Carers NSW
AUSTRALIA

Comments on the draft NSW Integrated Primary and Community Health Policy

Carers NSW firstly wishes to congratulate NSW Health on this important policy development work. We welcome the invitation to give comments on this draft document and wish to highlight a number of areas where we feel that the interests of carers and the community care sector should be incorporated in this policy.

We have also included the issues paper written by Carers NSW for the Health Futures Planning Process in 2005 as an appendix to this submission. The Health Issues paper contains supporting evidence for the recommendations made herein.

We support the objectives of this policy which include improving the integration and coordination of care for consumers in the community through improved integration within primary and community health and between primary and community health and general practice, acute sectors and population health sectors.

Our comments on this policy include carers and the health system generally and specifically carers and the Integrated Primary and Community Health (IPaCH) policy, the framework for action and interface of the policy with other aspects of community care.

1. Family Carers and the Health System

A carer is a family member or friend who supports someone with a disability, mental illness, chronic condition or who is frail aged. Carers are not paid for the support they provide which may range from full-time care including administration of medication and other health-care tasks to more intermittent support. The length and intensity of support that carers may provide varies significantly.

"From the perspective of the public health system, some carers could be providing care for a short period following patient discharge from a serious operation; others might need to provide care following hospitalisation on a continuing basis for the foreseeable future; others may have been caring for the person requiring hospital treatment for years prior to hospitalisation and will continue thereafter; others provide ongoing care between admissions; still others provide care for people requiring ongoing outpatient treatment or community health services, for example people with chronic mental illness" (Appendix).

Carers are not recognised in the IPaCH document for either their role as part of the health care team or for their own support needs. For this reason we wish to raise the following issues in regards to carers and the health system for consideration in further development of this policy.

Carers have been referred to as the "hidden army". There are at least 750,000 carers in NSW, which are people providing significant amounts of unpaid care and support to people living in the community. They constitute a central pillar in primary and community health

care systems as they enable continued care at home, particularly for people with complex health care needs.

Lister (2005) considered a plausible future for carer support in 2025, in a paper written for the NSW Health Planning for the Future process. In it he supported that, looking from the perspective of 2025, "informal care was given more recognition, support and funding".

Policy frameworks developed in the health sector must recognise the vast proportion of health care that is provided by family members and friends in the community without pay and often very little support now and increasingly in the coming decades.

Consumers or patients *and* their carers have distinct and often separate support needs in the health sector. **By supporting consumers it cannot be assumed that carers are also being supported.** For instance, a carer may require specific training if the medical needs of the person they support in the community change or increase. They may require referral to other supports that are specific to carers including provision of emotional support or respite for assistance to take breaks from their caring role.

Current trends in the health care system in Australia that affect the role of carers and lead to increased reliance on carers. Some of these are identified in the draft IPaCH policy document, including:

- The limited capacity of acute care systems which leads to increasingly early discharge from hospital;
- Population ageing means that an increased proportion of the population requires care;
- Workforce shortages in the health care system lead to greater reliance on carers.

In addition, the current limited capacity of the community care system can lead to increased responsibility on family carers. An example identified by Grimmer et al (2004) was limited availability of access to long term residential care places which can lead to premature return of an aged person from acute care back to the community. Carers NSW often hears that the lapse between discharge and the establishment of community services to assist them at home causes significant stress and disadvantage.

NSW Health listed reasons why it should be an aim of the NSW Health system that 'by 2025, admissions to hospital will only be for surgery, intensive care and emergencies' (NSW Health 2006 p3). This will have a clear and significant impact on families as the vast majority of health care will take place in the home and the community.

As identified in the accompanying issues paper 'Carers and the Health System', family carers are not only integral to the care of people going through the health system, they play a central role in the health care team. The issues paper identifies previous research demonstrating ways in which support for, and inclusion of family carers can lead to improved outcomes for the patient in the health care setting (see Appendix).

The Carers NSW Health Issues paper also identifies three key issues that carers raise in relation to the health system. These are:

- The need for health professionals to understand the role of carers;
- The need for inclusion of carers, as appropriate, throughout the patient journey;
- The need for a smooth transition between acute and community care.

This third point is vital to the current policy development on integrated primary and community health sectors. In order to provide integrated care to individuals, the transitions between sectors of acute, primary and community health and community care should be seamless and well coordinated.

Carers NSW agrees that there is a need for an Integrated Primary and Community Health Policy in NSW. The important role of family carers must not be overlooked in such a policy.

2. Carers and the Integrated Primary and Community Health Policy

There is a notable absence of carer recognition in the draft IPaCH policy document, as previously mentioned. For the reasons given above it is necessary to recognise both the role of carers and their need for support in addition to, and distinct from, consumers.

It is recognised that shifting the emphasis of care into the community setting will improve the capacity of the health care system in the face of increasing disease burden from chronic health conditions. It is also acknowledged that primary and community health care can reduce the need for expensive in-patient care.

However there is still a considerable cost associated with shifting care into the community setting. Many family carers shoulder the cost of caring in their own homes. This may be through direct costs associated with the caring role such as transport costs, heating or cooling for the comfort of the person they are supporting or purchase of medical supplies or indirectly their limited access to employment and education opportunities while they are caring.

These costs can be considerable. While families may recover financially if they are caring only for a short period of time, for many families the caring role is extensive and involves many transitions in and out of acute, primary and community health care as well as community care.

A recent study prepared for Carers Australia by StollzNow (2005) of sole parent carers (supporting a child with a disability) found that 45% of households surveyed spent more than 20% of their income on medical costs for disabled children.

If the policy focus on community health care is to increase there must also be recognition in the policy document that increased resourcing will need to be committed to the community health care sector in order for implementation to be feasible.

3. Framework for Action

Consumers and family carers are key stakeholders in the development of policy and service delivery standards for primary and community health. Carers' interests and needs should be incorporated into the values and operating statements of this policy. While carers' needs are often conflated with consumers', they sometimes have distinct needs which should be taken into account.

As such, carers should be consulted and considered in the proposed indicators for the IPaCH policy (NSW Health 2006, p13-19). In particular, carers have an interest in the following areas:

- Integrated service planning – consumer and care interests must be considered in planning processes, in particular where mechanisms such as single point of entry are

being considered in order to facilitate access to the primary and community health sectors.

- Integrated service delivery – NSW Health may consider consulting consumers and carers to identify opportunities for improvements in delivery of services, as well as GPs and other providers of health and community care.
- Improved models of care – any model of care used must recognise the role of family carers in the health care team (as previously noted).
- Partnerships – recognition of carers in health and community care partnerships is crucial to the success of effective integration of health and community sectors. Partnerships between Area Health Services and carers in ensuring effective and successful discharge planning as well as other joint service planning is key to an integrated health care system. Experience from Victoria has demonstrated that poor discharge practice can lead to compromised patient health and recovery and undue stress for family carers (Muldowney et al 2004).

Carers NSW recommends that the effectiveness of the new policy could also be measured from the perspective of consumers and their carers. Current indicators do not adequately measure the satisfaction or outcomes from the users' point of view but are more systems-focussed. **It would also ensure that care needs are not being deferred to other sectors because families are unable to cope with intensive care at home and in the community.**

4. Community care

While it is recognised in Appendix 1 of the draft IPaCH policy document that the primary and community health sector has insufficient links to community care providers, it is not clear elsewhere in the policy document how this will be addressed. The impacts of community health care on families have already been discussed. These include financial and physical stress resulting from a lack of support when caring for someone at home. Community care services (including in-home support services) are often required in conjunction with primary and community health services to ensure adequate care and support.

For carers this may involve respite care as well as other support services including home care, home modifications or assistance with transport. Navigating these services can be equally as challenging as navigating the health care system. Therefore by introducing a framework for stronger links and partnerships with community care providers the IPaCH policy would have greater benefits for consumers and their family carers.

5. Conclusions and Recommendations

Carers NSW supports the broad intentions of this policy development by NSW Health. This policy, appropriately developed, has the potential to benefit consumers and their family carers significantly. By employing strategies to reduce the barriers to accessing the primary and community health sectors and facilitating integration between primary and community health and other parts of the health sector this policy has the potential to set an improved framework for better integration of the health care system.

The recommendations we have made here reflect the important role that family carers play as part of the health care team. We have emphasised the importance of recognising the work they do and support they need in improving health outcomes in the community. We have recommended that the distinct needs of consumers *and* their carers be recognised consistently throughout the IPaCH policy document.

We have outlined areas of the policy document where the needs of carers could be better represented and areas of practice where carers should be included. We have also reiterated the importance of NSW Health and Area Health Services having strong links with community care services to provide holistic support to families. In the interests of a more effective integration of primary and community health services, the involvement of carers and consumers as partners in health care is a vital conceptual and practical development.

References

Muldowney and Nankervis (2004) 'Improving Hospital Discharge Outcomes for Patients and Family Carers: Key Issues and Experiences from Victoria', in Carers NSW 2005 *Shifting Paradigms in Health Care: Leading Practice in Carer Support*.

StollzNow (2005) *A crisis in caring, or a system that works?*, prepared for Carers Australia

Grimmer et al (2004) 'Carers' Perspectives on their Role in the Discharge of Ill Elderly People from the Acute Hospital Setting to the Community', in Carers NSW 2005 *Shifting Paradigms in Health Care: Leading Practice in Carer Support*.

NSW Health (2006) *NSW Integrated Primary and Community Health Policy 2006-2008*, Consultation draft 12 January 2006

Carers NSW (2005) *Carers and the Health System: Issue Paper*, available at carersnsw.asn.au (attached as appendix)

Carers and the Health System

Issue Paper

2005

Carers and the Health System

Issue Paper prepared by Carers NSW

1. Introduction

The Australian health and community care systems increasingly rely upon family, friends and neighbours who provide unpaid care and support to children and/or adults who have a disability, mental illness/disorder, chronic condition or who are frail aged. The creation of the Health Futures Planning Project offers a welcome opportunity to consider the relationship between these unpaid carers in NSW and the NSW public health care system in terms of key goals such as healthier people and quality health care.

NSW Health's Future Planning Project is particularly timely given the increasing body of research evidence pointing to: i) the effect of carers being part of the health care team on patient outcomes; and ii) the effects of caring on the health and well-being of carers which, in turn, can have important repercussions. Finally, this opportunity arises in a context where increasing emphasis is being placed on joining up models of care, particularly with regard to fostering co-operation between health and community care systems.

2. Major trends, challenges and future shaping forces

Current Carer Situation in NSW:
According to Australian Bureau of Statistics (ABS,2003a), 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

Each caring situation is unique. Some carers need to assist with the tasks of daily living, and are responsible for feeding, bathing, toileting, dressing wounds, administering medication, and managing incontinence, diabetes and other conditions. Others care for people who are fairly independent but need supervision or help with their finances and/or transport. Carers may also provide emotional support day in and day out for some of the most vulnerable and isolated members of society. Many carers spend substantial amounts of time on caring tasks; 45% of primary carers provide care for 40 hours or more per week. From the perspective of the public health system, some carers could be providing care for a short period following patient discharge from a serious operation; others might need to provide care following hospitalisation on a continuing basis for the foreseeable future; others may have been caring for the person requiring hospital treatment for years prior to hospitalisation and will continue thereafter; others provide ongoing care between admissions; still others provide care for people requiring ongoing outpatient treatment or community health services, for example people with chronic mental illness.

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." 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). It is a fact, however, which 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).

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.

While caring can provide considerable satisfaction and strengthen relationships, carers often feel exhausted, isolated and overwhelmed by their responsibilities. In a survey of carers conducted by Carers Association of Australia (2000) 58% reported that their physical health had been adversely affected, a third said that they had sustained a physical injury, and over half reported depression, anxiety, high levels of stress and other impacts on their 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.

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 their 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 support and health needs.

With a median weekly income of just $224 per week (compared to $435 for non- carers) carers as a group is at great risk of being in poverty. Over half of all primary carers rely on a

government payment as their principal source of income and almost a quarter are in the lowest income quintile in NSW (ABS, 2003a). There are numerous Australian studies that have also investigated the social impacts and health risks of carers as they can be forced to give up employment and forego community participation with increasing risk of social isolation (SPRC, 2004).

Appropriate support to carers can minimise the costs of caring to individual carers but also support the quality of life for the person being cared for.

2.1 Major Trends

The ageing of the Australian population is a demographic reality. According to the Productivity Commission (2005) the effects over the next 40 years will be pronounced. One quarter of the population will be aged 65 years or more by 2044-45, roughly double the present proportion of the population in that age cohort. The proportion of the oldest old (85 years and older) will increase even more, from 1.5 to 5 per cent over this period.

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

Disease and injury projections for NSW over the next twenty years demonstrate that there will be some significant trends in the incidence and prevalence of certain conditions and diseases a number of which are related to the ageing of the population (NSW Health, 2005). Cancer (particularly lung cancer in women), diabetes (relating to obesity) and mental disorders including anxiety disorder, drug and alcohol dependence and major depression are all projected to rise in incidence and/or prevalence in NSW. Associated with ageing, the incidence of injury as a result of falls is projected to increase by 94%. The prevalence and incidence of cardiovascular disease is projected to remain fairly constant and chronic obstructive pulmonary disease is projected to decline, however, the prevalence of these conditions will remain significant. For many of these conditions assistance is required with a range of tasks including direct personal care and physical assistance, administration of medication, supervision or transport.

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. By far the greatest proportion of care by hours and value is carried out by family carers.

There is considerable uncertainty about whether this can be maintained in the future. The ABS Social Trends (2002, 2003, 2004) has 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.

The are implications for NSW Health. For example, the imperative to early discharge needs to be considered in terms of these trends. 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.

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

2.2 Challenges

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

The key overall challenge for NSW Government in general and NSW Health in particular is therefore to find appropriate ways of supporting family carers over the next fifteen years and onwards in light of the abovementioned trends and to reach all carer populations with this support. An important aspect of this challenge will also be to ensure that alternative care is available for those without carers or where people are no longer able or willing to care.

i. Supporting carers

Carers NSW over the past twenty five years has identified the key components of carer support and the principles to guide effective carer support (Carers Support, 2003).

Key principles to guide effective carer support 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
- responsive and accessible systems
- culturally appropriate approaches
- using innovative and/or IT based methods of delivery of support
- understanding the impact of caring responsibilities on the life stages of carers and those they support.

At a minimum most carers need:

- relevant information that is timely and accurate about the supports and assistance available to carers and those they support
- emotional support
- respite
- education and training
- services that are flexible and appropriate
- increased financial assistance.

Recent research emerging from the Carers NSW Mental Health Project (2001-2005) indicates that it is not sufficient merely to provide this support but the support must be tailored to individual carer needs, taking into account when and how carers need it. The report (Carers NSW, 2005b) focuses on the development of a theoretically and empirically based framework that can be used as a practical tool to ensure that carers of people with a mental illness/disorder receive appropriate information and support interventions depending upon their place in the caring journey, their life course/life stage, and their relationship to the person with a mental illness/disorder. There is now scope to examine the applicability of the framework beyond the area of mental health.

A key challenge for NSW Health is to develop a framework for carer support across the health sector in collaboration with other agencies. Key values underpinning support would include: equity, so that carers are supported regardless of the nature of the disability, illness/disorder or chronic condition of the person they support and that they will receive this support no matter where they live in NSW; and continuity of that support to maximise engagement and minimise the stress and anxiety of carers. This framework would need to take into account the practice, service wisdom and research noted above but also some of the specific issues that carers raise with respect to the health system.

Specific issues that carers raise with respect to the health system:

First, the need for health professionals to understand the vital role of carers, what carers do and the impact caring can have. The complexity of the hospital system and community service systems means that there can be a lack of understanding about carers and awareness of the toll that caring can take. It can also lead to misunderstanding about the availability of support to carers.

Second, the need for inclusion of the carer, as appropriate, throughout the patient journey. The pressure within hospitals is toward clinical and technical health delivery which can mean that carers are viewed as extraneous to the process, notwithstanding that the non-hospital and health care for the patient will often reside with the family. Carers frequently do not receive the information, education and training that they need. At every level of the health

system carers need to be identified and supported whether it is at the birth of a child, diagnosis of a condition, the end of life, or at any stage throughout.

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

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

ii Reaching all carers

As noted above, according to the ABS there are at least 748,000 carers in NSW although Carers NSW, using research carried out by the Social Policy Research Centre (SPRC, 2004) considers this to be an underestimate.

It is the case that many people carrying out caring duties may not identify as carers. This means that they are not known as carers to any agencies or services and therefore receive no "formal/documented" support in their caring role. The danger contained in this to NSW Government and NSW Health, given the commitment to healthier people in NSW, is clear in light of the known impacts of caring.

Given the previously noted trends certain specific groups will need particular attention in any carer support framework, notably carers from culturally and linguistically diverse backgrounds, Aboriginal and Torres Strait Islander carers, male carers, young carers, remote carers and those with multiple caring responsibilities.

The number of carers from culturally and linguistically diverse backgrounds is already significant and is likely to increase in proportion over the next ten years. Services and support will need to be tailored accordingly, with due attention given to the diversity contained within this group.(Carers NSW and Multicultural Mental Health Australia, 2004)

Aboriginal and Torres Strait Islander carers as a group have some of the worst indicators of health. According to the ABS (2003) it is widely acknowledged that Aboriginal and Torres Strait Island people have substantially worse socio-economic and health indicators than the rest of the population. Higher hospitalisation rates require a family centred response from health services and one that is supportive not only of the patient but the whole care situation. There is also a higher rate of disability among the Aboriginal and Torres Strait Islander population.

Men currently comprise a significant proportion (46%) of all carers, although only 28% of primary carers. The growth in male carers is a significant trend and is likely to strengthen in tandem with the increasing longevity rates of men. The scenario of men caring for their spouses is likely to grow. The work of Ussher and Sandoval (Ussher and Sandoval, 2005) confirms that supportive interventions to cancer carers need to be tailored according to their gender.

There are currently 90,200 young carers under 25 in NSW, accounting for 4% of all people under 25 (ABS, 2003a). The increase in sole parent households (mostly single mothers) who comprised 15.4% of all Australian families in 2000, increases the likelihood of children and young people having significant caring responsibilities in families due to the absence of a partner, currently the greatest providers of care. According to the Carers Australia Young Carers Summit Report 2004, young carers need to feel recognised and acknowledged in the health system and assisted in finding services and being supported.

Access to health services is generally lower in rural and remote areas in Australia and about one third of carers in NSW live outside of capital cities. According to the AIHW (2005), there is a low prevalence of health professionals in regional, particularly remote, areas. It also found that in order to address this many clinicians work long hours and spend substantial amounts of time travelling. Where clinicians do not travel it is probable that carers will be required to provide transport.

The key overall challenge is therefore to develop a framework for carer support across NSW Health which takes particular heed of a range of population groups in light of demographic trends and/or social determinants of care. Underpinning this is the need to ensure that the best quality health care is delivered to patients and the health of carers in NSW is not undermined because of their caring role with consequences to both themselves and the public health system.

2.3 Future Shaping Forces

Many national studies (Intergenerational report, 2002; Economic Implications of an Ageing Australia, 2005) have been carried out with regard to the ageing of the population in particular, with a significant amount of attention given to implications for health costs. It is beyond the scope of this paper to reprise these discussions other than to note that the costs to NSW Health are clear.

According to NSW Treasury (2004):

- on average, an older person uses hospitals at four times the rate of a younger person
- it is estimated that, on any one day, some 51% of public health patients are over the age of 65 years.

Demographic change is taking place in a national and international environment in which consumers', patients' and carers' participation in health care is increasingly acknowledged. Graham Lister (2005, p4) writing from the perspective of 2025 imagines that, "(In 2025)[t]here 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."

In NSW there exist fragments of support to carers throughout the health and community care systems which will need to be brought together to develop an overarching framework across Government, and particularly across health. For example, there is a NSW Government Carers Statement and within the health system there is a NSW Carers Program. Both are extremely limited in scope and application and funding base but do provide a basis for future discussion.

3. Analysis of options for future directions

3.1 Recognition of carers

Acknowledging the contribution of carers to the community, acute and residential care sectors is an important beginning point for carers.

Within NSW Health there can be a lack of understanding at all levels of the role of carers in a range of settings and the impact of caring on a carer's own health and wellbeing as well as that of the person they care for.

In particular, carers often feel that their knowledge and experience is not sufficiently acknowledged or used in health and care planning.

A NSW Health carer policy – flowing from a whole-of-government carer policy – would provide a basis for recognition and map out appropriate supports.

3.2 Participation and representation of carers

Carers and their representative bodies need to be meaningfully engaged by NSW Health at all levels with respect to issues that involve and impact on them.

For instance, carers and their representative bodies will need to participate in planning, service delivery, policy and decision-making.

To do this carers will need to be represented throughout NSW Health.

NSW Health needs to develop a Carer Participation and Representation policy that runs across the entire department.

3.3 Framework for carer support

Central to the motivation for the development of a framework for carer support is the demonstrated need for carer inclusion, especially in care planning and discharge planning. Assumptions about a carer's capacity, confidence and willingness and indeed ability to provide care at home needs to be avoided. The carer's own physical and psychosocial health needs will need to be discussed and assessed. It cannot be assumed that the needs of carers are static and it should be recognised that these needs will change over time.

The principles included in the Royal Australian College of General Practioners Guidelines (2000) are a useful starting point for care planning. The NSW Primary Care Reference Group (Graham et al, 2004) has further developed these guidelines with a view to maximising patient and carer participation in health assessments and care planning. Amongst others, patients should be actively encouraged to include a family member, carer or advocate prior to assessment or in the process of developing a care plan. As the above paper notes (Graham, 2004, p2), "Of overarching importance is that there should be good and regular communication not only between the general practitioner, the patient and the patient's carer/advocate but also between the general practitioner and other relevant service providers."

With regard to discharge planning, consideration will need to be given to information provision and education for carers. Carers cannot be expected to know what to do once the person they are expected to care for returns home. For example, a carer may not know how

to lift properly. Failure to know this information may result in injury to patient and /or carer and the ability to provide care.

According to the Health Professionals Conference Report (Carers NSW, 2005c), inclusion could be furthered through pre-service and in-service education for health professionals on the following:

- understanding and acknowledging the role of carers
- promoting family conferencing in discharge planning
- listening to carers' needs, more open-ended questions and time
- partnership development
- appropriate and timely links to other services

It is important to acknowledge that information, training and policies do exist within the health care setting relating to care planning and discharge planning as noted above. However, there is no coherent framework of carer support that brings together these fragments of support and locates them within a vision of carer support incorporating the support carers need and how this will change over time. As noted in section 2.2.i above, a framework of carer support would need to be developed in terms of principles, values and minimum standards. Finally, according to Access Economics (Access Economics, 2003) carer support has demonstrable human and economic benefits.

To deal with the issues of inclusion and support in a systematic way NSW Health will need to develop a Carer Support Framework.

3.4 Interface Issues

Continuity of care from acute to home settings is a key issue for carers. It can be improved through greater coordination across community care, acute care and residential care and between health, ageing, disability and other key sectors. The effects of greater integration will benefit carers in accessing a range of services, not least in accessing appropriate equipment and transport.

Recognition of the need to improve the interface between NSW departments has also been addressed by the Department of Disability, Ageing and Home Care in their planning for the future of the Home and Community Care Program. The minutes from the February 2005 HACC Statewide Stakeholder Planning Forum identify, as a medium term strategy, the need to "strengthen strategic partnerships with other agencies including NSW Health, WorkCover Authority, Office of Fair Trading, Ministry of Transport and the Australian Government Departments of Health and Ageing and Veterans' Affairs".

Continuity of care from acute to home settings is required in regard to assessment, responsive services, carer-friendly services, monitoring and review.

3.5 Workforce Issues

In light of the Anti-Discrimination Amendment (Carers' Responsibilities) Bill 2000, part of the Anti-Discrimination Act 1977 (NSW), NSW Health should develop a policy for employees who are also carers. A study of working carers in the Greater Southern AHS by Roshier-Taks and Whyte (2005) highlights carer friendly work practices in NSW Health and the particular issues carers are faced with regarding the prevalence of part time and casual work amongst carers in the health workforce.

4. Recommendations

4.1 The options identified above, namely a NSW Health Carer policy, a NSW Health Carer Participation and Representation policy and a NSW Health Carer Support Framework, are incorporated in the Futures Planning Process of NSW Health informed by current initiatives and existing information
4.2 The issues and concerns raised by carers and families are considered and integrated into the recommendations across all issue papers being developed for NSW Health
4.3 Improved NSW Health data collection which always includes carers and consumers and reporting to outcomes for both
4.4 Further research on best practice carer support and subsequent policy development
4.5 Education and training for health professionals in carer inclusion and support and for carers
4.6 A NSW Health Carer Policy for employees.

5. Discussion prompts

5.1 If you agree that carers and families are a vital part of health care how can partnership with them be better achieved?
5.2 What are the steps that should be taken to build a framework of carer support?
5.3 How can better mechanisms for carer support be developed and integrated in NSW Health?
5.4 How can a better fit be established between the medical model of care on the one hand and the consumer and carer model on the other?

6. References

Access Economics, 2003, The Dementia Epidemic: Economic Impact and Positive Solutions for Australia, Alzheimers Australia, Canberra

Ageing and Disability Department and NSW Department of Health, 1999, NSW Government Carers Statement

Australian Bureau of Statistics 2003a, Survey of Disability, Ageing and Carers, Summary of Findings, NSW Tables, Canberra

Australian Bureau of Statistics 2003b, Survey of Disability, Ageing and Carers, Summary of Findings, Canberra

Australian Bureau of Statistics, 2002, Australian Social Trends, Canberra

Australian Bureau of Statistics, 2003, Australian Social Trends, Canberra

Australian Bureau of Statistics, 2004, Australian Social Trends, Canberra

Australian Bureau of Statistics, 2003, Overcoming Indigenous Disadvantage, Canberra

Australian Institute of Health and Welfare, 1999, Australia's Welfare, Canberra

Australian Institute of Health and Welfare, 2000, Disability and Ageing Australian Population Patterns and Implications, Canberra

Australian Institute of Health and Welfare, 2003, The Supply of Informal Care 2003 to 2013: Alternative Scenarios, Canberra

Australian Institute of Health and Welfare, 2005, Rural, Regional and Remote Health: Indicators of Health, Canberra

Australian Government, 2002, Intergenerational report, Canberra

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

Briggs H, Fisher D 2000, Warning: caring is a health hazard, Carers Association of Australia, Canberra

Brodarty, H, Green, A and Koschera, A, Meta-Analysis of Psychological Interventions for Caregivers of People with Dementia, Journal of the American Geriatrics Society, 51, 2003

Carers Association of Australia, 2000, Warning: caring is a health hazard, Carers Association of Australia, Canberra

Carers Association of Australia, 2004, Young Carers Summit Report, Canberra

Carers NSW, 2003, Carer Support, Carers NSW, Sydney

Carers NSW and Multicultural Mental Health Australia, 2004, In their own right – assessing the needs of carers in diverse communities, Sydney

Carers NSW, 2005a, Carers News Survey Analysis, Carers NSW, Sydney

Carers NSW, 2005b, Carer Life Course Framework: an Evidence-Based Approach to Effective Carer Education and Support 2005

Carers NSW, 2005c, Report on Conference, Shifting Paradigms in Health Care: Leading Practice in Carer Support Conference

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

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

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

Kiecolt-Glaser J, 2003, Proceedings of the National Academy of Sciences, 100 (15) July

Lee, C and Porteous, J, 2002, Experiences of Family Caregiving among Middle Aged Australian women, Feminism and Psychology, vol 12, no.1

Lee, S et al, 2003, Caregiving and risk of coronary heart disease in US women, A prospective study, American Journal of Preventative Medicine, vol 24.

Lister, G, 2005, Hopes and Fears for the Future of Australian Health –Scenario for Health and Care in 2025, NSW Health, Sydney

National Centre for Social and Economic Modelling (NATSEM), 2004,Who's Going to Care: Informal Care and an Ageing Population, Carers Australia, Canberra

NSW Health 2005, The NSW Health Care System: An Overview, Sydney

NSW Primary Care Reference Group, 2004, Maximising Participation of the Patient Principles in Health Assessments and Care Planning from the Patient and Carer Perspectives, Sydney

NSW Treasury, 2004, NSW Government Submission to Productivity Commission Research Study into Economic Implications of an Ageing Australia, Sydney

Performance Improvement Adviser, 2004, Caregivers can play a vital role in reducing readmissions, 8 (5): 58-60

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

Roshier-Taks, M and Whyte, J, 2005, Carers in the workplace: Caring for those who care, Conference Proceedings, Shifting Paradigms in Health Care: Leading Practice in Carer Support, Carers NSW and NSW Health, Sydney

Schofield, H et al 1998, Family Caregivers: disability, illness and ageing, Victoria

Schulz, R and Beach, S, 1999, Caregiving as a Risk Factor for Mortality: The Caregiver Health Effects Study, Journal of the American Medical Association, vol 282, no 23.

Schulz et al, 1997, Health Effects of Caregiving: The Caregiver Health Effects Study: An Ancillary Study of the Cardiovascular Health Study, Annals of Behavioural Medicine, vol 19, no.2

Social Policy Research Centre, 2004, Identifying isolated carers contacting carers with unmet needs for information and support, Sydney

Ussher, J and Sandoval, M, 2005, Gender Issues in the Experience of Cancer Care: A comparison of male and female cancer carers living in NSW, Conference Proceedings, Shifting Paradigms in Health Care: Leading Practice in Carer Support, Carers NSW and NSW Health, Sydney

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