement (NATSEM, 2008).

The NATSEM (2008) report presents two case studies: one of a woman aged 30 years, with two or more children and caring for a child with a disability and another of a woman aged 50 caring for her partner with a disability. Research findings include:

- Mothers caring for a child with a disability are likely to earn over their working life (depending on their level of education) between a quarter and half the income of women sharing the same characteristics but who are not primary carers
- The superannuation likely to be available to 30 year old mothers caring for children with a disability when they reach 65 years of age would be negligible for many and may be insufficient to provide an adequate retirement income for most
- For working women aged 50 years caring for a male partner with a disability, access to government income goes a considerable way, but does not totally compensate for the loss of income associated with becoming a primary carer (NATSEM, 2008).

The Taskforce on Care Costs, in its 2007 report *The Hidden Face of Care* found that carers represent an under-utilised workforce resource: 44 per cent of the carers surveyed choose a role below their skill level because it gave them flexibility they needed to balance work and caring responsibilities (TOCC, 2007). This represents a considerable loss in productivity for the national and state economies.

Some significant issues that carers report as barriers in accessing and staying in paid employment are:

- Lack of quality alternative care for the person they support
- Poor recognition from employment service providers
- Lack of flexible working arrangements
- Lack of understanding from colleagues and co-workers.

Access Economics reported that around 36 per cent of primary carers who were unemployed or not in the labour force expressed a desire to return to work, especially on a part-time basis. Similarly they found the opportunity cost of time devoted to informal care, measured as a reduction in paid employment, is estimated to be \$4.9 billion (Access Economics, 2005).

Currently there are initiatives underway at national and state and territory levels to promote support for carers in the workplace:

- In Western Australia, the Department of Consumer and Employment Protection has produced a *Work and Family-Employment Information Kit* for employers who are interested in implementing or extending work and family initiatives in their workplace
- In Victoria, the Victorian Equal Opportunity and Human Rights Commission has published a set of guidelines *Family Responsibilities-Guidelines for Employers and Employees* to provide practical information to employers and employees about the new rights under *the Equal Opportunity Act*
- In NSW two online resources are available - *Mature Aged Workers with Caring Responsibilities* and *The Working Carers Getaway* supported by NSW Health. The websites provide information and support to carers in NSW who are juggling both caring and workplace demands.

However, more is needed to adequately support carers in the workplace. Carers NSW is embarking on two educational projects in partnerships with NSW Government. One is the 'Train the Trainer' project funded by DADHC with the purpose of raising awareness amongst DADHC-funded carer service providers about carers' issues. The second one is a collaborative project with the human resource branch of NSW RailCorp with the sole purpose to gauge RailCorp's employees' need for flexible working practices for carers and to implement policies and practices to enable carers to successfully combine work and caring.

Carers NSW believes that there is a real need for more collaborative partnerships of this kind to be developed, not only in the public sector but also in the private sector. Such projects would effectively build on *NSW Carers Action Plan 2007-2012* initiatives as they would actively promote the necessity of carer inclusive workplaces, contribute to workforce retention and enable carers to care without relying on government income unnecessarily.

Recommendation:

That the NSW Government supports and promotes the development of carer friendly and inclusive workplaces.

3.3.2 Housing Support for Carers

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 people, 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 that concern carers 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 and find themselves 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 are likely to be depleted over time.

Carers' needs also must be considered in regard to the appropriateness of social housing (Carers Australia, 2007). Appropriateness includes access to transport and access to services and employment for the carer. It can also include things such as living in a home with appropriate facilities.

Housing NSW has partnered with nine other NSW Government human service and justice agencies to develop the *NSW Housing and Human Services Accord*. The objective of the Accord is to assist social housing tenants with complex needs to receive support services they need to live independently in the community and sustain their tenancies and to assist clients of human service agencies to gain access to social housing.

Carers NSW welcomes an announcement of a new housing and support partnership between DADHC and NSW Health under the Accord but recommends that carers should be included as a specific client group of the Accord as they often have specific needs in regards to housing that are separate to the needs of the person for whom they care.

Recommendation:

That the NSW Government continues to support carers' needs in social housing through the initiatives set in the *NSW Carers Action Plan 2007-2012* as well as including carers as a specific client category in the *NSW Housing and Human Services Accord*.

3.4 SERVICE DELIVERY AND SUPPORT TO CARERS

The provision of appropriate, affordable and good quality services for carers and the people for whom they care is one of the most important ways to support carers. This section of the submission recommends ongoing investment in key programs funded by the NSW Government: the Program of Appliances for Disabled People (PADP), the Older Parent Carer – Support Coordination Program and the Family and Carer Mental Health Program.

3.4.1 NSW Program for Appliances for Disabled People

The Program of Appliances for Disabled People (PADP) is an essential program for family carers in NSW as equipment and aids provide a fundamental support to them in their caring role. PADP is an integral part of the network of services that allows individual to leave hospital under earlier discharge to live in the community rather than in residential facilities. The timely provision of appropriate equipment is crucial as it helps people to avoid future hospital admissions and reduces demands on community care services by supporting people in the tasks of daily living.

The NSW Government recognises the need to support the equipment needs of carers and the people they care for in both the *NSW Carers Action Plan 2007-2012* and the *Stronger Together* framework. In the 2007-2008 Budget the PADP allocation increased by \$3 million to a total budget of \$26.8 million. This was welcomed by Carers NSW and other agencies, however Carers

NSW identifies there is still a high level of unmet need for appropriate equipment that assists the caring role.

The PADP has been a subject of review and reform. In 2005 PriceWaterhouseCoopers research for NSW Health established that the current funding is inadequate to meet the demand and that the demand on PADP will continue to increase with estimated increases in population prevalence of disability (PricewaterhouseCoopers, 2005).

Increases in funding have been advocated for years by a number of stakeholder groups and key organisations. Both NCOSS and the Physical Disability Council of NSW have recommended an increase of PADP funding to \$35.7 million. The latest inquiry into PADP by the NSW Parliament revealed that despite a significant injection of \$11 million to reduce the waiting list, there has been no substantial change to core ongoing funding to the program (NCOSS, 2008).

Carers NSW identified in a submission to the NSW Health review of the program (2006) the following issues in relation to PADP: long waiting lists to access equipment when needed; delays in processing applications for equipment and therefore people with a disability not receiving equipment when needed; and inappropriate equipment which can lead to poorer physical health for the care recipient while making the caring role more difficult.

Following the PriceWaterhouseCoopers report, The Program of Appliances for Disabled People report by the NSW Legislative Council General Purpose Standing Committee No.2 released in December 2008 made 21 recommendations about how PADP can be improved. Carers NSW recommends that these 21 recommendations are implemented by the NSW Government, particularly recommendations: one: to increase funding; two: to make PADP an entitlement; three: to ensure transparency including public reporting by EnableNSW; eight: the abolishment of co-payment; seventeen: to ensure that data is collected to establish the current, unmet and future demand for the program; and twenty-one: the coordination and integration of NSW Health and DADHC in the delivery of the program.

Moreover, anecdotal evidence from the Carers NSW Older Parent Carer – Support Coordination Program shows that many PADP eligible families have spent allocated funds under this program's Carers Assistance Packages to purchase a wheelchair and other necessary equipment which should be available under the PADP.

Carers NSW recommended in our submission to the PADP review that, given the current shortfalls in funding for the PADP, it is essential that a commitment is made by the NSW Government, not only to increase funding to a workable level but to incorporate into future funding the projected increase in numbers of people with a disability and its impact on community care programs.

Recommendations:

That the NSW Government increases funding of the Program of Appliances for Disabled People for an additional \$24.4 million in 2009-2010 as recommended by the NSW Council of Social Services and the Physical Disability Council of NSW.

That the NSW Government implements the 21 recommendations made in The Program of Appliances for Disabled People report by the NSW Legislative Council General Purpose Standing Committee No.2 released in December 2008.

3.4.2 Support for older parent carers

The needs of older parent carers, those over 65 (or over 45 if Aboriginal) and caring for an adult son or daughter, present a particular challenge on a number of fronts. Older parent carers are caring at the time when their own health may be deteriorating. Long term caring can take its toll, emotionally, physically and financially. Key concerns for many ageing carers with long-term caring responsibilities is their capacity to continue caring and what will happen to their children once they die. These fears are exacerbated if succession plans are not in place to ensure the future support and wellbeing of their son or daughter with a disability.

According to the AIHW (2007) report, *Current and Future Demand for Specialist Disability Services*, based on the users profile of Commonwealth/State/Territory Disability Agreement funded services, about 44 per cent of ageing carers had been in their role for 30 years or more. Ageing informal carers (aged 65 years and over) were most likely to be mothers caring for son or daughter (58 per cent). In NSW there are 45,148 CSTDA service users, which represent 22.5 per cent of all service users in Australia. A total of 1,566 service users in NSW (3.5 per cent) were of Aboriginal background; 54.3 per cent of Aboriginal service users in NSW reported the presence of an informal carer (AIHW, 2007).

The need for succession planning for this group of carers has been addressed under the Bilateral Agreement between the Australian Government and DADHC out of which funding has been provided to Carers NSW and nine other community organisations to implement the Older Parent Carer – Support Coordination Program for two financial years: 2007-2008 and 2008-2009.

The main aims of the program are to identify and engage “hidden” older parent carers by assisting them to build and strengthen their social supports and at the same time to prepare for the future needs of their adult child. Eligibility for the program has been established at an age of 65 although shorter life expectancies of Aboriginal people are recognised by acknowledging eligibility for the program at an age of 45.

There are 10 Older Parent Carer - Support Coordination Program providers across NSW. The program is delivered by Carers NSW in three regions across five sites in NSW: Sydney South East, Orana Far West and Mid North Coast and it is set to reach its target of assisting 120 carers for the 2008-2009 year. The flexibility of the program and the allocation of 70 Carers Assistance Packages have been very well received, as it empowers the persons with a disability and their carers to purchase specific services needed instead of relying on capacity and availability of services.

Carers NSW strongly supports DADHC initiatives of targeted delivery of services to older parent carers, yet has identified significant levels of unmet need among older parent carers, especially amongst rural and Aboriginal communities.

Available data from the AIHW 2007 report and anecdotal evidence from the Carers NSW Older Parent Carer – Support Coordination Program suggest that planning for the future of people with disability should ideally start at an earlier stage of their and their carers lives. AIHW estimates the number of primary carers by 2013 in the 25-59 age group will increase by 20 per cent as well as the number of carers older than 60 – the cohort in which carer numbers would grow by 47 per cent. Furthermore, CSTDA users aged 45-64 have consistently increased in numbers in the last four years, suggesting that the overall CSTDA population is ageing. Carers NSW experience from working with older carers confirms these estimates as the program has had to turn away carers who were not meeting the strict eligibility criteria for the program.

In addition, the large number of applications for supported accommodation (approximately 1,700) received by DADHC in the past 12 months as well as slow roll-out of the COAG Young People in Nursing Homes indicate that prompt action is needed by the NSW Government to address the chronic issues of carer stress and their worry for the future. An increased supply of supported accommodation is urgently required to ensure that accommodation options that provide greater independence and wellbeing of people with disabilities are met.

The successful transition of a person with a disability from the parental home to supported accommodation or to living in the community often takes time and resources and puts a significant emotional and financial strain on the family. New parameters in determining eligibility for the program therefore need to be set so that carers who have been caring for a long time are supported in the transition process.

Recommendations:

That the NSW Government in line with the *NSW Carers Action Plan 2007-2012 Priority 2* continues its commitment to older parent carers and extends funding for the Older Parent Carer – Support Coordination Program over the next three years to assist in sustainable planning for the

future of adult children with disabilities and their parent carers.

That the NSW Government expands investment into the development of supported accommodation options and other forms of supported community housing packages for people with a disability who have ageing parent carers.

That the NSW Government expands the eligibility criteria of the Older Parent Carers – Support Coordination Program so that the younger cohort of aging carers (60 years and above) is included.

3.4.3 Young People in Nursing Homes

There are 6,613 aged less than 65 years of age residing in aged care facilities in Australia. Of these more than a quarter (about 1,000) are younger than 50. In NSW there are 2,428 people aged less than 65 residing in nursing homes (AIHW, 2007).

Residential aged care facilities are designed to provide accommodation, personal and nursing care to frail older people at the end stage of their life. Aged care facilities are not designed or adequately resourced to facilitate the active involvement of younger residents with high clinical needs in everyday activities or support their continued participation in the life of their community. This can have a negative impact on their health and wellbeing and ability to recover. Additionally, young people who are inappropriately placed in aged care suffer from social isolation, boredom and disempowerment (Winkle et al, 2006).

At the Coalition of Australian Governments (COAG) meeting of 10 February 2006, governments announced their commitment to start to reduce the number of young people with disabilities living in residential aged care services. The COAG Young People in Nursing Homes program operates in every state and territory and has three streams:

- **Stream one** offers alternative community based accommodation and support arrangements to young people living in residential care facilities
- **Stream two** offers additional supports and services to young people living in residential aged care who choose not to move, either because their health will not allow it; or because remaining in the nursing home keeps them near their families and in their communities in remote areas
- **Stream three** aims to prevent young people with high and complex support needs being placed in aged care nursing homes now and in the future.

The COAG Young People in Nursing Homes Program has a total of \$244 million available over its five years of operation to achieve stated aims. Of this, the Australian Government has contributed \$122 million and each state and territory has agreed to match this funding, dollar for dollar, with the amounts calculated on per capita basis (COAG Communiqué Key Points).

Carers NSW is aware that the COAG Young People in Nursing Homes Program initiative has been rolling out slowly in NSW. By October 2008, only four young people had been moved out of nursing homes and seven had received packages supporting their stay in nursing home (NSW Parliament, 2008). The long term placement of young people in aged care is a social injustice and needs urgent attention.

Recommendation:

That the NSW Government ensures the expedient transition of young people from nursing homes to accommodation and care facilities that are compatible with their level of need for care and the social needs directly related to their life stage.

3.4.3 Support for Carers of People with Mental Health Illness

The 2007 National Survey of Mental Health and Wellbeing conducted by the Australian Bureau of Statistics found that of the 16 million Australians aged 18-85, 45 per cent (or 7.3 million) have had a mental disorder at some point in their life (ABS, 2008). Furthermore, only 35 per cent of people reporting mental disorder symptoms in the past 12 months had accessed health services (ABS, 2008). This suggests a large unmet need for mental health services.

Carers NSW has a long history of providing support to carers of people with a mental illness. As a part of the Carers Mental Health Project 2001-2005, Carers NSW developed the *Carers Life Course Framework* which provides a theoretical and empirical base showing:

- How carers needs change over time
- The dynamics of providing care for a person with mental illness and how this impacts on the life course of the carer
- The type of information, support and interventions required to meet these needs.

Research undertaken by Carers NSW in 2006 on carers and respite found that carers of people with mental illness identified the value of combined respite and carer education that assist with coping mechanisms. For many family carers of people with mental illness this type of support gives them a break, emotional support and skills for coping at the same time (Carers NSW, 2006).

The recent amendments to the Mental Health Act 2007 radically changed mental health service delivery by recognising the crucial role carers have in supporting people with mental illness. This has allowed carers to improved access to information and the right to be consulted in discharge planning.

Carers NSW welcomed the additional funding announced in 2006 to the Family and Carer Mental Health Program (\$13.5 million over four years) and since then has been delivering mental health programs in three regions of the state, in collaboration with three organisations: ARAFMI, Carers Assist and Uniting Care. The program focuses on improving carers' coping skills and enhancing carers' wellbeing, resilience and relationships. Carers NSW is strategically well placed to deliver services to this specific group of carers, as it delivers the program from four locations (three of these are in regional and rural NSW).

Carers NSW believes that the program should continue in 2009-2010 and into the future. Broken Hill and Dubbo offices work with a large number of Aboriginal carers and the level of unmet need is still large. The *Koori Yarning* manual developed by Carers NSW provides an invaluable resource to reach out to Aboriginal carers who often face greater difficulties in accessing community services than the general population of carers. Involvement of the whole family, not just the primary carer is a key to success in these communities.

The measure of the success of this program will be the extent to which people with mental illness and their carers are able to participate in their communities.

Recommendations:

That the NSW Government in line with the *NSW Carers Action Plan 2007-2012* continues funding the Family and Carer Mental Health Program in order for carers of people with a mental illness to be recognised and supported.

That the NSW Government increase funding to the Family and Carer Mental Health Program to improve support to Aboriginal carers of people with mental illness, including additional funding for specific training for Aboriginal people, to increase the number of Aboriginal respite workers and the availability of respite for Aboriginal carers.

Section 4:

CONCLUSION

The implementation of the *NSW Carers Action Plan 2007-2012* has provided a platform for the NSW Government to recognise and respond to the needs of carers. The recent Australian Government House of Representatives Inquiry into Better Support for Carers has highlighted the need for increased support for both carers and care recipients. In addition research has shown that investing in carers means investing in a sensitive social fabric that keeps our aged and community care systems functioning.

Carers NSW argues that ongoing financial investment by the NSW Government in carer support and carer recognition will bring about significant economic returns for government over the long term.

The identification of specific groups in this submission demonstrates the diversity of carers and the range of needs in the caring role. Carers from culturally and linguistically diverse backgrounds, young carers, carers of people with a mental illness and ageing parent carers have specific needs which must be addressed through appropriate government support. Further investments in existing programs such as the Family and Carer Mental Health Program, Older Parent Carer – Support Coordination Program, young carer funding and investment in supported accommodation are needed.

The NSW Government has a responsibility to assist carers so they are recognised, valued and supported. Carers NSW looks forward to working with the NSW Government to bring about continued change for carers in NSW now and into the future.

Location of Carers NSW offices



Carers NSW main office is located in Sydney with staff working across 9 state wide locations.

Counselling services are provided across all regions of NSW via 400 contracted counsellors, plus in house counsellors (funded by the Australian Government).

Partnerships with local service providers build on this capacity to ensure carers have access to the services they need.

Regional offices:

North Coast Area Health Service

1. Alstonville
2. Coffs Harbour
3. Tweed Heads
4. Wauchope

Greater Western Area Health Service

5. Broken Hill
6. Dubbo
7. Orange

South East Sydney/ Illawarra Health Service

8. Bulli
9. East Nowra

Contact details:

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W: www.carersnsw.asn.au

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