

Investing in our future:

**Support for carers
in the
State Budget 2007-08**

October 2006



“Adequate ongoing funding injections are required to increase services to carers, in particular for education, peer support and respite...[P]rograms that provide these services to carers can have seven-fold returns in terms of improving the quality of life of carers and the people they care for and delaying costly institutionalisations” (Access Economics, 2005)



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Key Facts

- A “carer crunch” is projected over the next 30 years – the National Centre for Social and Economic Modelling has projected that by 2031 carer numbers will have risen by 57% compared with a 160% increase in numbers of older people requiring care.
- Carers save the Australian government \$19.3 billion, equivalent to over \$6 billion in NSW.
- Investment in carer support has been shown to give returns of 7:1 to government in financial terms only, or up to \$34 for every dollar spent in one US study, not including the quality of life outcomes for carers and those they support.
- There are estimated to be at least 750,000 carers in NSW.
- Carers are overall a disadvantaged group as there are significant health, social and financial impacts of caring. A recent study showed that if a single person on an average wage were to give up work to become a carer their weekly income would drop from \$1,030 to \$294.
- More adequate support for carers is necessary as they are the cornerstone of our community care and health sectors, providing the vast majority of support to people requiring care.
- Government expenditure on carers equates to only a fraction of savings made. The only specific carer support program is funded at \$5.1 million recurrent, equal to just over \$5 a year per carer on average.

Therefore Carers NSW is recommending that the NSW Government invest in carers through these initiatives:

1. **NSW Carers Program** – additional investment of \$10.2m
 2. **Home and Community Care Program** – 30% increase
 3. **Commonwealth State/Territory Disability Agreement programs** – 20% increase
 4. **Health programs** – ongoing investment and commitment to improving: a) **mental health** services and b) the **Program of Appliances for Disabled People**
 5. **NSW Carer Policy** – ongoing commitment to developing a whole-of-government Carer Policy plus twofold implementation strategy: a) community **awareness** campaign and b) **Carer Card**
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Executive Summary

One in eight people in New South Wales is a carer. Carers NSW has prepared this submission on their behalf. Carers have been referred to as a “hidden army” or “invisible workforce” as, in their own homes or other peoples’, they provide a total of 1.2 billion hours of support, with an imputed value of \$19.3 billion annually.

Most people with disabilities, mental illness, chronic conditions and who are frail aged, rely on family and friends to provide them with the majority of their support needs. These carers provide emotional support, assistance with communicating, with transport and mobility and with personal care activities. Caring relationships usually evolve from existing relationships and can have benefits for both parties. Often however carers are not adequately supported themselves and the effects can include poor physical and emotional health, financial disadvantage, social isolation and lost opportunities.

The human and economic value of carers in Australia is high. The care and support they provide enables nearly 3 million people requiring assistance to continue living in the community. The replacement value of carers nationally has been estimated at \$30.5 billion. This equates to approximately \$10 billion in NSW.

The ageing population, amongst other demographic trends, is projected to influence the future of caring in Australia. As a consequence there will be a 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 on the way, and the extent to which, caring by family and friends takes place in the future.

There is local and international evidence cited in this submission that demonstrates the social and economic benefits and value of supporting carers. A range of services such as respite, training, counselling and emotional support are required.

The caring scenarios contained in this submission illustrate not only the benefits of supporting carers but the consequences of not supporting carers from an early stage. Not least of these are the health impacts on carers resulting in reduced capacity to provide care and increased use of acute and primary care services that could have been avoided or lessened.

Most importantly it is the social responsibility of the NSW Government to ensure that carers have choices in their caring roles. Many people choose to be the carers of their partners, parents, children and other family and friends. They should be supported in this choice with adequate services. Others choose not to become carers or to cease their caring role. These people should also be supported by the NSW Government in their decisions.

Carers’ entitlements to participate in the labour force, to education, to relaxation and rest time should be realised as they are for other members of society. As partners in care they are also entitled to recognition in community, health and residential care settings. Thus carers need to be supported through:

- A sound policy framework in which the role, rights and needs of carers are recognised as well as the government’s responsibility to support them and greater investment in the NSW Carers Program;
 - More resources for ageing, disability, mental health and general health programs and services which benefit carers directly and indirectly.
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Recommendations:

1. NSW Carers Program – Additional investment of \$10.2m for 2007-08

The NSW Department of Health increase the NSW Carers Program budget by 200% from \$5.1m recurrent (excluding Family and Carers Mental Health Program) to \$15.3m recurrent. Increased funding in the 2006-07 budget for the Family and Carers Mental Health Program demonstrates acknowledgment of the need for, and potential advantages of supporting carers of people with mental illness. This recognition now needs to be extended to carers in general. Specifically funding should be directed to large grants projects; outreach projects for CALD and ATSI carers and other 'hidden carers'; local area community projects and working with young carers. Appendix 1 contains some specific Carers NSW Project Proposals under an expanded NSW Carers Program.

2. Home and Community Care Program – a 30 percent increase

A one-off 30% increase to Home and Community Care Program funding is recommended and 6% growth per annum in HACC funding (to cover demographic ageing based prevalence increases). Carers NSW recognises recent increases of 8% to HACC Program funding however the level of unmet need in the community is vast particularly for carers who constitute only 1.7% of service users in NSW (despite being a legislated target group of the program).

3. Commonwealth State/Territory Disability Agreement Programs – a 20 percent increase

A one-off 20% increase to programs funded under the Commonwealth State/Territory Disability Agreement is recommended. This is a vital program for people with disabilities and their carers. While we recognise the increased funding in the 2006-07 budget this will only address the periphery of unmet need for services such as accommodation support and respite. In particular, support for ageing parent carers requires increased funding through this program.

4. Health funding – ongoing commitment to increased spending in Mental Health Services and in the Program of Appliances for Disabled People

There is a need for ongoing commitment to improving health programs in light of their importance for carers. Whilst recent funding increases are welcomed, Carers NSW recommends increased funding for mental health services and the program of appliances for disabled people, recognising the high levels of unmet need and the preventative effect of early intervention in caring relationships to be gained.

5. NSW Carer Policy development – ongoing commitment to develop and implement a whole-of-government Carer Policy

Ongoing investment is recommended to further the NSW Government's commitment to reviewing the 1999 Carers Statement and developing a whole-of-government carer policy for NSW. A twofold strategy to enhance implementation is recommended: 1) an awareness campaign for the community; 2) introduction of a Carer Card in NSW.

Section 1:

Baseline Information

1.1 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 wages or government pensions and benefits.

1.2 What they 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 to 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. From the perspective of the health system, carers provide care for short, intensive periods of time following discharge from hospital. Others provide care intermittently for someone between hospital visits and there are also carers who provide care for many years to people requiring ongoing medical treatment and community support.

1.3 Brief profile of carers in NSW

The most recent statistics on carers from the Australian Bureau of Statistics (ABS 2004a; ABS 2004c) show the following. In 2003:

- Approximately one-third of all carers in Australia lived in NSW
- There were 748,000 carers (11% of the population) 20% of whom were primary carers¹
- 40% of primary carers cared for a partner, 29% for a child, 32% for other (eg sibling, parent)
- Women aged 45-54 years were the largest single group of carers
- 45% of primary carers provided 40 hours or more care per week on average
- 78% of primary carers lived with the person they supported
- 75% of carers were of workforce age although 45% were not in the workforce
- The median gross personal income for a primary carer was \$224, other carers \$365 and non-carers \$435
- 55% of primary carers relied on a government allowance or pension as their principal sources of income

1.4 Costs of caring

Caring comes for many at a high personal cost, which in turn, can affect the public health system and the NSW 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, a lot of which could be prevented by more effective and innovative support options for carers.

There are direct financial costs associated with caring including 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. Recent research on sole parent carers 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).

Linked to financial stress and also the high demands of caring, often without sufficient breaks, are the physical/mental health and quality of life impacts of caring. The National Survey of Carer Health and Wellbeing conducted in 1999 (Carers Association of Australia 2000) showed that 58% of carers reported that their physical health had been adversely affected due to their caring role, a third said they had sustained a physical injury, over half reported depression, anxiety, high levels of stress and other impacts on their mental health.

International studies have found that carers are at high risk of psychiatric morbidity, bodily pain and obesity. The physical and mental health aspects of caring have been found themselves to be predictors of premature mortality and a wide range of supports are needed. Improved health of carers can impact positively on the health of the people they support. For example, an association has been made between improved mental health of carers and improved mental health of care recipients and in a study of stroke patients following discharge from hospital, implicating the value of carer training, support and education programs (Tooth et al 2005).

Recent research demonstrates other negative affects of caring associated with quality of life such as reduced community participation and risk of social isolation of carers (ABS, 2005; SPRC, 2004; Llewelyn et al 2003).

The costs of caring on a macroeconomic scale have also been found to be significant. For example, a study of the economic costs of Multiple Sclerosis (MS) in Australia (Access Economics, 2005) found that informal care (based on replacement valuation) was the single greatest cost associated with MS (43% of the total). In comparison, residential care was 4% and community care was 1% of the economic cost of MS.

1.5 Carer savings

The value of work undertaken by unpaid carers is high, according to recent estimates by research bodies such as the Australian Institute of Health and Welfare (AIHW), Access Economics and the National Centre for Social and Economic Modelling (NATSEM). Carers save the government \$19.3 billion annually, equating to more than \$6 billion in New South Wales (AIHW 2003). The replacement value of informal carers (ie the cost of replacing all informal carers with paid care workers) is estimated at \$30.5 billion annually (equivalent to 3.5% of forecast GDP and 62.6% of other formal health care) (Access Economics 2005). This would equate to nearly \$10 billion for

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“The physical and mental health aspects of caring have been found themselves to be predictors of premature mortality and a wide range of supports are needed.”

New South Wales. In the sense that carers assist people to remain living in the community for longer they also make substantial savings on premature admission to costly residential care or supported accommodation options.

Carers are the “largest source of emotional, practical and financial support for older people: more than 90 per cent of older people living in the community in 2003 who required help with self-care, mobility or communication received assistance from the informal care network of family, friends and neighbours”, according to the Productivity Commission (2006, 12.3). Carers also provide the majority of support for young people with disabilities. In 2003, 70% of younger people requiring assistance² received it from informal providers only. A further 28% were receiving support from both formal and informal providers (AIHW 2005).

Thus carers are a valuable resource for governments and are essential for the effective operation of community care and health systems in NSW.

1.6 Current Carer Supports

As we have described above, the costs to carers of providing essential support in the community to those who need it can be immense. Yet government expenditure on carer support constitutes only a fraction of the estimated replacement costs of carers.

The NSW Government currently provides support for carers through a number of programs. Such support can be found within general ageing or disability programs, for example the Home and Community Care (HACC), the Commonwealth, State/Territory Disability Agreement (CSTDA) and the Disability Services Programs. In addition, the pioneering NSW Carers Program provides specific support to carers. This program includes the NSW Family and Carers Mental Health Program. The HACC and CSTDA programs are both jointly funded by the Australian and NSW Governments.

The Australian Government provides financial support to carers through the Carer Payment and Carer Allowance. Carers also access generic supports such as the hospital system and NSW Government concessions to low income earners and those who are disadvantaged, which carers generally are. Support for carers in NSW, although existent, is fragmented and in most cases not focussed specifically on carers’ needs (Payne, forthcoming).

Currently many carers require further support. One in five carers of younger people with disabilities require more assistance in their caring role (AIHW, 2005). While respite is considered a key element of carer support, only 13% of primary carers had ever used it in 2003 (ABS 2004b).

Research has demonstrated that support services for carers, including information, emotional support and counselling, education and training amongst other supports, can help to reduce carer stress and depression and can improve overall wellbeing (Feinberg et al 2006).

“...more than 90 per cent of older people living in the community in 2003 who required help with self-care, mobility or communication received assistance from the informal care network of family, friends and neighbours”, according to the Productivity Commission ”

“My health is poor because of growing used to the stress related to caring for my 24 year old [son with Down Syndrome] with a severe mobility problem. My GP hasn’t given me any special consideration, just treated like a normal family”

(carer, respondent to Carers News Survey 2004).

Section 2:

The Changing Environment

In recent years the ageing of the population has been high on the NSW and national social policy agendas. Determining how to best support people requiring assistance and their carers in the community in this changing environment is a key imperative of policy makers in NSW. There is evidence to demonstrate significant levels of unmet need already for these groups in the community (Productivity Commission 2006, Vol 2; Auditor General 2004) as well as increasing demand for services and supports in the future.

The NSW Government recognises that “ageing is an increasingly important factor in rising health costs” and that “strong demand for Department of Ageing, Disability and Home Care services is expected to continue, with expenditure driven by an ageing population, ageing carers, and higher costs associated with enhanced life expectancy” (NSW Treasury, 2006).

The 2006-07 State Budget included significant increases to mental health and disability spending. However evidence in Section 3 of this submission demonstrates that the proposed additional services will only partially address existing and increasing demand and unmet need.

2.1 Projections on ageing and disability

The Australian population is ageing. The effects on the economy, on health and community care systems, disability and aged care services as well as families and individuals will be pronounced. In NSW, by 2044, the proportion of the population aged 65 and over is projected to have doubled from 13.7 percent in 2005 to 24.8% in 2044 (NSW Treasury, 2006). It has also been projected that the percentage of the Australian population aged over 85 will increase even more, from 1.5 to 5% of the total population over this period (Productivity Commission 2005).

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 disability requiring assistance as a result of ageing (Giles et al, 2003). Technological advancement is contributing to increased longevity of people with disabilities, which subsequently increases the number and length of informal care relationships (AIHW 2000).

The projections on ageing and disability have clear implications for the future of community, hospital and residential care. Already, according to Professor Hogan (2005), “about half the users of aged care services require access as a result of some incident leading to entry to hospital.”

Projections on disease and injury trends show that, over the coming decades, a number of age-related conditions are likely to prevail. In particular, cancer, diabetes and mental disorders are projected to increase in prevalence. Injury as a result of falls is projected to increase by 94% in the next two decades (NSW Health, 2005). The implications of these trends on carers and on the public health system are likely to be profound.

2.2 Projections on unpaid caring

The forecast that many more people will require care in the future gives rise to consideration of carers’ ability and availability to meet increased demand.

There are a number of broad social trends that will influence the supply of informal carers. The impact of the changing composition of Australian families on unpaid care is likely to be substantial. The

following trends will influence the likelihood of individuals becoming carers (ABS 2005; ABS 2006). In NSW:

- The percentage of **lone person households** increased from 23.9% to 25.2% from 2001 to 2005. This trend increases the likelihood that informal care arrangements will involve neighbours and friends;
- The percentage of **one parent families** with dependent children increased from 20.7% to 21.6% 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;
- The **fertility rate** dropped from 1.815 to 1.794 between 2000 and 2005 implicating middle-aged and older people as carers;
- **Life expectancy** at birth increased from 76.4 and 81.9 years for males and females respectively in 2000 to 78.0 and 83.3 in 2004;
- The percentage of the **population aged 65 and over** has increased from 13% to 13.7% between 2000 and 2005 and **85 and over** has increased from 1.4% to 1.6% over the same period;
- Nationally, **participation of women in the workforce** has nearly doubled in the last twenty years indicating that the profile of carers will change as traditional primary carers (women aged 45-54) assume different roles.

The results of a NATSEM study (2004) modelling the supply and availability of carers over the next 30 years shows a dramatic drop in the ratio of carers to older people needing care. From 2001 to 2031 the ratio of carers to older people requiring care in the community is projected to drop from 57 primary carers per 100 people needing care to just 35. While the number of carers will rise by 57% the number of aged people needing care is projected to rise by 160%. The shortfall of available carers will be almost four times what it is today.

2.3 Projections and benefits of investment

It is clear, given the trends identified in this submission, that we face a potential “carer crunch” whereby the demand for care from family and friends far outstrips supply. It has been recognised by the NSW Government that these trends will require greater investment in health and social services in the coming decades.

Already the Health Budget for NSW is over 27% of total expenditure and NSW Treasury has projected that, in the most extreme scenario, health spending could consume the entire NSW State taxation in 40 years’ time owing to the demographic pressures of an ageing population (NSW Treasury, 2006). It is also recognised that increased investment in disability and other social services will be required in future budgets. The demographic trends driving these shifts include the ageing population. As carers will also be ageing there is a significant need now to invest in preventative and early intervention supports for carers as well as addressing existing unmet needs for carer support.

A report by Access Economics (2005) recommended that “adequate ongoing funding injections are required to increase services to carers, in particular for education, peer support and respite”. The report considers this the “key issue in order to avoid the additional real resource cost and poorer quality outcome of care being institutionalised”. In that study the cost of care in the community (of which the replacement value of informal carers constitutes 43%) is 60% less than high care residential care.

“NSW Treasury has projected that, in the most extreme scenario, health spending could consume the entire NSW State taxation in 40 years’ time owing to the demographic pressures of an ageing population”

As there continues to be a general preference in the community for living at home the value of family carers as a resource for the Australian economy will continue to increase. As shown above, there are considerable economic advantages to community care, as opposed to residential care. In addition there is a growing body of evidence to demonstrate that there are significant cost-benefits to the health and community care sectors associated with investment in carer support.

A number of recent studies have demonstrated significant returns on investment in carer support in terms of economic as well as quality of life outcomes. For example a 1995 American study, cited by Premier lemma in July 2005, demonstrated cost savings of \$34 for every dollar spent on a family education program for carers of people with schizophrenia (McFarlane et al 1995, cited in Access Economics 2002). The Premier further noted that "better support for families and carers has significant long-term benefits for the whole community, not just those being cared for." Hansard 23 June 2005, NSW Parliament). A British study recently reported savings of GBP4000 over a year for patients whose carers received training, largely due to reduced length of stays in hospital (Patel et al, 2004).

“A 1995 American study, cited by Premier lemma in July 2005, demonstrated cost savings of \$34 for every dollar spent on a family education program for carers”

Carers are a vital part of the health care support team. There are documented advantages to including them as partners in care. A recent study (MacLeod et al 2005) of the role of carers in early hospital rehabilitation found that carers were key providers (in hospital) of practical and psychological support. It recommended that carers should be regarded by hospital staff as a vital resource in the rehabilitation of patients with hip fracture. A Queensland study also found that carers in rural and remote areas provide the bulk of discharge care to patients leaving hospital (Williams et al 2006).

There have been a number of studies to demonstrate that respite care can decrease or postpone institutionalisation of those requiring care (cited by Jeon et al 2005; Arksey et al 2004). Other research has shown that carer inclusion in the health care setting can benefit patient quality of care (Droes 2000; Kelly and Newstead 2004). Carer support has also been found to be a factor in reduced readmission rates (Bridge and Barbe 2004).

“[Health Professionals need] to include the carer when a consumer is to return home from hospital by informing them of the condition and the care required”
(mental health carer, Carers News Survey 2004).

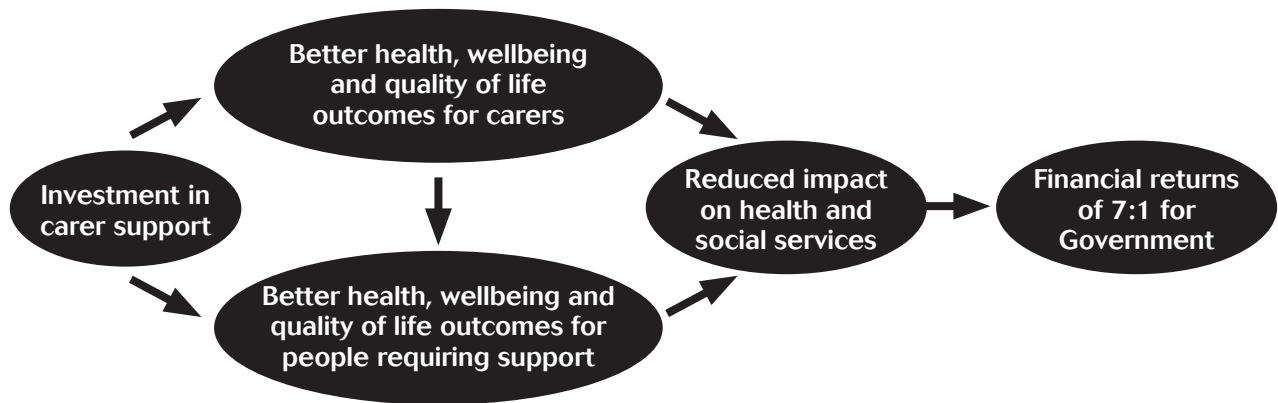
Savings made by delayed institutionalisation cannot be viewed without consideration of the costs. Access Economics (2003) estimated that while delaying residential care of people with dementia for one year saves the Australian government \$600m it makes family carers \$320m worse off.

Access Economics (2003) has also attempted to quantify the cost-benefits of government investment in carer support finding that returns of 7:1 have been accrued in financial terms. This is in addition to the improved outcomes for carers.

The aim of supporting carers is to improve outcomes for them and to support them in their choices. However as can be seen from the evidence listed above, there are other social and economic benefits to be gained. This has been recognised by NSW leaders for some time. As Premier lemma stated in the 'Stronger Together' document, "I would like to personally acknowledge the efforts of families in caring for their children and other family members with a disability. We want to work with them to make their lives easier".

“Access Economics (2003) has also attempted to quantify the cost-benefits of government investment in carer support finding that returns of 7:1 have been accrued in financial terms.”

The evidence for benefits of carer support can be demonstrated diagrammatically as shown:



Furthermore there are potential consequences of not adequately supporting and recognising carers. The health and wellbeing, social and financial impacts of caring on individuals have already been noted. Where there is no support for people to remain in the community, the alternatives are extremely costly to government. In 2003-04 the cost per hospital separation³ in NSW was nearly \$3,536 (Productivity Commission 2006). Residential aged care is also costly. The average annual Australian Government subsidy for each occupied place in June 2005 was \$29,839 in NSW.

The NSW Carers Program is the primary instrument through which the NSW Government can support carers. It currently has the capacity to support carers through education and training, counselling and emotional support, training for service providers amongst other support mechanisms. This program already delivers innovative and responsive support to carers and has the capacity for a greater role in early intervention and preventative supports for carers. As demonstrated in evidence provided above, carer support programs have the potential save the NSW Government significant amounts in years to come.

“ The present funding of the NSW Carers Program at one tenth of half a percent of the Department Budget in which it sits (NSW Health) is paltry.”

The recurrent funding for the NSW Carers Program for 2003-07 has been \$5.1m. This equates to around \$5 per carer or less than \$35 for every primary carer in NSW. The innovative program delivery and the ability to address specific local needs and statewide carer issues have enormous potential for this program. However with current funding levels its reach is limited. The NSW Government has recognised the importance of supporting carers of people with mental illness by increasing funding for the Family and Carers Mental Health Program. It must recognise the needs of all carers, especially ‘hidden carers’ who currently do not access help or support of any kind (see recommendations in Appendix One).

The reality of demographic pressures and the realised need to provide specific supports, not only to people who will require care, but to their carers, is identified in this submission. The NSW Carers Program is the obvious avenue through which the NSW Government can continue to improve its support to a larger group of carers. By improving funding to the NSW Carers Program and continuing to develop models of support that are grounded in international best practice and demonstrated outcomes, the NSW Government can provide preventative support to sustain caring relationships in the community. Improved outcomes and quality of life for carers and the people they support are the main goals of carer support. It has also been demonstrated that there are economic, as well as social imperatives for government. The key recommendation of this submission is therefore a significant increase of 200% in investment for the NSW Carers Program from 2007-08 onwards.

Caring Scenarios

The following care scenarios (1 and 2) highlight the critical role that intervening early in caring situations can contribute to outcomes for the carer as well as cost savings to government. Scenario 3 demonstrates the risk of not adequately supporting carers and the importance of providing outreach services to carers from culturally and linguistically diverse backgrounds. It shows how this can, in turn, reduce pressure on the public health system. All people in these scenarios are fictional but the events are based on lived experiences of carers who come into contact with Carers NSW.

Scenario 1

Amy is the only child of Maria, who uses a wheelchair after having been injured in a car accident. Maria also has a mild brain injury and needs prompting to do things. Maria was injured when Amy was just 12 years old and, after her Dad left home six months after the accident, Amy became her mother's primary carer. Amy had just started high school.

Amy had always been a somewhat quiet child, but had enjoyed playing with friends after school and going to ballet lessons and swimming. She did fairly well at school.

Since becoming her mother's primary carer, Amy could no longer go to ballet or swimming and neither could she play with friends after school, as she always had to come home and assist her mother. Amy had to put washing on, prepare dinner and do other household chores. She rarely got much time to do homework and her grades started to suffer.

Although Amy's mother got some assistance with personal care, Amy was not recognised as a 'young carer' and thus no respite was provided (which may have enabled her to continue ballet and swimming and allowed her extra study time). Amy was never told about where she could meet other young carers like herself. She once found out about Carers NSW and young carer camps, and applied to go to one, but wasn't accepted as the camp was full.

Amy eventually dropped out of school after Year 10 and couldn't get a job, as she didn't have her HSC. She spent all her time at home looking after her mother and had no social contact. She developed severe depression and became a client of the local Mental Health Service, spending some time in hospital, then needed ongoing case management. Her mother also required more services to help her stay at home because Amy couldn't care for her properly any more.

Scenario 2

Amy was just 12 years old when she became her mother Maria's full-time carer after her father left home. Up until that time, Amy had played with her friends, gone to activities after school and done fairly well at school.

Since becoming her mother's primary carer, Amy could no longer go to activities or play with friends after school, as she always had to come home and assist her mother. Amy had to put washing on, prepare dinner and do other household chores. She rarely got much time to do homework and her grades started to suffer.

Noticing the changes in her grades, Amy's teacher referred her to the school counsellor. The school counsellor talked to Amy about what had happened and told Amy that she was a 'young carer'. It was the first time Amy had heard that term. The counsellor also organised some services to provide assistance to her mother mornings and evenings and some regular respite. Although Amy still didn't have a lot of time to herself, her grades improved back to their previous level and she seemed

happier. Amy also found out about Carers NSW's young carer camps and got to go on one. She had a fantastic time, because she met other young people like herself who were caring and she made some friends to keep in contact with. After she came home from the camp, she would ring and email her new young carer friends, so she didn't feel so alone anymore.

Amy knew that she could ring the young carer workers at Carers NSW anytime and, once when she did, they suggested that she take part in a young carers' telephone group counselling program. She did that for one hour a week eight weeks in a row. The group talked about some really hard stuff, but Amy found that it helped her to cope better with her caring responsibilities. Amy had also been thinking of leaving school, but after talking with the young carer workers she decided not to.

Eventually Amy did her HSC, got a job as a childcare worker and studied part-time at TAFE. She really enjoyed her job and studies and still talked to some of her young carer friends occasionally. Amy didn't think she'd ever get to do what she wanted to, but the encouragement of the young carer workers, the camps she went to and the friends she made helped her realise that she didn't have to shoulder the entire caring responsibility herself. She could still have her own life and be involved in her Mum's care. Amy knows that without the support she received as a young carer, her life would be very different now.

Analysis:

Analysis: Amy is a young carer who, like many young carers, finds that she gradually becomes removed from regular social, sporting and recreation activities. In addition her caring role begins to impinge on her schooling. In the first scenario, the lack of services and outreach available to her prevents her from accessing any support. Consequently she drops out of school and in later years develops severe depression for which she requires acute and community health services. Additional services are also required by her mother. In the second scenario, a school counsellor refers Amy to services which enable her to better balance caring with other activities and to develop supportive networks. She found out about respite and domestic assistance at an early stage through those networks and was able to access breaks so she could study and carry on her other activities with less disruption. Her relationship with her mother and her life generally was more 'normal'. There was also no loss to the economy of a person who could work and pay tax.

Scenario 3

Guiseppe is 67 years old and cares for his wife, Gianna, who had a stroke about six months ago. Gianna has some paralysis on one side and needs a walking stick to help her be steady on her feet. Guiseppe was a builder all his working life and so was a fit, healthy man. He had been enjoying his retirement until Gianna had the stroke, then everything changed. Guiseppe's English, while functional, is not the best.

After her stroke, Gianna spent two months in hospital and rehabilitation. When she was sent home, the staff made a referral to The Home Care Service of NSW for Guiseppe to get some help with Gianna's personal care. However, the local Home Care branch was at full capacity and no service could be provided. He was told to phone them in three months. The hospital never followed up with Guiseppe to see whether he got any help. Nor did Guiseppe and Gianna get to speak to a social worker in the hospital. In addition, because no interpreter was used, Guiseppe never had 'respite' or the types of support available to him as a carer explained.

Guiseppe and Gianna have three adult children who all have children of their own and who work full-time. Thus they can't provide any assistance to their parents during the week, but usually come on the weekends to visit and help around the house.

Although he seems to be managing Gianna's care needs OK on his own at the moment, Guiseppe finds that he's really busy, with no time for himself. As a result, he can't find the time to exercise and has put on a lot of weight over the last six months. Diabetes runs in his family, so his lack of exercise and weight problem do not augur well for his future health.

Guiseppe doesn't know what services exist and doesn't understand the concept of 'respite', so he just continues to do what he can for his wife. He has a fall when assisting his wife to get out of the shower one day and calls '000'. He is in hospital for several weeks with a fractured collar bone. For this period Gianna stays in residential respite. As Guiseppe has significant ongoing pain and has lost some movement in his right hand the social workers at the hospital refer him to services for extensive support at home. While they are waiting for these services to commence Gianna remains in respite for another four weeks.

Analysis:

Guiseppe, like many other carers from CALD backgrounds, is unable to access services. Moreover he does not understand the service system and a lot of the jargon used by health professionals and service providers. He gets by as best he can but eventually ends up in hospital for several weeks. The couple ultimately requires a high level of community care and an extended period of residential respite. A preventative, outreach approach to supporting them would most likely have prevented this situation from occurring.

Section 3:

Proposals for NSW Government Investment in Carers

Below are five recommendations that Carers NSW, representing at least 750,000 carers in this state, have formulated for investment in statewide Government programs in the 2007-08 NSW Budget. These are the NSW Carers Program, the Home and Community Care Program, the Commonwealth State/Territory Disability Agreement, NSW Health programs and the NSW Carer Policy.

3.1 NSW Carers Program – 200% increase

The NSW Carers Program, administered by NSW Health, is the only carer specific program in NSW. It is designed to meet the needs of carers through carer education, counselling and emotional support, training for service providers and other support mechanisms for carers.

The current NSW Carers Program provides:

- Large grant projects to increase direct statewide support services to specific carer populations
- Local area community projects which target NGOs, local community groups, Local Government Authorities and local services
- Young carers project work
- Family and Carers Mental Health Program
- Area Health Service carer support service
- Statewide peak body funding for information and research; education and training; advice and coordination (delivered by Carers NSW)

The budget for the NSW Carers Program is \$5.1m per year recurrent 2003-07. The 2006-07 NSW State Budget included a substantial increase of \$1.5m in 2006-07 (\$13.5m over 5 years) to the Family and Carers Mental Health Program which forms part of the NSW Carers Program but does not affect the recurrent Program funding.

In 2006, the NSW Government began a review of the NSW Carers Program as part of its review of the 1999 NSW Government Carers Statement. Carers NSW believes that the potential for a much more significant and wide-reaching program for carers exists. Recognising both the existing levels of unmet need and the future demands that carers in NSW face (discussed in Sections 1 and 2 of this submission).

International evidence suggests that increased investment in carer support not only improves quality of life for carers and those they support but also can present significant long-term savings to government (as cited in Section 2). Access Economics (2002) calculated the cost-benefits for government of supporting carers were 7:1 in financial terms.

There is also strong local evidence on the effectiveness of activities funded by the NSW Carers Program in supporting carers (Appendix One outlines some of these activities). However the scope of these projects is limited and they are able to reach only a small proportion of the carer population. There are certain projects funded by the existing NSW Carers Program that focus on specific carer populations (for example working carers, specific CALD communities, young carers)

providing outreach for typically 'hard to reach' carers. Carers NSW makes further recommendations on how, based on existing evidence from research, these programs could be extended to reach more carers in need (Appendix One).

It has now been recognised that carers of people with mental illness require innovative types of support. Increased funding for the Family and Carers Mental Health Program in NSW demonstrates the NSW Government's commitment to support these carers. Given that approximately 10% of all carers support someone with a mental illness (based on Carer NSW estimates Appendix 1, 1.2) there are approximately 75,000 such carers in NSW. Therefore recurrent funding of \$3 million to support these carers equates to approximately \$40 per carer per year or \$200 for each primary carer in this group.

While this seems to be a small amount, recurrent funding for all carers (750,000 to one million in NSW) is just \$5.1 million recurrent. This equates to only \$5 per carer per year or less than \$35 per year for each primary carer in NSW.

The need identified for carers of people with mental illness now sets a benchmark for general carer support. Carers in NSW save the government approximately \$6 billion annually. The current budget for the NSW Carers Program, therefore, equates to less than one working day's worth of savings to the government. The social justice, equity and economic imperatives of improving and enhancing this vital program for carers are significant. This should be recognised by the NSW Government through greater investment in carers.

Recommendation: Carers NSW recommends a 200% increase in the NSW Carers Program, from \$5.1m to \$15.3m per year. We propose the extension and development of a range of existing projects as well as a range of new initiatives (see Appendix One).

3.2 Home and Community Care (HACC) Program – 30% increase

The HACC Program funds seventeen service types, including domestic assistance, respite care, transport, home modifications, home maintenance and personal care. The program mainly provides basic maintenance services to assist people with low-level needs to remain in the community. The target population is defined as people living in the community who are at risk of premature or inappropriate residential care and comprises frail aged people, younger people with a disability, and their carers.

The majority of HACC clients in NSW are aged 70 years and over (73%); 18% are aged 50 to 69 and just 10% are aged under 50 years. NSW has the lowest proportion of HACC clients aged under 50 years in the country (Productivity Commission 2006; Table 12A.33).

The HACC program is jointly funded by the Australian and NSW Governments with 60:40 distribution. We recognise that in the 2006-07 budget both Commonwealth and NSW Governments have contributed an 8% increase in funding to this essential program. This brings the total HACC budget for NSW to \$504.7 million. In 2005 NSW had the lowest annual average expenditure per HACC client at just \$614 compared with \$774 in the Northern Territory (Productivity Commission 2006, Table 12A.51).

This increased funding will go some way towards addressing existing unmet need. However there is evidence to suggest that much more needs to be done now and in the future to support frail aged people, people with disabilities and their carers wishing to remain at home. It has been estimated that there are 108,000 people aged 65 and over in NSW with an unmet need for assistance (Productivity Commission 2006).

“It has been estimated that there are 108,000 people aged 65 and over in NSW with an unmet need for assistance (Productivity Commission 2006).”

Given that carers are a target group of the HACC program, it remains of concern that a very small number of carers access these services. The most recent available data from the HACC Minimum Data Set indicates that nationally only 4% of HACC clients are carers. In NSW just 1.7% of HACC clients are carers compared with 12.6% in the ACT. This means that, of the 181,698 HACC clients in 2003-04, just 3090 were carers. To put this in context 3090 carers, out of 750,000 accessed HACC services in 2003-04. This equates to less than one in every 240 carers, or one in 48 primary carers. In NSW 446,115 hours of respite were received. Assuming that carers were mainly receiving respite services, this amounts to less than 145 hours of respite a year, or 2.7 hours per week on average for 3090 carers (DoHA 2005). Given that nearly half of all primary carers care for 40 hours or more per week in NSW the need for more services for carers is clear.

Another key HACC service for carers is transport. Carers NSW frequently hears from carers that there is insufficient transport to enable them to use other services, for instance centre-based respite.

The DADHC-operated Home Care Service (HCS) is the largest single provider of HACC services in NSW. Carers NSW hears regularly from carers around the state that they have difficulty accessing any services or an adequate amount of support from the HCS. While a significant funding increase was made to the HCS in 2005-06 (6% or \$10.5m), the budget was underspent by \$4.8m in that financial year. The 2006-07 budget is \$186.4m, a decrease of 0.5% on the previous years' budget. Hours of service are estimated to remain similar to previous years (NSW Treasury 2005; NSW Treasury 2006a). Significant growth in the HCS is required, as well as measures to ensure that money is appropriately allocated and spent if this service is to better meet the needs of carers and those they support.

NSW recommends a substantial one-off increase to the HACC program and then consistent growth funding each year.

Recommendation: Carers NSW recommends a one-off 30% increase to the Home and Community Care program. Plus a 6% growth per annum in HACC funding (to cover demographic ageing based prevalence increases) plus an indexation amount that more adequately covers increased costs in service delivery, to be negotiated in consultation with key stakeholders. A significant percentage of this increase to be earmarked for the Home Care Service of NSW, for respite and for transport.

3.3 Commonwealth State/Territory Disability Agreement (CSTDA) – 20% increase

People with disabilities benefit from a range of services provided under the CSTDA. Their carers benefit directly and indirectly from many of these. The services include accommodation support, community support, community access, respite, employment, advocacy, information and print disability. Forty-two percent of CSTDA service users (nationally) reported having an informal carer (AIHW 2005a).

In May 2006 the NSW Government made a commitment to significantly increase funding for disability services with the announcement of a \$1.3 billion funding package over five years. The services plan 'Stronger Together' (NSW Government, 2006) also provides benchmarks in terms of service delivery to which the NSW Government can transparently demonstrate its achievement of the goals detailed in the plan by way of reporting in an annual report card.

Carers NSW recognises that the share of funding committed by the NSW Government has increased in recent years from 79% to 84% of the total agreement. The commitment shown to improving the lives of people with disabilities and their family carers in NSW recently has been welcomed and it is our hope that this commitment will continue, recognising the high levels of existing unmet need.

NSW has also fallen behind in terms of service delivery. Despite having about one third of Australia's population, only 23% of CSTDA service users live in NSW (AIHW 2005a).

Given current service-use data the increases to funding will only address the periphery of unmet need in NSW. Already NSW has the second lowest number of service users per 1000 potential population with only 117 compared with 322 in Victoria (Australian Healthcare Associates 2005).

As explored in Section 1, many carers of people with disabilities are now ageing in an environment where people with disabilities are living longer in the community supported primarily by unpaid carers and informal networks (Section 1). Actuarial advice to the Minister for Disability Services (unpublished) in 2005 gave the following estimates prior to budgetary increases in 2006-07. In NSW:

- there are approximately 400,000 people with severe or profound disability living in the community in NSW;
- 37.5% of them receive some service from DADHC;
- of those, 94% share just over half the total budget, meaning they receive minimal amounts of services;
- there are approximately 275,000 carers providing support to people with severe or profound disability;
- of these approximately 60,000 carers are aged 65 and over, 24,000 of whom are aged over 75.

The 60,000 ageing carers of people with disabilities and the significant numbers in the next age cohort (45-64) require a range of supports. Many of these carers are likely to be parents who have been providing support for decades. The AIHW (2005) recently reported that parent carers were more likely than any other carers to be providing care for extended periods of time – 23% had cared for their son or daughter for 10-14 years; 10% for 15-19 years and 17% for 20 or more years.

Carers of children with disabilities have a significant unmet need for respite and other types of support. Forty percent of all carers requiring support in this category identified respite as their greatest need (AIHW 2006). Yet in 2003-04 respite had the lowest number of service users of all the service types funded under the CSTDA. Furthermore there were half as many respite users in NSW as in Victoria that year (AIHW 2005a).

Further examination of the 'Stronger Together' plan reveals a number of areas where there is an immediate need for increased investment in order to address existing need and also to better support people with disabilities and their carers from an earlier stage in their care relationship.

While increases to respite for carers of people with disabilities, announced in the 2006-07 NSW Budget are much needed, other specific supports such as supported accommodation for people with disabilities and the development of succession planning models are required.

CSTDA Minimum Data Set statistics show that in 2003-04 there were 6,440 people receiving accommodation support funded by the CSTDA in NSW. Of those, over half were accommodated in group homes, nearly a third in large residential or institutional accommodation and less than 10% in hostels. The remainder were receiving some form of in-home accommodation support.

Two-thirds of the 990 new supported accommodation places announced in 'Stronger Together' to be developed over the next five years will be for people leaving Department of Community Services housing or leaving Corrective Services. A large percentage of the other places are likely to be allocated to people with disabilities living with foster families or leaving nursing homes. In 2005, for the 976 people that applied for supported accommodation there were only 99 vacancies⁴. This indicates a considerable dearth of accommodation to meet existing need, despite the likelihood that this need will grow in the coming years.

In order to prevent the next cohort of families caring at home from entering crisis, measures should be ensured to introduce families to services from an earlier stage in their caring relationship. Outreach and early intervention (in relation to the stage in the care relationship rather than just the age of the person with a disability) in terms of support programs for ageing carers of people with disabilities require further investment. Many carers in this category access no services until they are no longer able to care at which time they often experience a long wait for services (Carers Australia 2005). This could be done through the community support programs offered by the CSTDA.

Recommendation: Carers NSW recommends a one-off 20% increase to programs funded under the Commonwealth State/Territory Disability Agreement, and a subsequent 6% growth per annum and a commitment to increasing the resources for ageing parent carers, respite and accommodation support in particular.

3.4 NSW Health Programs – increases to PADP and Mental Health Services

Many health services have a significant influence on carers' lives, not only on the health of the person they support but also on their own health. Two of the key areas for investment are in Mental Health services and the Program of Appliances for Disabled People (PADP).

Carers NSW welcomed the 2006-07 State Budget mental health initiative announced by the NSW Government, matching its population share of the Commonwealth Government's \$600 million mental health package. However as acknowledged by Morris lemma in 2006 "none of us have got too much to be proud of in mental health"⁵. Ongoing support for people with mental illness and their carers will likely result in a reduction in inappropriate use of generic health and emergency services as well as an over-representation of people with mental illness in the prison system.

Increased funding to provide outreach to families from culturally and linguistically diverse (CALD) backgrounds and Aboriginal and Torres Strait Islander (ATSI) families in particular is now required to ensure that there is equitable access to mental health services for these carers.

Indigenous Australians are currently nearly twice as likely as the total population to be admitted to hospital for overnight psychiatric care (Productivity Commission 2006).

A study on carers of people with mental illness from CALD backgrounds (MMHA 2004) found that while this group was likely to face the same barriers to accessing services as other carers, these would be compounded by a range of cultural factors. Health workers, amongst others, were seen as a key linkage point to services for these CALD carers.

Recommendation: That the NSW Government continues its focus on mental health services to address high levels of unmet need with particular focus on outreach to ATSI and CALD communities.

The PADP is a key service for families of people with disabilities. In our submission to the NSW Health review of the PADP (January 2006) by PriceWaterhouseCoopers, we identified the key issues for carers as:

- delays in processing applications and receipt of equipment – this is particularly an issue where people are returning home from hospital but cannot receive community services until appropriate equipment is in place
- long waiting lists – sometimes waiting lists are so long, in fact, that by the time people get the equipment they need, it is no longer appropriate for them

- inappropriate equipment – this is particularly an issue for children and can hinder growth and functioning
- inconsistency in waiting lists and the types of equipment/appliances available between regions

The lack of available equipment is an issue often raised by carers who contact Carers NSW. Most significantly it is one of the key services that enables access to other services such as respite and community access. If unable to access these services or required to wait for extended periods, many carers experience deterioration in their own health. Furthermore carers' physical health can be negatively affected by lack of appropriate equipment if they are required to do a lot of lifting and transferring on their own. In the 1999 National Survey of Carer Health and Wellbeing, 34% of carers reported upper body problems. These were mostly long-term carers and carers of children. Seventy percent of injuries to carers were due to sprains and strains of joints or muscles (Carers Australia 2000).

The implications of poor carer health on the health system, as well as their own wellbeing and that of the person they support is clear. Equipment is a vital service and one that can positively impact on the health of carers and the people they support with implications for the broader health system.

Analysis of ABS data by the AIHW (2003) found that nationally:

- Around 40% of people who needed assistance with self-care or mobility used the required aids.
- a slight reduction in primary care hours was noted for those under 65 years old using aids and equipment, suggesting that these services positively impacted on the intensity of caring roles while providing the person with greater independence in their self-care, communication and mobility.
- the majority of people who require assistance with self-care, mobility and communication in Australia relied solely on a primary carer for assistance (43.9%, 47.9%, 47% respectively). Only 8% of people who require assistance with communication use aids and equipment.

Carers NSW recommended in our submission to the PADP Review that, given the current shortfalls of the 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 demographic pressures on community care programs into future funding. Better data on need for aids and equipment in NSW is also required in order to ensure equitable distribution of resources across the state.

Equipment and aids are costly. A recent study on people with MS and their carers by Access Economics found that, in 2005, 85.7% of this cost was borne by individuals.

The annual budget for the PADP was \$21.8 million in 2004-05 with planned increases of \$0.5 million in the 2005-06 and 2007-08 budgets (PriceWaterhouseCoopers 2005). Significant increases to funding for this program are required in order to assist people with disabilities and their carers with activities of daily living.

Recommendation: That a significant increase to the PADP, similar to that made in 2004-05 is made again in 2007-08.

3.5 Whole-of-Government NSW Carer Policy - ongoing investment

During 2006 NSW Health and DADHC began the review of the NSW Carers Statement (1999) and exploration of options for the development of a whole-of-government carer policy. Carers NSW has welcomed the NSW Government's commitment to this and proposes investment in the further development, implementation and education and training associated with a Carer Policy in NSW.

Carers NSW anticipates that a NSW Carer Policy will ensure:

- Commitment by Government to greater empowerment, inclusion and timely support for carers in all phases of the care journey
- Formal recognition of the invaluable contribution carers make to community care outcomes, their role, rights and choices as partners in care provision, and their need for support
- A comprehensive cross-department framework upon which each Division, Stream or Unit can base carer sensitive policies, protocols and practice guidelines
- Funded services will work in partnership with carers to determine both the care needs of the individual client and the support needs of the carer, and the services required
- Services will work with carers in the provision of services, and will ensure the participation of carers in the planning, implementation and evaluation of service policies and programs
- Funded services are responsive to the needs of carers in their own right, independently of the person for whom they care.

Recommendation: That the NSW Government furthers its commitment to develop a whole-of-government NSW Carer Policy

Carers NSW also recommends that the NSW Government adopts a two-pronged to implement and enhance the Carer Policy.

Carers NSW, in consultation with community organisations across the mental health, disability and community care sectors, has developed a proposal for a Carer Card in NSW that is based on the Seniors Card model⁶. We estimate that this would assist around 80,000 carers with access to a range of benefits offered by business and community organisations, as well as transport concessions. It also provides a tangible mechanism for the NSW Government to demonstrate its recognition of carers as shown by its commitment to develop a whole-of-government Carer Policy for NSW.

Recommendation: That the NSW Government adopts a two-pronged strategy to complement the NSW Carer Policy:

- 1) a promotion and education campaign targeted at carers and service providers;
- 2) a NSW Carer Card.

Conclusion

In recent years there has been increased recognition from all members of the NSW Parliament that carers do and will play a central role in the future of health care, community care and a range of other government portfolio areas. The challenges of an ageing population and the availability of carers to continue to provide assistance have also been recognised. As partners in care and support for people who are ageing, who have disabilities, mental illness or other chronic conditions, carers are fundamental to the effectiveness and continuity of many programs.

The evidence in this submission has demonstrated that there are social, health and economic advantages to better support for carers. Support programs include respite, training and education, emotional support and information amongst others in addition to the benefits received from general service provided to people requiring support and care.

It is timely to extend the growing recognition of carers into better support in actual terms. The NSW Carers Program has the potential, with increased resources, to achieve better, further reaching support options for carers. The implications of not adequately and appropriately supporting carers are clear: poor health and wellbeing outcomes for carers and for people they support; unnecessary use of costly residential alternatives; poor social outcomes.

In an environment of growing demand and limited resources it is essential that innovative support models are explored. In particular we feel that the NSW Carers Program provides a program basis for the development and expansion of carer support options which, not only achieve better outcomes for carers, but offer potential costs savings to government.

In addition to investment in the NSW Carers Program and other ageing and disability programs without which many carers would not be able to provide support at home, a policy framework is necessary. Carers NSW urges the NSW Government to continue the momentous development of a whole-of-government Carer Policy by way of the strategies recommended herein.

The need to support carers is part of our future. As Graham Lister (2005) writing from the perspective of 2025 imagines that, "(In 2025) there has been a decline in family care for elderly relatives. While in 2005 informal care was some 8-10 times the level of paid care the increasing age of carers and changing family structures and attitudes has greatly reduced this ratio producing a major crisis in care staffing. In response, **informal care was given more recognition, support and funding**, and local voluntary groups formed to provide care developed in other forms of social engagement with health...In health and other issues concerning consumer and citizens rights there is a level of engagement that would have been very surprising 20 years before."

Appendix One:

Carers NSW Project Proposals under an Expanded NSW Carers Program

Carers NSW currently carries out a range of activities to support carers across NSW. These can be grouped as:

- Carer Services
- Information and Referral
- Carer Support Kit
- Counselling Support Program
- Specific Carer Projects
- Education and Training
- Service Providers
- Carers
- Policy Development, Community Sector Development, Carer Representation, Research

Much of our work spans these areas and is funded by a mix of State, Federal, member donations and corporate funding.

Below are a number of proposals for which we seek funding under an expanded NSW Carers Program. These proposals either extend on current projects run by Carers NSW or respond to a particular need identified through our research and policy activities. Detailed proposals with costings for any of the following activities can be provided on request.

1. Existing Projects under the NSW Carers Program

1.1 Young Carer Project

There are estimated to be approximately 90,200 young carers aged under 25 in NSW according to recent ABS statistics (ABS 2004). Young carers can be as young as six years of age, according to service providers.

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 are at a much higher risk than other young people of not making successful transitions into employment and gaining financial stability and independence. Their education is likely to suffer as a result of caring responsibilities. Young carers from minority groups, such as indigenous and culturally and linguistically diverse carers, face possible double disadvantage.

The young carer statewide project has been created to:

- promote the issues and needs of young carers through statewide 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.

Carers NSW currently receives \$214,000 per year to support those 25 years and younger who have caring responsibilities. Previously this funding was to support only young carers aged 18 and under. While there has been an important recognition in the past year of the needs of 'young adult carers' (the 18-25 age group) the young carer project does not receive additional funding to support this much larger group of carers. Over the last year Carers NSW has achieved the following successes:

- holding two statewide young carer camps;
 - training for young carer camp volunteers;
-

- quarterly newsletter;
- website development;
- two Telegroup Counselling Programs (8 sessions per program);
- liaison with Department of Education
- consultations on a range of publications;
- networking with groups in the field, particularly regional NSW.

Partly in recognition of these achievements the NSW Young Carer Project received an international award for best practice in 2002. Yet much more can be done to support young carers. In the UK, for example, there is an extensive network of support for young carers with over 100 programs funded by the Princess Royal Trust which reach approximately 12,000 young carers. There is even a question in the UK Census on young carers to ensure good quantitative data. There are other initiatives such as an annual Young Carer Festival in the UK. Schools have been identified as a valuable location to identify young carers and provide support.

There are a number of initiatives that the Young Carers Project could undertake immediately if further funding were granted. These include:

- At least one further camp per year. At present Carers NSW is forced to turn away up to 45 young people from each of its camps. Furthermore Rotary is no longer able to provide its significant contribution to these camps (each camp costs approximately \$30,000 to run).
- A camp to support 18-25 year old young carers which would take place on a regular basis. Although the needs of 'young adult carers' are now recognised, the Young Carer Project does not receive additional funding to provide services to this group yet a camp held in 2005 proved extremely successful (each camp costs approximately \$30,000).
- Further identification of young carers. In particular, we need to ensure that rural and remote areas are being reached and that those minority groups who run the risk of double disadvantage are identified and assisted appropriately. There has been increased regional demand in 2005/06 for more young carer education, in particular workshops and training.
- Further website development and the maximising of new technologies through the exploration of eSupport and chatroom support for young carers. The Carers NSW Young Carer website receives 44,000 hits each month on average. The number of visits to the website increased by 66% from May 2005 to July 2006.
- Development of a young carer specific Mentoring Project.
- Further development, refinement and distribution of resources (newsletter, brochures and fact sheets) to meet sharply increasing demand. Currently we distribute around 10,000 Young Carer Newsletters by post each month and are facing the challenges of increasing demand.
- Employment of a part-time young carer worker. A significant one-off private donation in 2005-06 has allowed Carers NSW to employ a part time young carer worker until July 2007 to assist with increasing demand. However from July 2007 additional resources will be required to continue this position.

A Young Carer Summit was held by Carers Australia in 2004 in which education was identified as a key priority area for young carers and as a result it was included on the agenda for further consideration at the August 2006 young carer summit. Carers NSW has developed a pilot Young Carers Schools Program, based on a UK model which has proven extremely successful. Interest in this pilot has been shown by schools in a number of NSW regions and funding is urgently required to implement this initiative.

These initiatives would all address areas of identified need for the young carer population and result in substantial increases to access of services by this group. These outcomes would help to create equal opportunities for young carers with other young people in NSW.

The measure of success of this Project will be the extent to which young carers are able to feel part of the community and to make successful transitions in life. This project enables Carers NSW to specifically make a difference in the lives of young carers.

Carers NSW requests \$300,000 per year recurrent.

1.2 Mental Health Project

Most recent figures from the national Survey of Mental Health and Wellbeing show that 18% of adults reported a mental disorder in the 12 months prior to the survey. Depression was the most common disorder (ABS 1997). Nationally it has also been estimated that depression is the leading cause of non-fatal disease burden. Mental disorders are now the third leading cause overall of disease burden (after cardiovascular diseases and cancers), accounting for 14% of the total burden of disease (AIHW 1999).

In 2004, results of the New South Wales Population Health Survey (NSW Health 2004) showed that 64.2% of people were classed as having 'low' levels of psychological distress, 22.5% as having 'moderate' levels of psychological distress, 9.8% as having 'high' levels of psychological distress, and 3.5% as having 'very high' levels of psychological distress. Of those aged 16 years and over, the average number of days they were totally unable to work, study, or manage their day-to-day activities because of their psychological distress was 0.71 days. On average, people aged 16 years and over saw a doctor or other health professional about their psychological distress 0.16 times in the 4 weeks prior to the survey.

There are no reliable estimates on the number of people caring for someone with a mental illness or disorder. However data from Carers NSW shows that approximately 10% of calls to our carer support line are from carers in this category. If this is indicative of the wider population, there could be around 75,000 carers of people with mental illness in NSW. ABS statistics also demonstrate that 12% of all people receiving some assistance from an informal provider report a mental disorder as their main health condition (this excludes behavioural and developmental disorders).

Carers NSW welcomed the additional funding announced in 2006 to the Family and Carers Mental Health Program (\$13.5 million over four years) as well as a range of other measures to improve mental health that were announced in by the NSW Government. Carers NSW will now be delivering Mental Health Programs in three regions of the state. It is fundamental to the success of these programs that there is effective coordination and an ongoing commitment to involve consumers and carers in service planning and delivery as outlined in the National Standards for Mental Health Services..

Carers NSW requests ongoing funding commitment to the Mental Health Program in line with current and future need for carers.

2. New initiatives to be undertaken by Carers NSW

Carers NSW request \$1.75m for new initiatives to better support carers in 2007-08

2.1 Working with GPs /Reaching Hidden Carers

General Practitioners have always been an important contact point for carers, as many carers accompany the person they are caring for to medical appointments. GPs can provide information and emotional support to carers, as well as monitoring their health. Recent research reports have, once again, emphasised the importance of GPs as a contact point for carers (SPRC 2004; Carers Western Australia 2003).

Carers Australia is currently working with the Australian Government Department of Health and Ageing's Primary Health Care Branch on a proposal to develop Carers' Health Checks as an item on the Medical Benefits Scheme. Such an item would identify some carers (eligibility yet to be determined) as an 'at-risk' group whose health status requires monitoring. We are confident that such a proposal will be implemented once details such as eligibility have been decided.

In advance of such an initiative and because GPs are such an important contact point for carers, Carers NSW is aware of the importance of undertaking a project with GPs to ensure that they are aware of who carers are, their needs and the importance of providing information and support to carers. Such a project would comprise a number of elements: first, an education program, developed in conjunction with the Royal Australian College of General Practitioners, which would provide GPs with CDPE (professional development) points; second, promotional strategies across NSW so that GPs and other practice staff are aware of carers, Carers NSW and where they can refer carers for support; third, the identification of carers through outreach initiatives; and

fourth, liaison with Divisions of General Practice across NSW. Work with GPs and practice staff is one area which Carers NSW has been able to undertake very little of in the past due to lack of resourcing.

Carers NSW requests \$200,000 per annum recurrent to employ 3 regionally-based workers across the state to implement a project working with GPs and reaching 'hidden' carers.

2.2 Marginalised Carers

■ Aboriginal and Torres Strait Islander Carers

There are approximately 120,000 Aboriginal and Torres Strait Islander people in NSW. Based on the proportion of carers to the general population, estimates of the number of Aboriginal and Torres Strait Islander carers are of at least 15,000 carers.

The number of Aboriginal and Torres Strait Islander people who are carers is likely, however, to be much higher. First, the high rate of disability owing to environment and trauma-related disabilities suggests that the number of people requiring care is likely to be higher than with other population groups. Second, Aboriginal and Torres Strait Islander households are larger than others. More family members are likely to be involved in care and many may be involved in multiple care relationships.

Carers NSW is committed to providing information, support and referral to Aboriginal and Torres Strait Islander carers. An Aboriginal Development Officer has been employed for some years. During the course of our development work with Aboriginal and Torres Strait Islander carers and service providers in general, it has become obvious that these 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 and Torres Strait Islander carers face. Therefore, Carers NSW believes in a two-pronged approach:

- a statewide training program for generalist community services on Aboriginal and Torres Strait Islander carer issues is necessary to increase the access of those carers to the support which is available. This will build on work already done with service providers by the Carers NSW Aboriginal Development Officer. A manual arising out of this work, "Koori Yarning", has been produced.
- employment of an Aboriginal Training Officer to implement the training program
- the development of an Aboriginal and Torres Strait Islander carer profile tool for use by services so that Aboriginal and Torres Strait Islander carers can be assessed in their own right.

Carers NSW requests \$150,000 per annum recurrent to improve access to training and services for Aboriginal and Torres Strait Islander Carers.

■ Culturally and Linguistically Diverse Carers

There are a significant number of carers from culturally and linguistically diverse (CALD) backgrounds already in NSW. Based on general population statistics this number is likely to be around 150,000, given that more than one-sixth of the total population in NSW is born in a non-English speaking country.

The proportion of the elderly from non-English speaking countries is forecast to increase from 17.8% in 1996 to 21.2% in 2026.

There is likely to be a particularly high level of unmet need amongst CALD carers as access of CALD communities to services is typically low. Program data shows that between eight and nine percent of Home Care Service and CSTDA and HACC funded service clients are from CALD backgrounds.

Recent research by the Ethnic Communities Council, Carers NSW, Ethnic Child Care and Family and Community Services Co-Op Ltd. has provided further support for the additional needs of CALD carers in rural and remote communities. Research on respite conducted by Carers NSW during 2005 also demonstrated that CALD carers were as likely to have a need for respite as other carers but less likely to access services.

Resource equity

Carers NSW aims to be inclusive of carers from culturally and linguistically diverse backgrounds. We provide information, referral and support to CALDB communities through the Carer Resource Centre, as well as through the Carer Support Kit which is available in community languages. These services are funded by the Australian Government through the National Respite for Carers program.

Carers NSW received \$100,000 from the Department of Ageing, Disability and Home Care last financial year to translate certain key materials for carers from CALDB communities. That was an important first step, which has allowed us to translate materials on key concepts and some of our factsheets for CALDB carers. These concepts include who is a carer, what respite is and services which are available to support carers (such as support groups and counselling). We have translated this material into the top 10 community languages in NSW.

However there is still further information that needs to be translated and other languages into which it could be translated. Carers NSW would like to have a full range of caring-related information available for CALDB communities.

Carers NSW requests a further one-off grant of \$100,000 to continue its program of translation (including community consultation, distribution and printing costs).

Additional worker for CALDB communities

Despite the vast number of CALD carers in NSW and the issues they face particularly around access to information and services, Carers NSW currently has only one dedicated position which involves coordination, training, community development, representation and support for a host of CALD carer projects, activities and committees. Where possible this work is incorporated into our general work however CALD communities often require a specialised approach and this brings with it the need for specialised skills and experience. Carers NSW requires at least one additional CALDB worker in order to better meet the information and support needs of CALD carers in addition to enabling Carers NSW to continue community development in relation to CALD carers.

Carers NSW requests funding for an additional worker to work with CALDB carers and communities. The cost is budgeted at \$125,000 per annum.

'Connections project' for CALDB communities

Carers NSW recently conducted a pilot project with funding received from the Commonwealth Department of Family and Community Services to support families of people with intellectual disability. It was called 'Connections' and involved trialing of new methods of carer support particularly for families living in rural areas who could not easily access services. New programs using communication technology such as email support groups (in real-time, with facilitation), internet chat groups (available 24 hours a day) and telegroup counselling were provided.

Carers NSW wishes to build on the knowledge from this pilot program to develop best practice in supporting carers from CALD backgrounds by adapting the project for this group. We believe it will assist to reduce isolation of CALD carers, particularly those living in rural and remote areas..

Carers NSW requests funding for a 'Connections' program for CALDB carers. This is costed at \$125,000 per annum

2.3 Better models of carer support

A number of key pieces of carer research that have recently been completed by Carers NSW or other organisations provide evidence for how to better support a number of carer population groups who currently are not benefiting fully from funded services. These are detailed below and include respite in a carer support framework; support for ageing carers of younger people with disabilities; male carers; and education and training for carers and service providers.

■ Respite in a carer support framework

Respite has been shown to have a number of positive outcomes for both carers and the people they support (reference). Yet nationally only 13% of all primary carers have ever access respite services (ABS 2004b). Despite this, respite was raised by carers as the main service that they required in our survey of Carers News members in 2004.

Research recently conducted by Carers NSW, entitled Reconceptualising Respite identifies a number of ways in which respite could be delivered more effectively to carers. In particular our findings included the inappropriateness of many existing respite models for carers of people with mental illness and young people

with disabilities. Previous research by Marchant and Payne (2003) identified the respite and support needs of carers of children with Attention Deficit (Hyperactivity) Disorder (AD(H)D).

In each of these reports Carers NSW makes a comprehensive list of recommendations to the NSW Government and various Government Departments regarding improved support for carers.

Carers NSW requests \$100,000 one-off funding to further recommendations around developing pilot respite and support models, based on evidence from our and other research, for carers of young people with disabilities, people with mental illness and children with AD(H)D.

■ Ageing carers of younger people with disabilities

In 2003 there were estimated to be 6,400 ageing parent carers nationally (ABS 2004). The next cohort of parent primary carers however is much larger (44,400). Approximately one-third of these carers are likely to reside in NSW in keeping with the general carer population.

In the last three years the Carers Coalition has undertaken a range of research activities including the preparation of an issues paper; an ageing parent carers workshop and workshop report; and a mapping project of services for ageing parent carers. The Carers Coalition is an affiliation of around 50 organisations statewide, convened by Carers NSW. This work demonstrated that there are a range of generic and ageing and disability services which ageing parent carers can access. However there are few programs or services that are designed to specifically address the needs of this group.

A Carers Australia (2005) paper has demonstrated that, while respite for ageing parent carers is important, a support system is required including outreach, service coordination and futures planning for this group.

Carers NSW requests \$100,000 per year recurrent to provide statewide coordination of programs for ageing parent carers and to ensure consistency and access for carers across programs.

■ Male carers

Men comprise 46% of all carers in NSW. Twenty-eight per cent of primary carers are men, however in the older age groups (65 years and over) at least 50% of primary carers are male. Male carers are more likely to look after a spouse than female carers and often care for their wives with dementia.

As the ratio of carers to people requiring care is likely to diminish in the future (NATSEM, 2004), society may be more reliant on men to provide care. Given that men usually bring a different set of skills, knowledge, experience, expectations and approaches to caring (Payne, 2005), existing carer support initiatives may not meet the needs of male carers as well as they could. It will be important for society in the future, given the shorter supply of carers, to ensure that all groups of carers are well supported. In the past, little attention has been paid to the specific needs of male carers.

Carers NSW, based on its knowledge and experience, wishes to implement a project which works specifically with men to trial and evaluate gender-specific support interventions with a view towards better supporting male carers across NSW.

Carers NSW requests \$100,000 per annum recurrent to develop, implement and evaluate a Male Carer Support Project with a view to developing a 'best practice' model for the support of male carers across the state.

■ Building connections with families of people with disabilities

There are nearly 115,000 parents providing support to people with a disability in NSW (ABS 2004). This group of carers can often go unsupported as their caring duties are blurred with regular parenting duties. Carers NSW has identified a significant need to further an earlier project for connecting parent carers with the service system.

Carers NSW welcomes the budget announcements, as part of the NSW Government's 'Stronger Together' disability package, to introduce new parenting programs, to trial carer support programs and develop information kits for families of children with disabilities.

Previously Carers NSW was funded by the Commonwealth Department of Family and Community Services to conduct a pilot project with families of people with developmental disabilities. It involved trialing new methods of supporting carers, especially those in rural areas, through web and email-based facilitated support programs.

Besides achieving specific outcomes associated with the Project key learnings have emerged. Research has been conducted in these areas and workshopped with key stakeholders. This has resulted in a set of recommendations to assist the disability sector in planning strategic outcomes for service providers in the delivery of carer support to parent carers.

Central to these recommendations is the need for a statewide, collaborative approach and building partnerships which enable effective coordination, service development, planning and evaluation of support services.

Carers NSW requests further investment for the statewide coordination of support for parent carers of family members with disabilities. With additional funding Carers NSW could also coordinate a statewide training program for carers of people with disabilities.

Carers NSW requests \$50,000 per annum recurrent.

■ Education and Training

In order to assist family carers to manage and cope with their caring responsibilities, carers require education and training in the physical aspects of caring, information about the community service system and where to access help and support with the psychological and emotional aspects of caring.

At present access to carer education and training is not equitable across the state as it is delivered on an ad hoc basis. It generally depends on whether a health or carer support worker in a region organises training.

An effective method to improve the equity of access to carer education and training across NSW is through a 'train the trainer' workshop to service providers. A recent British study found that training carers of stroke survivors in basic nursing skills improves quality of life and saves money, as noted previously. Carer training like that for service providers, needs to be available across the state.

Carers NSW requests funding for carer education and training to be developed into a 'train the trainer' education package to be delivered to service providers across the state at a cost of \$150,000 per annum.

Workshops for Carer Support Group Coordinators

In April 2006 Carers NSW conducted a survey of approximately 300 carer support group coordinators to which 94 responded. The survey included questions about the type of support they require from Carers NSW. About half of the respondents requested training in group work skills and dealing with loss and grief. Seventy-three percent of respondents wanted Carers NSW to organise training workshops.

Carers NSW requests funding to facilitate workshops for carer support group coordinators at the cost of \$100,000 per annum.

Vocational Education and Training

The incorporation of carer-specific competencies into the Community Services Training Package is anticipated to occur during the review of the training package from 2006-2008. The inclusion of these carer specific competencies will provide workers and prospective workers in community services with the opportunity to complete carer specific units of competency as part of their training.

Carers NSW requests one-off funding of \$50,000 to participate in the Review of the Community Services Training Package

■ Carer Life Course Framework

As part of the Carers Mental Health Project (2001 – 2005) Carers NSW has developed the Carer Life Course Framework which provides a theoretical and empirical base showing:

- how carers' needs change over time depending on the length of time caring, the relationship to the person with the mental illness/disorder, and the carer's own life course/ life stage, and
- the type of information, support and interventions required to meet these needs.

The Framework has practical application for carers as it provides a map of what other carers have experienced with links to relevant information and support services. It is also useful for *policy and government organisations* as it can identify gaps in what is needed and plan for more integrated carer support as well as *service providers* to enable them to provide the most effective interventions at the most appropriate time.

Whilst the Framework has been developed for carers of people with mental illness/ disorder it has applicability to other carer groups.

To ensure easy accessibility and use of the Framework it is proposed that an interactive website be designed and maintained.

The on-line medium more accurately reflects the multi-dimensional issues and needs of carers identified in the Framework.

It will enable immediate and targeted information to be accessible to carers, service providers and government departments.

Carers NSW is seeking \$300,000 to examine how the Carer Life Course Framework can be expanded to include carers from a range of disability groups as well as indigenous carers and those from culturally and linguistically diverse backgrounds.

Carers NSW also seeks \$100,000 per annum to develop and maintain an interactive website for the Carer Life Course Framework.

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Endnotes

1. The ABS defines 'primary carer' as a person of any age who provides the most informal assistance to a person with one or more disabilities that is likely to be ongoing for at least six months.
 2. People aged under 65 with severe or profound disability requiring assistance with core activities which are self-care, mobility and communication.
 3. A separation is defined as a total hospital stay (from admission to discharge, transfer or death) or a portion of a hospital stay beginning or ending in a change in the type of care for an admitted patient.
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ISBN 1 876637 08 0