



Anne Cumming
Principal Policy Officer
NSW Dementia Policy Team

6 August 2010

Re: The NSW Dementia Services Framework 2010–2015 Draft

Dear Anne Cumming,

Carers NSW welcomes the opportunity to comment on the *NSW Dementia Services Framework 2010-2015 Draft*. As the peak body representing carers in NSW, Carers NSW was pleased to have been involved in early discussions and consultations to develop the framework. Carers NSW has particular interest in how the NSW Department of Health, in partnership with Ageing, Disability and Home Care Human Services NSW, are planning future service provision for both people with dementia and their carers. It is gratifying to see that there is a commitment by the NSW Government to address the growing dementia epidemic and how it impacts the family members and friends who currently, and will increasingly be called upon in the future, to support people with dementia.

This submission will provide some feedback on the Framework.

About Carers NSW

Carers NSW is the peak organisation for carers in NSW. It is a member of the national Network of Carers Associations and has an exclusive focus on supporting and advocating for all carers in the state.

The core work of Carers NSW is to:

- Be the voice for carers in NSW
- Undertake research, policy development and advocacy
- Provide carer services and programs
- Provide education and training for carers and services providers
- Build capacity in the sector.

Carers NSW vision is that caring is accepted as a shared community responsibility and that all carers in NSW are recognised, valued and supported by their communities and by governments.

The goal of all of the work Carers NSW undertakes is for carers in NSW to have improved opportunities and access to services that meet their needs regardless of their age, gender, circumstances, location or cultural and linguistic backgrounds.

Who Carers NSW represents

Carers NSW defines a carer as any individual who provides unpaid care and support to a family member or friend who has a disability, mental illness, drug and alcohol dependencies, chronic condition, terminal illness or who is frail.

Carers come from all walks of life, cultural backgrounds and age groups. For many caring is a 24 hour job that is often emotionally, physically and financially stressful. Across NSW there is an estimated 750,000 carers, comprising individuals as young as 8 years of age through to the very elderly.

Key statistics about caring in NSW

According to statistics on carers from the Australian Bureau of Statistics 2003 Survey of Disability, Ageing and Carers (SDAC):

- Approximately one third of all carers in Australia live in NSW
- 40 per cent of primary¹ carers cared for a partner, 29 per cent for a child, 32 per cent for other (eg sibling, parent)
- Women aged 45-54 years were the largest single group of carers
- 45 per cent of primary carers provided 40 hours or more care per week on average
- 78 per cent of primary carers lived with the person they supported
- 75 per cent of carers were of workforce age although 45 per cent were not in the workforce
- 55 per cent of primary carers relied on a government allowance or pension as their principal source of income²
- 4 per cent of all people under 25 (90,200) in NSW are young carers.

Submission Format

This response addresses aspects of the *NSW Dementia Services Framework 2010-2015 Draft* in regards to how carers are recognised, and the way in which their needs are addressed through future development of dementia policies and service provisions.

Carers NSW comments on the NSW Dementia Services Framework 2010-2015 Draft

Dementia is a growing epidemic. In Australia it is projected that the number of people who have dementia will increase from approximately 230,000 in 2008, to over 730,000 in 2050.³ As the epidemic progresses there will be a greater need for care for people with dementia from formal care services and from carers.

The majority of people with dementia are cared for at home by a family member,⁴ with 37 per cent of people with dementia receiving no formal care.⁵ Access Economics has estimated that the cost of replacing carers of people with dementia with formal care services at \$5.5 billion per annum.¹ It is clear that recognition and support of carers must be essential elements in the design of future service provision for the person with dementia and the carer themselves.

¹ A primary carer is someone who takes on the main caring responsibilities of a care recipient. Australian Bureau of Statistics defines a primary carer as a person who provides the most informal assistance on an ongoing basis, to another person who is restricted by one or more core activities in the areas of communication, mobility and self care. A secondary carer provides informal care in a supporting role where either another family member or formal services provide the majority of care.

² ABS (2004) Survey of Disability, Ageing and Carers (SDAC) Summary of Findings, Australian Bureau of Statistics, Canberra.

³ Access Economics (2009) Making Choices Future dementia care: projections, problems and preferences, report prepared for Alzheimer's Australia, Canberra.

⁴ Department of Health, 1992 cited in Dementia in Australia: national data analysis and development, AIHW, 2006, Canberra.

⁵ Access Economics (2009) Making Choices Future dementia care: projections, problems and preferences, report prepared for Alzheimer's Australia, Canberra.

Carers NSW is therefore pleased that the *NSW Dementia Services Framework 2010-2015 Draft* recognises the key role carers play in the ongoing care and wellbeing of people with dementia and addresses the importance of carer support and inclusion in ongoing care plans and options as the dementia progresses. Carers NSW is especially pleased to see the key Priorities for Action of the *NSW Carers Action Plan 2007-2012* reflected in the Framework. These include that:

- Carers are recognised, respected and valued
- Hidden carers are identified and supported
- Services for carers and the people they care for are improved
- Carers are partners in care, and
- Carers are supported to combine caring and work.

While it is pleasing to see these Priorities reflected in the Framework, Carers NSW suggests that the Framework could go further in addressing how carers are identified, included and supported. Carers NSW comments broken down in order of the three sections of the Framework.

SECTION ONE

1. Recommendations (pp 7-11)

1.1 Gay, lesbian, bisexual, transgender and intersex (GLBTI) carers

Carers NSW recognises that GLBTI people have unique needs and experiences when it comes to the role of caring. While some caring experiences can be generalised over age, gender, culture, sexuality and health condition, GLBTI people face unique challenges legally, financially and socially which can deter them from accessing services and supports that are available to the general community.

These challenges include: lack of acknowledgement and fear of discriminatory treatment by mainstream services; increased risk of isolation due to lack of family support; lack of legal recognition of informal 'family' relationships; discrimination in residential care facilities forcing gay and lesbian people back into the closet.⁶ The second Priority for Action in the *NSW Carers Action Plan 2007-2012* is that hidden carers are identified and supported. GLBTI people are hidden carers, and thus need particular consideration.

The Framework has failed to recognise that the needs and concerns of GLBTI carers are far more complex than has been illustrated. As a hidden carer group, Carers NSW recommends that GLBTI people be included alongside CALD and Aboriginal people where appropriate throughout the document.

Recommendation 1:

Carers NSW recommends that GLBTI people be recognised alongside CALD and Aboriginal people where appropriate, including in Recommendations 1.4, 1.5, 3.7, 4.2, 4.7, 4.9, 4.10, 5.4, 7.7.

1.2 Carer Support

Carers NSW is pleased to see that some important carer needs are addressed throughout the eight Recommendations, and more specifically, in Recommendation 3. However, Carers NSW would like to see the inclusion of a ninth Recommendation that specifically outlines carer supports.

⁶ Alzheimer's Australia (2009) *Dementia: Lesbians and Gay Men*, Canberra.

Recommendation 2:

Carers NSW recommends that a ninth recommendation is added to the Framework to address the needs of carers for services and support.

1.2.1 Carer Health and Wellbeing

Carers NSW would like to see health maintenance initiatives included in the Recommendations for carers themselves. It was recommended in the *Carers Health Project - The Sharing Health Care Initiative: Final Report* that carers should “receive regular carer health checks underpinned by Australian Government MBS items”⁷. It has been recognised that caring for someone with dementia is particularly challenging due to the characteristics of the condition and that the impact on the health of the carer may be greater, especially over a long period of time.⁸

Under the Medicare Benefits Scheme (MBS) there are existing items for integrated care plans and other care management plans that can be utilised to incorporate support for carers through health checks and other health-related services. (The *Who Cares ...?* Report recognises the need for carers access to their own health care support and recommended the implementation of a preventative health program for carers, and that the Enhanced Primary Care MBS items could be utilised for this purpose) Carers who have good health and wellbeing may enable carers to continue their caring role longer, if they choose. This would delay entry into residential care for the person with dementia.

Recommendation 3:

Carers NSW recommends that health maintenance initiatives for carers be included in the Recommendations.

1.3 Hospital Care

Carers NSW is disappointed to see that carers are not included here. It is noted later in the Framework Draft that “improving the hospital experience for people with dementia is a critical priority area” (p45). It is also highlighted that a person with dementia can become increasingly agitated when placed in an unfamiliar environment. Carers NSW recommend that there be an inclusion that recognises carers as partners in care. This is in line with Priority 4 in the *NSW Carers Action Plan 2007-2012* which states:

“Carers play a crucial role as care partners. They are often experts in the care of the person requiring care and can assist with care planning and delivery, with the agreement of the care recipient.”⁹

In a hospital context, this priority would see the carer consulted and included in the care provision during the hospital stay, in the interests of carer and the person with dementia, who may experience less anxiety and agitation.

Recommendation 4:

Carers NSW recommends that the Framework recognise carers as partners in care, including in the context of hospital care.

⁷ Carers Australia Carers Health Project - The Sharing Health Care Initiative: Final Report (2007) pp34, Canberra.

⁸ Access Economics (2009) Making Choices Future dementia care: projections, problems and preferences, report prepared for Alzheimer’s Australia, Canberra.

⁹ NSW Carers Action Plan 2007 – 2012 (2007) pp9.

2. Introduction (pp 12-20)

2.1 Carers

Carers NSW is pleased that the Framework recognises there will be a proportional increase in the demand on carers as the dementia epidemic grows. However, it is disappointing that the seriousness of the situation is not reflected in this section. The statement made that “It is likely that the number of carers will increase but not as fast as those needing care...” seriously understates the seriousness of the situation and the potential care crisis that could develop.

It is important to remember that the increased demand for dementia carers will coincide with an overall increase in the demand for carers from older people and people with disabilities, mental illness, chronic conditions and so on. Demand for carers for people with disabilities and older people will grow significantly over the next 25 years. For example, the number of older Australians with disabilities will grow by 150 per cent, while the number of very old people (aged 85 and over) will grow by 200 per cent. At the same time, the proportion of people available to provide care (the carer ratio) is contracting, and has been projected to fall from the current level of 2.5 to less than one over the next 50 years.¹⁰ The cost of replacing carers with formal care services is immense. Just a 10 per cent reduction in informal care would translate to a 40 per cent increase in demand for formal care.¹¹ It is clear that more recognition and support must be given to carers, if caring is to be made more sustainable and if we wish to avoid a care crisis.

Carers NSW is pleased to see that the *Carer Life Course Framework* has been identified as a potential guide for carers and service providers in assessing appropriate carer support interventions over the life of the caring role. Carers NSW has now developed the *Carer Life Course Framework* as an online tool that includes an e-learning module. This tool can be expanded to address how and when carers can access support as they navigate the present and future needs of the person with dementia.

Carers NSW supports the acknowledgement in this section that carers of people with dementia are at high risk of social isolation and psychological morbidity. As noted previously, this issue is not adequately addressed in the Recommendations. The acknowledgement made here of the significant impacts of caring for a person with dementia supports Carers NSW recommendation that a recommendation relating to carer health and wellbeing be added to the Framework.

2.3 Sexual Minorities

It was pleasing to note the inclusion of sexual minorities in the list of defined Specific Population Groups. Carers NSW regards the term ‘Sexual Minority’, however, as pejorative, especially when positioned between the ‘Intellectual Disability’ and ‘Non-progressive Cognitive Impairment’ groups.

Recommendation 5:

Carers NSW recommends that the term ‘Sexual Minority’ be replaced by ‘Gay Lesbian Bisexual Transgender and Intersex (GLBTI) Communities’.

¹⁰ NATSEM 2006, Who cares? The cost of caring in Australia 2002 to 2005, Income and Wealth Report Issue 13 May 2006, Canberra.

¹¹ Disability Investment Group 2009, The Way Forward: A New Disability Policy Framework for Australia. Canberra.

3. Purpose and Scope (pp 21-22)

3.1 Principles

3.1.1 Re: Principle 3: Carers NSW would like to see Principle 3 expanded to include specific reference to recognition of, and support for, carers to balance caring with paid employment and education. For example 'Carers and families are recognised, valued and supported - both in their caring role and in their right to employment /education'.

3.1.2 Re: Principle 4: Carers NSW is pleased to see the parallel between this Principle and the Partners in Care Priority in the *NSW Carers Action Plan*. Carers NSW recommends that Principle 4 be followed through in the Hospital Recommendations outlined in 1.3 of this document.

3.1.3 Carers NSW is pleased to see carer needs represented in the eight Principles. In order to fulfill the fifth Priority for Action *NSW Carers Action Plan* Carers NSW recommends the inclusion of a ninth Principle: 'Carers and family have the right to choose if, when and how they will provide care'.

Recommendation 6:

Carers NSW recommends that Principle 3 states: 'Carers and families are recognised, valued and supported - both in their caring role and in their right to employment /education'

Recommendation 7: Carers NSW recommends that Principle 4 be followed through in the Hospital Recommendations outlined in 1.3 of this document.

Recommendation 8: Carers NSW recommends the inclusion of a ninth Principle: 'Carers and family have the right to choose if, when and how they will provide care'.

4. Policy and Planning Context (pp 22-24)

4.1 Carers Policy

Carers NSW is aware that many carers and organisations do not think that the Commonwealth Government showed sufficient commitment to carers and the people they care for in not implementing the 50 recommendations of this report. While, it is unlikely that all recommendations would have been able to be implemented many key ones were not actioned by the government. These include equal right for all carers to access flexible working hours, expanded eligibility for the Carer Payment to allow carers to increase the number of hours for work, volunteering or studying, and the implementation of a preventative health program for carers. The Strategic Carers Action Network identified the monitoring of the implementation of the 50 recommendations of the report as a priority item in their work agenda.

SECTION 2

5. Service Pathway (pp 27-28)

5.1 Carers NSW suggests that a key enabler for the service pathway in the care of a person with dementia, is the health and wellbeing of their carer. When and how services are accessed and implemented depends on the willingness and ability of the carer to adequately care for that person. Carers NSW recommends that the model be adjusted to include carer health and wellbeing as a key enabler.

Recommendation 9:

Carers NSW recommends that the model be adjusted to include 'Carer Health and Wellbeing' as a 'Key Enabler'.

6. Dementia Awareness (pp 28-32)

6.1 The Framework outlines the difficulty in diagnosing people with younger onset dementia. Delays in diagnosis and treatment can be particularly stressful for family members and friends, not only because of the confusion and uncertainty it can cause, but because there is difficulty in accessing mainstream dementia services.¹²

In the Alzheimer's Australia 2006 consultation report, *Exploring the Needs of Younger People with Dementia in Australia* it was suggested that increasing awareness of the existence of dementia in younger people would help alert individuals, their families and friends to the early warning signs of dementia, leading to earlier diagnosis.¹³ From a caring perspective this allows earlier access to information and support so that family and friends can start planning care.

Carers NSW recommends that younger onset dementia be included in the Dementia Awareness section of the Framework. The importance of addressing the needs of this particular group is reinforced by the recent commitment of the NSW Government to fund a research project by Alzheimer's Australia to "address the different types of support people with younger onset dementia need to maintain their quality of life".¹⁴

Recommendation 10:

Carers NSW recommends that public awareness campaigns around the existence of early onset dementia be included in the Framework.

7. Assessment, Diagnosis and Ongoing Management (pp 32-40)

7.1 Carers NSW strongly supports the recommendation to have a key worker in place for the carer and the person with dementia. Not only does this alleviate some confusion for the carer around what supports to access for the person with dementia, but importantly someone is available to suggest and access supports for the carer. Carers NSW recommends that key workers will benefit in their role by having training in the Carer Life Course Framework or other carer awareness training.

Recommendation 11:

Carers NSW recommends that key workers will benefit in their role by having training in the Carer Life Course Framework, or other carer awareness training.

7.2 Outcomes for people with dementia, family and carers

Carer health and wellbeing is integral to the wellbeing outcomes for a person with dementia and impacts on how long they are able to remain in community care. Carers NSW is therefore pleased to see the assessment of the carer's own physical and emotional wellbeing mentioned as part of the overall assessment.

¹² <http://news.ninemsn.com.au/health/7933941/nsw-govt-funds-dementia-study> (accessed 5 August, 2010)

¹³ *Exploring the Needs of Younger People with Dementia in Australia*, Alzheimer's Australia (2006)

¹⁴ <http://news.ninemsn.com.au/health/7933941/nsw-govt-funds-dementia-study> (accessed 5 August, 2010)

7.3 Examples of Existing Good Practice

Carers NSW recommends the inclusion of two Carers NSW resources to this list.

1. Carer Support Group Kit and Facilitator Guide.
2. Carer Life Course Framework – This is a web-based e-learning tool (www.carerlifecourse.org.au) for carers and service providers to map the life course of the caring role so that relevant services and supports can be accessed at appropriate stages and caring can be planned.

Recommendation 12:

Carers NSW recommends the inclusion of the Carer Support Group Kit and Facilitator Guide and the Carer Life Course Framework as examples of Good Practice.

8. Information Counselling and Carer Education (pp 37-40)

8.1 It is stated in the Outcomes that “carers are provided with support to enable them to maintain their own health, social and emotional wellbeing”. Carers NSW would like to highlight that carers may not be able to maintain these things without practical support – in particular, adequate and flexible respite.¹⁵

9. Community Support (pp 40-45)

There have been some promising advances in health technology internationally to support people with dementia in community care. One example is Telecare, an electronic system that can be installed into the home whereby dementia patients can self monitor their schedules through interactive computer programs as well as access to skype-type communication with a health worker and/or to a tea room style social network.

Carers Scotland, in conjunction with the University of Leeds, recently conducted research into the Telecare system and carer outcomes included feeling less stressed, feeling more confident about the wellbeing of the person they cared for, improvements in the relationship with the person they care for and for some, ability to remain in paid employment.¹⁶ Carers NSW recommends further research into, and inclusion of, new health technologies in order to maximise positive carer outcomes going into the future.

Recommendation 13:

Carers NSW recommends further research into, and inclusion of, new health technologies in order to maximise positive carer outcomes going into the future.

Key recommendations

Recommendation 1:

Carers NSW recommends that GLBTI people be recognised alongside CALD and Aboriginal people where appropriate, including in Recommendations 1.4, 1.5, 3.7, 4.2, 4.7, 4.9, 4.10, 5.4, 7.7.

Recommendation 2:

Carers NSW recommends that a ninth recommendation is added to the Framework to address the needs of carers for services and support.

Recommendation 3:

Carers NSW recommends that health maintenance initiatives for carers be included in the Recommendations.

¹⁵ Respite Care for People Living with Dementia. Discussion Paper 17, Alzheimer’s Australia (May 2009)

¹⁶ ‘A weight off my mind: exploring the impact and potential benefits of telecare for unpaid carers in Scotland’. Carers Scotland (November 2009)

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Conclusion

Carers NSW thanks NSW Department of Health and Ageing, Disability and Home Care Human Services NSW for the opportunity to comment on the NSW Dementia Services Framework 2010-2015 Draft.

If you require any further information about Carers NSW response to the policy, please contact Lorna Clarkson on 02 9280 4744 or email lornac@carersnsw.asn.au.

Yours sincerely,



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