

Response to NSW Health draft Population Health Plan

November 2006

Opening remarks

Carers NSW is the peak body in this state representing 750,000 people caring for a family member, friend or neighbour who has a disability, chronic or mental illness or who is frail aged. Many carers we represent frequently deal with the public health system - both in the acute and community care setting. Carers NSW believes the key challenge for the public health system is to ensure that the health of carers in NSW is not undermined because of their caring role with consequences to themselves, the people they care for and the public health system.

Whilst we acknowledge that not every initiative can be mentioned in this draft strategy, the links to the NSW Carers Program and the proposed development of a NSW Carer Policy, have not been articulated in the document. Neither have they been mentioned in Appendix 1: *Mapping to the NSW Health Seven Strategic Directions*, developed through Futures Planning to date. NSW Health is one of the key agencies involved in service delivery and policy development to carers. Carers NSW finds it disappointing and concerning that **carers as a key population group** and the fact that carers traverse all areas of health services is, is not included. Carers provide a vital function to the community health and community care system and there is now ample evidence of the benefits of supporting carers which Carers NSW has cited in a number of submissions to NSW Health, and are appended to this document as background information. They also contain references made herein.

The creation of *Healthy People 2010 The Population Health Plan for New South Wales*, offers a welcome opportunity to again consider the importance of the relationship between carers in NSW and the NSW public health systems in promoting healthier people and quality health care.

Background

Carers New South Wales (CNSW) has been an active member on various committees and participated in key forums regarding Futures Health Planning in NSW. At the request of NSW Health, Carers NSW submitted an Issues Paper exploring the key issues, trends and challenges that carers face in dealing with the Health system, titled: *Carers and the Health System Paper, June 2005*. In July this year Carers NSW provided a response to the 'Fit for the Future Have your say about future directions for health in NSW.'

This response to *Healthy People 2010 The Population Health Plan for NSW*, reinforces Carers NSW position about on the important role carers play as part of the health care support team and that better investment in carers means better quality care for those they support and long term cost savings for government.

In this submission we have identified areas of the population health plan where there should be better inclusion of carers in relation to their role in the health care team need for to better supports to in relation to, what has become an increasingly more dependent and complex patient population.

Caring is a natural part of the life course and carers are as diverse as the population. Almost everyone at sometime will provide informal care and support. Whilst each care situation is unique Carers provide a range of practical assistance, health care, emotional support, supervision and monitoring and advocacy.

Current carer profile in NSW:

According to the Australian Bureau of Statistics (2003 Survey of Disability, Ageing and Carers), in NSW there are:

- 748,000 carers
- 149,700 primary carers (primary carers are those who provide the most informal assistance in terms of health or supervision to a person with one or more disabilities)
- 46% of all carers are men whereas they comprise only 28% of primary carers
- the greatest proportion of carers are aged between 45 and 54
- 76% of all carers are of workforce age
- 55% of primary carers rely on a government benefit or allowance as the principal source of income
- 40% of carers are caring for a partner, 29% for a child and 32% other

Question 1: Is this broadly the right direction for the strategy?

While CNSW supports the focus on prevention and population health, there should be a stronger focus in the plan on community health as this is where most health activities will be taking place in the future. Increasing trends towards reduction in hospital stays and provision of health care at home mean that people will increasingly be called on to 'self manage' which often involves assistance from a family member or friend (informal carer).

Healthy People 2010, does set the platform for population health action in NSW over the next five years. However the draft plan does not identify one of its key population groups emerging from changing profile of our community, **carers**.

The NSW health and community care systems increasingly rely upon family, friends and neighbours to provide informal care and support in an unpaid capacity. There is now a significant body of evidence and research pointing to i) the benefits of carers inclusion in the health care team on patient outcomes; and ii) the negative effects of caring on the health and well being of carers which, in turn, can have negative repercussions on patient health.

Over the last twenty-five years CNSW has identified key components of carer support and the principles to guide effective carer support. These include:

- Inclusion of carers at every stage of service planning and delivery
- Flexibility of services
- Maintaining quality of life and choices for carers and those they support
- Supporting the total caring situation
- Affordability of services
- Responsiveness and accessible systems
- Culturally appropriate approaches
- Understanding the impact of caring responsibilities on the life stages and life transitions of carers and those they support

It is also noted that the plan does not acknowledge or recognise the range and diversity of population groups including people from different cultural backgrounds. Healthy People 2010 does not acknowledge the differing issues facing people and communities in rural and remote areas both in terms of health issues and lack of affordable and accessible transport to health services. This diversity is not reflected or integrated throughout the key sections of the document.

Acknowledging the contribution of carers to the community, acute and residential care sectors is important. In particular carers often feel that their knowledge and experience is not sufficiently acknowledged or used in health and care planning. Carers contribute to better patient outcomes, continuity and quality of health care, and more efficient use of health resources. A failure in considering the needs of the carer can result in two, not one, consumers of the health system.

Question 2: If not what do you think should be the direction? Please give a clear explanation of why.

While we support the focus on prevention and population health there should be a greater focus in the plan on community health as this is where most health activities will be taking place in the future. Increasing trends towards reduction in hospital stays and provision of health care at home, means that people will be called on to 'self manage' which often involves assistance from a family member or friend (informal carer).

Carers are a vital part of the health care support team. This is a fact which is increasingly acknowledged in international literature (Performance Improvement Advisor, 2004, p58), "Family members that care for patients at home can provide valuable information and feedback to health care professionals. Educating and training caregivers can increase compliance with discharge plans and prevent readmissions. During hospitalisations, caregivers can act as quality monitors, alerting staff to potential costly problems before they happen."

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

Carers NSW believes it is useful to think about three key groups along the health continuum that the health service serves:

- First, the general population, for whom prevention is most important. In addition, we believe that, as per the National Chronic Disease Strategy, prevention applies across the entire health/disease continuum, from people who are healthy to those already living with chronic disease¹.

1 National Chronic Disease Strategy, Australian Health Ministers' Conference, 2005.

- Second, those who are acutely ill, for whom timely, evidence based services are the most important; and
- Third, those with a chronic condition, who are often supported by a carer in their home. For this latter group, increased care available in the community and better carer support is needed

There is considerable uncertainty about whether this can be maintained in the future. The ABS Social Trends (2002, 2003, 2004, 2005) have provided evidence of the changing composition of Australian families which has various implications for carers. These include:

- the low fertility rate
- the increase in lone person households
- the increase in the participation of women in the workforce
- high levels of geographical mobility

Both AIHW (2003) and the National Centre for Social and Economic Modelling (NATSEM), (2004), have considered the future supply of carers. The AIHW, examining the period 2003 to 2013 suggests that the ratio of carers to people with a severe or profound disability is likely to fall from 0.43 carers per 100 people with a disability in 2003 to 0.40 in 2013. This is not insubstantial and will increase as the population ages after 2013.

NATSEM in examining the period 2001 to 2031 finds that the potential total pool of carers will not rise as quickly as those likely to require care. It projects that in this period the number of older people likely to need assistance because of severe or profound disability is likely to increase by 160% whereas the number of people likely to provide care will only increase by 57%.

According to Carers NSW analysis (2005a) of the 2003 ABS Survey of Disability Ageing and Carers (2003b) for NSW key trends from 1998 to 2003 include:

- the number and proportion of older carers (75+) has increased
- there are more ageing carers who have recently begun caring
- the proportion of carers not in the labour force has increased from 61% to 64%
- the proportion of carers caring for 40 hours or more per week has increased
- the high proportion of people with mental and behavioural disorders who need assistance received neither formal nor family assistance.

There are implications for NSW Health. For example, the imperative for early discharge needs to be considered in terms of these trends. Few hospitals actively follow up after discharge or have in place systematic patient feedback processes that provide data on carers experience and outcomes. Similarly, with regard to the treatment of chronic illness there is a trend away from acute settings in favour of self-care or community care without acknowledging that such care frequently falls onto families, and that this can impact on the health and well being of family carers.

In short, there will be an ageing population overall and an increasingly aged carer population. It is likely too, given existing policy trends, that in the longer term there will be a shortage of people available to care. This raises the spectre of the demand for better formal support systems and closer examination of the relationship between formal and informal care.

Question 3: What are the gaps in the document?

Healthy People 2010, does not clearly set out specific outcomes to be achieved or attempt to set targets around particular population groups to achieve better quality health outcomes. The draft plan is lacking in specific goals and measures to improve the living standards of carers as a population group across NSW.

Section 4 Vision: Good health and well being for all people of NSW

This plan does not address the social determinants of health. For carers as a population group identifying these factors is critical in order to address inequities in health access service and provision.

Carers by virtue of their caring responsibilities are at higher risk of developing health problems. Carers are more likely to suffer injuries, chronic diseases, or have poorer mental health than non-carers. They are also more likely to experience stress, social exclusion and workforce exclusion all of which have been found to be poor determinants of health by the World Health Organisation. The draft plan should ensure that as a population group, carers are identified, and that strategies are developed that address carer specific issues and needs.

Carers are consumers in their own right, and their needs for support and services can be separate to the person they are caring for. Carers need time out from their caring role and responsibilities so that they can engage in health promoting behaviour and programs in order to look after their own health and well being.

Section 5 Approach: Population Health Approach

© 5.2 Effective action on the factors that influence health

International research indicates that **carer inclusion** has many benefits to patient quality of care and can reduce readmission rates to acute care facilities. 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 hospital staff should regard carers as a vital resource in the rehabilitation of patients with hip fractures. 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). Other research has shown that carer inclusion in the health care setting can benefit the 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)

Relapse prevention planning involving carers, is vital in order to strengthen primary and continuing care in the community otherwise there is a real risk that future health care in NSW might become unaffordable for the government and the community. Research into carer interventions and support demonstrates that carer inclusion in patient care has a two-fold benefit. Firstly, outcomes for patients are improved; and secondly, carer inclusion can reduce the actual costs to the health system in the long term. Carers are a key partner in the health care team and as such can increase compliance with discharge plans, prevent readmissions and ensure optimal patient outcomes.

© 5.4 Work in Partnership

Carers provide the vast bulk of care. It has been estimated from figures in the AIHW (1999) report that carers provide 74% of the care needs of Australians while Home and Community Care services provide only 9%. Most people want to remain and be cared for in the community; that is, in their own homes (Productivity Commission, 2005). This is also current policy at all levels of government. Family carers carry out by far the greatest proportion of care by hours and value. With proper support, information training and education carers can become a more integral part of the health care team improving outcomes for patients and reducing health care costs. According to Brodarty et al (2003), when there is no carer or the carer is stressed, the likelihood of nursing home admission rises sharply. This study also showed that for carers of people with Alzheimers Disease carer interventions could improve outcomes for carers and patients. A skilful blend of carer knowledge and professional knowledge is essential to ensure optimum levels care. Achieving this synthesis requires health professionals and the health system to work in different ways.

The Population Health Planning document does not address the need for partnerships between General Practitioners, mental health and other health professionals, and community care providers. This is a fundamental aspect of improving outcomes for patients and their carers, as it facilitates smoother transitions between hospital and home.

Section 6 Primary Functions: Promote health, Prevent Disease, Disability and Injury

Carers NSW supports this primary function but would like to see it expanded to include *well being*. Expanding this primary function to include wellbeing recognises the holistic nature of health outcomes, in particular their link to socioeconomic and environmental factors. The key message of chronic diseases, obesity, tobacco smoking, alcohol misuse, oral health, illicit drugs and mental health all require a greater level of analysis. Although these issues affect the whole NSW population, it is certain population groups that are likely to be carrying the burden of these health issues.

Recent international studies (Lee, S et al, 2003; Schulz and Beach, 1999; Schulz et al, 1997; Kiecolt-Glaser J, 2003) have in various ways sought to quantify the effects of caring on carers' health and well-being. They provide further evidence to support the broad findings reached in population-based Australian research (Schofield H et al, 1998) that carers felt more overloaded, had lower life satisfaction and had poorer self-rated health than non-carers. Conclusions reached in the international studies suggest, subject to qualification, that carers have poorer immune system function, increased susceptibility to cardiovascular disease, slow wound healing time, increased incidence of degenerative diseases such as arthritis and a higher use of health care services.

These effects demonstrate two things. Firstly, that carers can become physically and emotionally exhausted influencing their capacity to care and the quality of care they are able to offer. Secondly, that carers will often put there own health and well being after that of the person they support. Yet there is a tendency for the health system to focus on the patient and overlook the carer's health and well being needs. Although it is recognised that the plan does not attempt to identify every initiative, carer inclusion as partners in care, needs to be addressed within this draft strategy.

© 6.2 Create environments that promote health

Aboriginal Health

Aboriginal and Torres Strait Islander people access mainstream health services such as private practice general practitioners (GPs) and the Pharmaceutical benefits scheme (PBS) 80% less that the overall Australian population (DoHA2002). Indigenous people face a

number of barriers to accessing health services, including distance from services, lack of transport (particularly in remote areas, financial difficulties and proximity of culturally appropriate services). The draft plan is lacking in specific goals and measures that will improve the living standards of Aboriginal people and their carers across NSW.

Hospitalisations and Health risk factors

The National Aboriginal and Torres Strait Islander Health Survey, 2004 –2005, stated that, adjusting for age differences, Indigenous Australians were admitted to hospital at 1.3 times the rate of non-Indigenous Australians. They were also two and half times more likely to have visited the casualty or outpatient department of a Hospital (ABS 2006).

Healthy People 2010, does not recognise that Aboriginal and Torres Strait Islander people generally have a higher prevalence of most risk factors which contribute to ill health and premature mortality. The involvement of carers in care throughout a patient's journey is essential to ensure positive outcomes for indigenous families and their communities.

© 6.3 Implement strategies that prevent disability and injury

Injuries are responsible for a large burden of ill health and suffering in our community and are generally preventable. Prevention as it relates to carers involves recognising carers who, by virtue of their caring responsibilities, are a group at high risk of health problems (injuries, chronic diseases and poor mental health).

According to Women's health Australia, (Lee, C and Porteous, J 2002) carers are more likely to report overall health as fair or poor and more likely to report the following six symptoms: back pain, stiff or painful joints, constant tiredness, chest pain, indigestion/heartburn and breathing difficulty. Carers are also more likely to have been admitted to hospital in the past year.

Healthy People 2010, needs to incorporate strategies in each section to more broadly reconfigure our narrow illness focused health care system to one that is inclusive of all the populations, understanding the contexts in which they live and get sick, and acknowledging their difference and their priorities.

Lack of appropriate equipment can also cause carers injury. In the 1999 National Survey of Carer Health and Wellbeing, 34% of carers reported upper body problems. Seventy percent of injuries were due to sprains and strains of joints or muscles (Carers Australia 2000). Therefore Carers NSW is advocating for significant increases to NSW Health Program of Appliances for Disabled People in our 2007-08 pre-budget submission.

The range of care giving situations, diversity of impacts and changing nature of carer needs mean that policies and practices that acknowledge and explore carer needs , are important wherever carers are encountered in the health care system. While the increasing emphasis is being placed on joining up models of care and fostering cooperation between health and community care systems, there is still a need to reinforce the importance of looking at carers needs in a holistic and preventative manner.

Other gaps:

- Population groups from different cultural backgrounds who are less likely than others to access services.

- The need for research for population groups that we have previously known little about. For example the ABS Census 2006 contains data on people requiring assistance and on people providing informal care. This data will be available from December 2006.

Question 5: What do you see as being the most important things that we could do within population health to ensure a healthy community?

One of the most important things that we could do within population health is to create better experiences for people using the health system *and their carers*. Carers NSW often receives feedback from carers that when a person is discharged from hospital, carers are not informed, are told at short notice or are sent home without appropriate supports in place. Because most care happens in people's homes, the strengthening of primary and continuing care in the community is important to assist carers in their role.

In other words, hospital staff assume that carers are able and willing to care when this may not be the case. If proper supports are not in place, carers often struggle to manage at home and may injure themselves in the process. Thus we believe that discharge planning practices, including better partnerships with the community care sector, across the entire health system require urgent attention.

Another issue about which Carers NSW receives regular feedback is the lack of inclusion of carers in the care provided to the patient/consumer. Carers often relate that their knowledge and experience about the person is ignored by health professionals. This not only diminishes carers' efforts, but also can lead to poor quality health care being provided. Because carers often spend 24 hours a day with the person they are supporting and know their history and symptoms, carers can be a valuable source of information for health professionals to draw on when making a diagnosis, assessing medication regimes and understanding changes in a person's condition. Ambivalent and sometimes negative attitudes towards families by health professionals (especially in hospital settings) can prevent the inclusion of informal carers in the discharge planning process.

In addition, carers require information from health professionals on illnesses, symptoms, medication, side-effects, and the prognosis of the person they are supporting, especially where they are actively involved in managing the person's care at home. The experience of carers using the health system will be much improved if all health professionals view carers as part of the health care team and include them in decision-making. The basis of such inclusion is *good communication*: health professionals who listen, convey information sensitively, are empathetic, ask appropriate questions, explore carers' needs and treat carers (and patients) with respect.

Question 6: What are the future challenges and opportunities that you believe are important over the next five years for population health?

The Population Health Planning plan identifies the increasing demand for informal carers as a current pressure and future challenge (p7). However, there is no detail or broad strategy in the document regarding how NSW Health believes this issue should be addressed. Yet the implications of this future trend are significant for both carers, consumers and the public health system.

The economic and social imperatives (as outlined in the "Fit for the Future" document) moving our health system towards the need to contain costs means that family carers are likely to shoulder an even greater proportion of care in the future. 'Hospital In the Home' schemes, a greater proportion of day surgery, increased chronic illness and fewer health

professionals means that carers will be even more crucial to our system of health care in the future.

Apart from reducing the likelihood that people become carers through health promotion and prevention, the health system needs to better engage with carers and to ensure that they are supported in their role. This can be done better at both a system-wide level and at an individual health practitioner level. Every Area Health Service needs to have mechanisms in place to involve carers in planning and to receive regular feedback and evaluation from them. Individual practitioners can better engage with carers by seeing the support of carers as a key part of their role in delivering health care to consumers.

On the issue of access to health services, *timeliness* can impact significantly on carers. Timely access to health care can prevent deterioration of certain health conditions and can minimise the impact of health crises. Both of these in turn have an effect on the level of disability of consumers, which in turn impacts on the level of care which has to be provided by carers.

Carers are very often the 'care managers' for their relative, playing a large part in managing a person's appointments, transporting them to and from those appointments as well as accompanying them. This can be extremely time-consuming and, at times, frustrating for carers. Co-ordination of services needs to occur not just *within* the health system but *between* the health and community care sectors as well.

Consumers face additional costs due to ill health and carers have increased costs due to caring. Carers, as a group, tend to have lower incomes than non-carers⁷ and therefore the *cost* of health services, a major issue in equity of access, impacts on carers and the people they are supporting. Carers NSW considers it essential that public health services remain free of charge, especially for disadvantaged groups such as Aboriginal and Torres Strait Islander people.

Costs impacts on carers (and consumers) in three ways: first, travelling long distances increases the amount of time that carers have to devote to caring work. Second, cost is also increased with longer travel distances. Third, if carers cannot accompany consumers for in-patient treatment their capacity, and that of other family members, to visit is compromised. Most people want contact with their carers and/or family while receiving in-patient treatment.

Equity is particularly important for Aboriginal and Torres Strait Islander communities, where there is a higher likelihood of people having caring responsibilities due to poorer health (although statistics on this are not currently available). Given the well-documented differences in the health status of indigenous and non-indigenous Australians, better equity and cultural appropriateness in the delivery of health services will hopefully lead to more equitable *health outcomes*.

Conclusion and Recommendations

Another point to consider is how we will know if the NSW health system is achieving its goals. We urge NSW Health to develop and implement health outcomes measures within the strategy so that it can assess whether the health system is making progress towards its

⁷ Australian Bureau of Statistics (2004), "Survey of Disability, Ageing and Carers: Summary of Findings", Cat. No. 4430.0, Canberra.

goals. We believe that such measures should be developed in conjunction with the community, allowing it to determine what it defines as success with respect to health outcomes.

Recommendation 1: That the NSW Carers Program and development of a NSW Carer Policy be included in the Population Health Plan for NSW as carers are a key population group requiring support.

Recommendation 2: That the Population Health Plan for NSW includes people in rural and remote communities as a significant population group particularly in terms of equity of health care and services.

Recommendation 3: That the Population Health Plan for NSW looks at flexible workplace practices and other measures that enable people in the health care industry to balance work and care.

Recommendation 4: That the Population Health Plan for NSW takes a leadership role in developing best practice Health Carer policies for employees.

Recommendation 5: That the Population Health Plan for NSW includes strategies for education and training of health professionals about carer inclusion and better support for carers.

Recommendation 6: That the Population Health Plan for NSW develops strategies that facilitate smooth transitions between hospital and home.

Recommendation 7: That the Population Health Plan for NSW develops strategies around better partnerships between acute care, primary care and community care

Recommendation 8: That the Population Health Plan for NSW includes in its vision preventative strategies to tackle the social determinants of health.

Recommendation 9: That the Population Health Plan for NSW includes strategies for carers and consumers to contribute to planning, development, implementation and evaluation of health processes and services.