



National Carer Strategy
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Carers NSW response to *Towards a National Carer Strategy*

Carers NSW welcomes the opportunity to provide comments on *Towards a National Carer Strategy* a discussion paper from the Australian Government. This submission will address some of the questions posed in the submission form and other issues.

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 aged 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 primary 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 income.¹

Carers NSW response to *Towards a National Carer Strategy*

Carers NSW welcomes the release of this discussion paper, and the recent enactment of the *Carer Recognition Act 2010*. It is pleasing to see evidence that the Australian Government is honouring the commitment made in October 2009 to a National Carer Recognition Framework, and that both components of the Framework are progressing.

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. We look forward to a time when all carers have choice in their caring role.

Carers NSW hopes that the Strategy will be a real step towards achieving this vision. The Government must also ensure that the Strategy leads to real change.

1. Choice for carers

Carers are often forced into their caring role, and forced to continue providing levels of care they are not able and/or are not willing to provide. In the absence of formal care services, carers often find their role thrust upon them, with no say in whether (or how) they begin, continue or cease their caring role, or as to how they balance caring with other aspects of their life, including family and work responsibilities. Whether it is the parent of an adult child with severe disabilities, a carer of somebody being discharged from hospital with chronic or terminal illness, or the carer of a person with a mental illness, rarely are they offered a choice, consulted with, or given the services and supports they need to manage these responsibilities.

The Strategy must provide carers with the right to choice. People have the right to choose whether or not they will be carers, and if so, how much they can take on, and for how long. Choice for carers is not just about a choice of services, or a choice of providers. Choice also means to choose, to continue in the caring role or not. This must be reflected in the Strategy through the addition of a sixth goal pertaining to the right to choice, and to choose (or not) to continue in their caring role.

* 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.

Recommendation 1: Carers NSW recommends the Government adds a sixth goal to the Strategy pertaining to the right of carers to choice, including the choice to continue (or not) in their caring role.

2. Revisit recommendations of *Who Cares...? Inquiry*

The development of a 'nationally consistent carer recognition framework' was one of the recommendations of the *Who Cares...? Report on the inquiry into better support for carers*. When developing the Strategy, the Australian Government can look to the other 49 recommendations of the *Who Cares...? report* for guidance. The Discussion Paper indicates that the first Strategy will include what the Australian Government agreed to do in its response to this Inquiry. Carers NSW believes that the Australian Government should revisit these recommendations, and reconsider the adequacy of their response. Carers need more action than what was committed to in 2009, and this should be reflected in the Strategy.

Recommendation 2: Carers NSW recommends that the Government revisits and strengthens its commitment to the recommendations of the *Who cares...? report*.

3. Interaction between the *Carer Recognition Act 2010* and the Strategy

Carer recognition legislation is already in place in Western Australia, South Australia, the Northern Territory, Queensland, the Australian Capital Territory and more recently, in New South Wales. The Australian Government must look to the experiences of these jurisdictions to ensure the *Carer Recognition Act 2010* is effective.

The Western Australian experience is instructive. Western Australia introduced similar carer recognition legislation in 2004 and conducted a comprehensive review of its effectiveness in 2008.² This review provides clear guidance on the action required to effectively implement carer recognition legislation. Findings included that the Western Australian Act had not been effective in achieving its objectives of increasing recognition of the role of carers and including carers in service planning. This was attributed to several factors, including a lack of an awareness-raising campaign and training of key personnel within relevant organisations, which has contributed to low awareness and understanding of the Act, and continuing confusion around the term 'carer'.³

The experience of Western Australia could very easily be replicated at a national level if the Strategy does not support the legislation. Critics consider that legislation which does not award carers legally enforceable obligations is a 'legislated pat on the back' or 'legislative lip service'.⁴ If these critics are to be proved wrong, the Strategy will need to incorporate an awareness campaign to raise awareness of the legislation and of the contribution and needs of carers, targeted at the general community and at public sector agencies and employers. The Strategy will also need to incorporate the provision of information, advice and resources to public sector agencies to facilitate their compliance with the Act, including their obligations relating to internal human resources policies, carer consultation and implementation of the Statement for Australia's carers.

Recommendation 3: Carers NSW recommends that the Strategy supports the effectiveness of the *Carer Recognition Act 2010* through the delivery of an awareness campaign targeted at the general community, public sector agencies and employers.

Recommendation 4: Carers NSW recommends that the Strategy supports the effectiveness of the *Carer Recognition Act 2010* through the provision of information, advice and resources to public sector agencies to facilitate compliance with the Act.

4. Support after the caring role ends

The Strategy needs to recognise the need of carers for support beyond their caring role. As the discussion paper acknowledges, carers often experience poor health and wellbeing, financial stress, and social exclusion. Obviously, these and other impacts of caring do not end with the caring role. For example, carers who leave employment because of their caring role are unlikely to re-enter the work force once their caring role ends.⁵ Caring for just one year has a negative impact on earnings, and can have sustained effects over the carer's lifetime.⁶ The same can be said of the effects on physical, mental and emotional health and wellbeing, on relationships and on the social connectedness of carers. The costs of caring do not cease with the caring role, and nor should the provision of services and support, including financial assistance.

Recommendation 5: Carers NSW recommends that the Strategy recognises under goal three the need of carers for continued financial support by the Government after the caring role ends.

The Strategy must explicitly recognise this need of carers for continued support after the caring role ends in goal three. The Strategy should incorporate initiatives in recognition of this need. In particular, amendments must be made to eligibility for the Carer Payment to ensure that carers are not placed under even greater financial and emotional strain at the end of their caring role. The current situation, where carers are transferred from Carer Payment (\$658.40 per fortnight, single) to New Start (\$469.70 per fortnight) after just 14 weeks means that people who are already vulnerable and often going through a very difficult time are placed under even greater strain. This is often exacerbated if people have been caring for many years, or who have not been able to maintain or update skills to enter employment, or who are older and will experience employment discrimination or disadvantage because of their age. This is not a just reward for the contribution they have made as carers.

Recommendation 6: Carers NSW recommends that the Strategy recognises under goal three the need of long-term carers to remain eligible for the Carer Payment for as long as needed, or until they are able to transition to other government income support such as the Age Pension.

The need of carers for assistance to re-enter the workforce after their caring role ends should also be acknowledged in goal 4, and initiatives should be included to support this by improving access education, training and support to re-enter the workforce and to find appropriate, secure employment.

Recommendation 7: Carers NSW recommends that the Strategy addresses the need of carers for assistance to re-enter the workforce through access to education, training and support.

5. Addressing the financial costs of caring

For many, caring has significant and long-term financial impacts. Carers are likely to have low income, high dependence on government financial assistance, little or no capacity to save for retirement, and experience high financial stress due to the combination of low income and high expenditure on health and care services, equipment, medications and so forth. Although the Strategy does acknowledge “eligible carers who are unable to work being supported by the income support system”, the Strategy will need to include a greater and broader commitment to improving the financial situation of carers. Carers NSW believes that the hugely significant and selfless contribution of carers should not be rewarded with poverty, and expects the Strategy to address this issue.

The Strategy needs to ensure first of all that those carers who need to are able to access financial support by improving awareness of these entitlements and amending the application and assessment processes, particularly for carers of people with a mental illness. Too often Carers NSW hears of carers struggling to prove their eligibility for income support, or discovering their eligibility long after they were first entitled to such payments. Estimates suggest that Australia-wide there are at least 115,632 eligible carers who do not receive Carer Allowance.⁷ The Australian Government and Centrelink have a responsibility to ensure that carers are aware of and able to access the support they are entitled to.

Recommendation 8: Carers NSW recommends that the Strategy improves awareness of entitlements to government income assistance.

Recommendation 9: Carers NSW recommends that the Strategy improves application and assessment processes for government income assistance, particularly for carers of people with a mental illness.

Secondly, the Strategy must look to improve the income support that carers receive, and their capacity to save for retirement. The *Who Cares...? Report* recommended a significant increase of the base rate of carer payments. The Government agreed to this Recommendation, and cited a \$32.50 per week increase in the pension rate (\$10.15 per week for couples combined) as their implementation of this recommendation.⁸ This is much less than what is required. In the absence of significant raises to the Carer Payment the Government must at least implement recommendation 6 of this submission to ensure that carers are not disadvantaged at the end of their caring role by being transferred to Newstart Allowance.

The Government must also provide a superannuation scheme for carers, as advocated for by the Network of Carer Associations and the Human Rights and Equal Opportunity Commission (HREOC) in its report, *It's About Time: women, men, work and family*.⁹ Due to their low workforce participation, many carers have little opportunity to accumulate superannuation, as identified by the National Centre for Social and Economic Modelling in the *Women Carers in Financial Stress Report*. According to this report, a 30 year old mother caring for children with a disability would have insufficient, if not negligible, superannuation at 65 years of age.¹⁰

Recommendation 10: Carers NSW recommends that the Strategy implements a superannuation scheme for unemployed primary carers equivalent to the superannuation payable to a full-time employee on the National Minimum Wage.

Finally, the Strategy must also respond to the need to reduce the financial expenses associated with caring. 98 per cent of respondents to the Carers NSW 2010 Carer

Survey had additional financial costs as a result of their caring role. Among the most commonly experienced costs were medicines (72 per cent of respondents), travel costs (62 per cent) and respite (55 per cent). 58 per cent of respondents had to borrow money as a result of their caring role.¹¹

The recently released *2008 Community Care Census* indicates that of the carers caring for an older person accessing the National Respite for Carers Program around 23 per cent were reported to be in 'financial hardship', accounting for 24 per cent of all female carers and 21 per cent of male carers. (Note, that 'financial hardship' defined in the census has a set of perimeters that may not be applicable to other carers.)¹²

As well as improving carers' income and capacity to save for retirement, the Strategy should also address the need to lower the costs associated with caring which compound the financial stress caused by low income and dependence on income support.

Recommendation 11: Carers NSW recommends that the Strategy includes initiatives to reduce the financial expenses associated with caring.

6. Carer diversity

The acknowledgement in the Discussion Paper of the diversity of carers, and the different circumstances facing different groups is important. Carers NSW was pleased to see a commitment to meeting the needs of young carers, older carers, Aboriginal carers, carers from culturally and linguistically diverse backgrounds, carers living in rural and remote areas and veteran and war widow/widower carers.

Carers NSW would also like to see explicit recognition of the needs of Gay, Lesbian, Bisexual, Transgender and Intersex (GLBTI) carers. GLBTI carers have unique needs and experiences of caring. While some aspects of their caring experience are common to other carers, GLBTI carers face unique legal, financial and social challenges 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; and discrimination in residential care facilities forcing gay and lesbian people back into the closet.¹³ GLBTI people are amongst the most hidden of hidden carers, and thus need particular consideration in the Strategy alongside other diverse carer groups.

Carers NSW hopes that the Strategy will improve the accessibility and appropriateness of services to all carers, as well as supporting targeted interventions for specific populations where necessary.

Summary of Recommendations

1. Carers NSW recommends the Government adds a sixth goal to the Strategy pertaining to the right of carers to choice, including the choice to continue (or not) in their caring role.
2. Carers NSW recommends that the Government revisits and strengthens its commitment to the recommendations of the *Who cares...?* report.

3. Carers NSW recommends that the Strategy supports the effectiveness of the *Carer Recognition Act 2010* through the delivery of an awareness campaign targeted at the general community, public sector agencies and employers.
4. Carers NSW recommends that the Strategy supports the effectiveness of the *Carer Recognition Act 2010* through the provision of information, advice and resources to public sector agencies to facilitate compliance with the Act.
5. Carers NSW recommends that the Strategy recognises under goal three the need of carers for continued support after the caring role ends.
6. Carers NSW recommends that long-term carers remain eligible for the Carer Payment for as long as needed, or until they are able to transition to other government income support such as the Age Pension.
7. Carers NSW recommends that the Strategy addresses the need of carers for assistance to re-enter the workforce through access to education, training and support.
8. Carers NSW recommends that the Strategy improves awareness of entitlements to government income assistance.
9. Carers NSW recommends that the Strategy improves application and assessment processes for government income assistance, particularly for carers of people with a mental illness.
10. Carers NSW recommends that the Strategy implement a superannuation scheme for unemployed primary carers equivalent to the superannuation payable to a full-time employee on national minimum wage.
11. Carers NSW recommends that the Strategy includes initiatives to reduce the financial expenses associated with caring.

Conclusion

Carers NSW appreciates the opportunity to comment on this discussion paper. If you require any further information please contact Alison Parkinson on 02 9280 4744 or email alisonp@carersnsw.asn.au.

Yours sincerely



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Endnotes

- ¹ Australian Bureau of Statistics, Survey of Disability, Ageing and Carers (SDAC) Summary of Findings, Canberra, 2004.
- ² D Murray et al, Review of the Carers Recognition Act 2004: Final Report, Western Australia, 2008.
- ³ Ibid, p 4.
- ⁴ Working Carers Gateway, 'National Carer Recognition Bill tabled' [Online], Available at: <http://www.workingcarers.org.au/options/1106-national-carer-recognition-bill-tabled>, 2010.
- ⁵ A Page et al. *Taking Care: Mature age workers with elder care responsibilities*, University of Sydney, Sydney, 2009.
- ⁶ C Thomson et al, *Negotiating caring and employment*, Final report for the Australian Research Council Linkage Grant Program, University of New South Wales, Sydney, 2008.
- ⁷ D Baker, *Missing out: Unclaimed government assistance and concession benefits*, The Australia Institute, policy brief no. 14, Sydney, 2010.
- ⁸ Australian Government, 'Government Response to the House of Representatives Standing Committee on Family, Community, Housing and Youth report: Who Cares ...? Report on the inquiry into better support for carers', Canberra, 2009.
- ⁹ Human Rights and Equal Opportunity Commission, *It's About Time: women, men, work and family*, Sydney, 2010.
- ¹⁰ National Centre for Social and Economic Modelling, *Women Carers in Financial Stress Report*, University of Canberra, Canberra, 2008.
- ¹¹ Carers NSW, 'Carers NSW 2010 Carer Survey', Sydney, 2010.
- ¹² Australian Government Department of Health and Ageing, 2010, The 2008 Community Care Census, Canberra, 2010.
- ¹³ Alzheimer's Australia, *Dementia: Lesbians and Gay Men*, Canberra, 2009.