



## **A New Direction for NSW**

# **Comments on the NSW State Plan**

September 2006

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*For more information on any aspect of this submission please contact:*

***Kathy Wood***

*Acting Chief Executive Officer*

*Carers NSW*

*PO Box 20156*

*World Square NSW 2002*

*Ph: (02) 9280 4744*

*Fx: (20) 9280 4755*

## Executive Summary

Carers NSW, in its role as the peak body representing informal carers across NSW, wants to ensure that the NSW community care system continues to improve its responsiveness to carers' needs and to recognise that carers are part of the care journey and a core part of the community.

In the next decade, NSW will face many challenges in the supply and demand for government services especially those services to carers and the people they care for. The shaping of public policy over the next ten years and the agreement to include carers in the design and to deliver of the priorities in the State Plan is welcomed, and Carers NSW believes will mark a profound shift in the way Government operates in NSW. Ultimately, this is not only sensible, but also cost-effective, as carer support is an investment, which prevents the caring relationship from breaking down, prevents the carer's health from deteriorating and delays institutional care for the person requiring care.

### The Challenges Ahead for the NSW Government and Carers NSW:

- The pressure an ageing population will place on the availability of informal carers to be able to care now and in the future.
- Ensuring rights and choices for carers and those they care for.
- The support available to enable carers to fulfil carer responsibilities and continue their employment including access to quality, and affordable types of care, for working carers of all ages.
- Supporting ageing carers in their caring capacity and the expressed future needs and preferences of ageing carers and the people for whom they care.
- The changing and diverse support needs of Aboriginal carers.
- The undue pressure placed on an individual carers health and wellbeing and their ability to continue in their caring role.
- The increasing number of young carers aged up to 25 who are at a much higher risk than other young people of not making successful transitions into employment and gaining financial stability and independence.
- Long term care policy that supports informal carers as key partners in the care journey at each stage.

Carers NSW believes that informal care and ongoing care should not be assumed as a readily available free resource.

The imminent challenge facing the NSW government is the establishment of comprehensive, affordable and balanced **long term care system** that meets the needs, values and preferences both of persons who need ongoing care and support and informal carers who are their primary carers.

If long term strategies and priorities do not build in support for **carers as a distinct target group** they may ultimately have the undesirable effect of draining an essential resource.

## **Use of the Term Carer**

In recent years there has been confusion about who exactly is a carer.

This is because 'carer' has been applied to different groups of people. Sometimes it has been applied to family members of people who are frail or who have a disability or a chronic or mental illness. Sometimes it has been used for volunteers, and it is often used for paid staff in the residential, community care and child care sectors. As a result, it is not clear which group is being referred to when the term 'carer' is used.

In short, we ask that the term 'carer' be used to apply to informal carers only, that is parents partners, significant others, family members ,friends and neighbours (ie people who care on an unpaid basis)

## Key Facts at a Glance about the Population group of Carers in NSW



- Nearly 1,000,000 people in NSW are carers - that equates to about 11% of total population
- 600,000 people of work forces age have caring responsibilities in NSW (Taskforce on care costs 2006)
- 6,400 parents carers aged over 65 nationally (ABS, 2004)
- The number of ageing carers can be anticipated to rapidly increase over the next two decades. In size of the next cohort of parent primary carers (45-64) has increased from an estimated 27,700 in 1998 to an estimated 44,400 in the same age cohort in 2003, an increase of 59% in five years.
- 90% 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 (Productivity Commission 2006)
- 90,200 young carers aged under 25, (8% of all people in that age group have caring responsibilities and they made up 6.5% of all carers, affecting boys and girls equally)
- The National Survey of Carer Health and Wellbeing conducted in 1999 showed that 58% of carers surveyed reported that their physical health had been adversely affected due to their caring role

## Background



### Who are Carers

- Carers are usually family members who provide support to children or adults who have a disability; mental illness chronic condition or who are frail aged.
- Carers can be parents, partners, brothers, sisters ,friends or children of any age.
- Carers may care for a few hours a week or all day every day.
- Some carers are eligible for government benefits, while others are employed or have a private income.
- Carers are as diverse as the rest of the population in terms of culture, age, interests and values.

### What do carers do

- Each care situation is unique.
- Some carers need to assist with tasks of daily living, and spend their days feeding bathing, dressing, toileting, transferring or administering medications.
- Other care for people who are fairly independent but need supervision or help with their finances and transport.
- Carers also provide emotional support day in , day out for some of the most vulnerable , isolated members of our community

## Theme 3 Improving Services



With an ageing population, increasing rates of disability and a shift in emphasis from institutional and acute care to community care there is an escalating expectation that it is families who will care for people with chronic illness, people with disabilities and family and relatives who are ageing.

With an overall decline in the propensity of people to care. It is therefore not surprising that it will be necessary for carers to continue to become a major focus in shaping public policy over the next decade and beyond.

Ultimately, better support for carers will prevent the caring relationship from breaking down, prevent the carers health from deteriorating and reduces the costs to the community by delaying the institutionalisation of people requiring support and reducing impacts of ageing and disability and chronic illness on the public health system and or readmission to hospital of people requiring support. Health policies need to ensure that there are measures to address carers support and needs. Carers need to be supported included and supported throughout the patient journey including discharge planning self management process and primary and acute care if the health system is to be sustained over the next ten years.

## Theme 3 Improving Services

### Draft Priority NSW State Plan: Reduced Hospital admission of aged people and people with chronic illness

#### Opening remarks

The maintenance of health of carers (should be) a significant public health priority as it determines their capacity to provide care for people in their homes who would otherwise have to rely on publicly funded institutional health care

Ultimately carer support is an investment which prevents the caring relationship from breaking down, prevents the carers health from deteriorating and reduce the costs to the community by delaying the institutionalisation of people requiring support and reducing impacts of ageing and disability on public health system.

#### Key facts

- Research has shown that carer inclusion in the health care setting can benefit patient quality of care (Droes 2000 ; Kelly and Newstead 2004)
- Increased Projections of disease and injury for NSW are related to the ageing population (by NSW Health) and for many of these conditions informal care is the bulk of care provided
- Trend away from acute setting and imperative to early discharge

#### Why support Carers

- Carer support has also been found to be a factor in reduced admission rates. (Bridge and Barbe 2004)
- As there continues to be a general preferences in the community for living at home the value of family carers as a resource for the economy will continue to increase.

#### Compelling Evidence for Action

- Carers provide 74% of the care needs of Australians while Home and community care provide 9% ( AIHW 1999)
- There are more ageing carers who have recently begun caring now than in 1998 (ABS analysis)
- Out of the 34 community consultation held across NSW on the draft priorities in the State plan, 33 of the consultation summaries posted on the NSW Premier website mentioned as a major challenge health and support issues and issues with regards to ageing which also encompasses their carers the most important (August 2006 NSW Premiers Department)
- Out of the stakeholder forum consultation summary these issues were also strongly echoed

#### Recommendation on the Priority

*Reduced Hospital Admission of aged people and people with chronic illness and include carers throughout the patient journey*

## Theme 3 Improving Services



A lot of young people have caring responsibility. Many of the issues they face have arisen during their young carer role and continue into early adulthood.

However, if young carers aren't given proper support there can be some serious negative impacts:

Impaired education, social, emotional and physical development, Incomplete schooling, Poor social skills  
Permanent physical injuries (eg back injuries from lifting) and unemployed

The young carers most at risk are those caring for parents, particularly sole parents. In some cases young people in these situations are caring on their own with little or no help.

Sometimes though young carers say that caring can affect how they feel, how much time they get to spend with friends, doing schoolwork or holding down a job, and that often they need some help.

## Theme3 : Improving services

### Draft Priorities NSW State Plan : More students completing year 12 or equivalent across NSW

#### Opening remarks:

CNSW recommends inclusion of who are disadvantaged in the existing state plan priority. This should include young carers as well as other disadvantaged young people. Outcomes should be based on creating equal opportunities for young people with caring responsibilities with other young people in NSW

#### Key facts

- Carers NSW data base at present we have 1200 registered young carers ranging from seven (7) to twenty five (25) .
- Significant issues for all young carers include attendance at school (and other education facilities), barriers to social participation and lack of understanding and recognition of their role from service providers, health professionals and the general community.
- Currently in NSW these young adult carers become ineligible for many young carer services and supports when they turn eighteen and are required to access adult carer services.

#### Why support Young carers

- Young carers as a group require a different approach when being supported because of their particular life stage and developmental needs.
- 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
- reduced opportunities ill health and ; For many the realisation that their caring role will impact on their lives well into the future has a significant impact on their own sense of well being and their relationships with others

#### Compelling Evidence for Action

- 90,200 young carers aged under 25 in NSW and affect boys and girls equally( ABS 2004 )
- In 1998 60% of young carers across Australia, aged 25 and under, were not in the labour force compared with 38% of the general population in that age group.
- Research on young carers from the United Kingdom supports this trend with its finding that caring reduced young people's access to education and consequently reduced their employment opportunities.

#### Recommendation on the Priority

*Increase the proportion of students who are disadvantaged completing year 12 or equivalent.*

### Theme 3 Improving Services



The Ageing population is one of the key trends identified in the state plan. In NSW concern about ageing carers has been emerging for a decade. It results from awareness of increasing longevity of people with disabilities and mental health issues , and awareness of the crisis, dislocations and family traumas that may occur with carer ill health.

For many ageing carers with long term care responsibilities, a key concern is their capacity to continue caring and what will happen to the person they care for if there is no succession planning , when they can no longer be the primary carer. This can cause stress and strain on the carer whose health and capacity to care is likely to be diminishing with age and anxiety from not having a long term arrangements in place for their loved one. Planning for the future involves three main areas: guardianship, financial and residential.

A major concern is the quality and availability of care and support for those people who are also ageing. This has been an increasing public policy issue as a consequence of increased life expectancy of people with disabilities, with them outliving their parents and the expectation people will continue to live in the community with informal and formal support.

Informal care and ongoing care by family members should not be assumed. The numbers of ageing carers can be anticipated to increase rapidly over the next two decades. However they must be properly supported from an early stage to prevent crises from occurring.

The size of the next cohort of parent carers (aged 45-64) has increased by 59% in 5 years from an estimated 27,700 in 1998 (ABS 1998) to an estimated 44,400 (ABS 2003) in the same age cohort in 2003.

## Theme 3 Improving services

### **Draft Priorities NSW State Plan: Increase the employment participation rate of people with mental illness and people with a disability.**

#### **Key Facts**

Ageing Carers with Long term caring responsibilities

- Issues are complex around succession planning including estate planning social security payments trust arrangements and taxation
- Ageing carers are known to be less likely to use services than their younger counterparts because: many never engaged with formal services, negative experiences.
- The needs of ageing carers and the people for whom they care can change rapidly as a consequence of a family crisis a breakdown in carer health or carer death.

#### **Compelling Evidence for Action**

- 6,400 parents cares aged over 65 (ABS )
- Increasing number of parents facing the issues of succession planning for their son or daughter (27,000 in 1998 to 44,400 in 2003) in the 45 –64 years.
- The role of carers is paramount in considering how care to our ageing population is provided as the bulk of care is provided as unpaid informal care in the persons home.

#### **Recommendation on this Priority**

Increase the employment participation rate of people with mental illness and people with a disability include *and their family carers*.

*We feel that the priority is limited and should not only be about increasing employment rates of these people but also ensuring that ongoing support quality of life outcomes.*

## Theme 4 Growing Prosperity across NSW



Most people in NSW will be Carers at some stage in their lives. Research by the Taskforce on Care Costs (2000) has clearly demonstrated that the financial costs of services and alternative care arrangements is perceived to be 'too high' carers are forced to leave the paid workforce rather than balancing paid work and care.

Reforms to ameliorate the cost of care (particular for people in the workforce managing multiple caring responsibilities) have the potential to enhance workforce participation rates, stimulate an increase in the availability of caring arrangements, and improve outcomes for carers.

### Key Select findings from *2006 Interim review on Taskforce on Care Costs*

- The cost of care affects men and women in: 2006 one third of working men self identified as having caring responsibilities
- Skills are walking out the business door: 2006 affordability of care influenced the departure of 64% of employed carers from the workforce and 60% would return to the workforce if care was more affordable
- Care costs inhibit labour force growth , access to formal and informal care is diminishing , the shortfall in carers and formal care services needs to be addressed in order to limit long term labour supply shortage.

## Theme 4 Growing prosperity across NSW

### Draft Priorities NSW Draft Plan: Increasing the total productivity of the NSW economy

#### Opening remarks:

The potential for carers to continue being productive is an untapped resources, by ensuring access to Quality, affordable types of care, these being all critical to work/care decisions, workforce participation rates would increase for a significant skilled portion of the NSW population

#### Key Facts

- There are about 600,000 people of workforce age with caring responsibilities in NSW
- Approximately 1 in 4 workers with caring responsibilities are still at risk of leaving the workforce because of the cost of care, and 1 in 4 workers with caring responsibilities have already reduced their hours of work because of the cost of care
- In 2006 79% of workers with caring responsibilities say that affordability of care influenced their current working arrangements, up 12% from 67% in 2004

#### Why Support carers

The relationship between the cost of care and employment choices affects employees on all incomes, ie. from those on relatively high incomes (defined as AUS\$90,000 and above) to those on relatively low family incomes (defined as below \$50,000) with the impact on employees on low incomes amplified. Hence strategies to address all income groups will have a significant impact upon choice and workforce participation for all employees.

#### Compelling Evidence for Action

- The ABS survey found that nationally 61% of primary carers are not in the labour force, compared with 32% of non-carers.
- Around one in ten primary carers of workforce age said that they had left work in order to commence or increase care
- Over 35% of primary carers who were not working said that they would like to work. Lack of alternative care arrangements and lack of workplace flexibility were the main barriers.
- NSW needs to reconcile the competing economic and social aspects of caring of combining paid work and caring responsibilities into a policy framework that will support families now and in the future, the high cost of care will continue to put workforce participation rates of carers are severe risk.

### Recommendations on the Priority

Increasing the total productivity of the NSW economy including the workforce participation rates of carers

## References

ABS (2004) Survey of Disability, Ageing and Carers, Australian Bureau of Statistics

Carers Australia (2000) Warning Caring is a Health Hazard, Results of the 1999 National Survey of Carer Health and Wellbeing

Productivity Commission (2006) Report on Government Services

Droes et al (2000) 'Effect of integrated family support versus day care only on behaviour mood of patients with dementia', in International Psychogeriatrics, 12, 1

Taskforce on Care Costs (2006) Where are we now? 2006 Interim Review of the 2005 Creating Choice: Employment and the Cost of Care Report

Carers Australia (2005) Ageing carers: Succession planning and long term needs: A response to the Federal Government's Budget Initiative 2005-09

Bridge and Barbe (2004) Reducing hospital readmission in depression and schizophrenia: current evidence, in Current Opinion in Psychiatry

AIHW (1999) Australia's Welfare