



The future of carer support in NSW

Carers NSW Budget Submission 2010-11 to the NSW Government

February 2010

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.

This submission was prepared by the Policy, Strategy and Education Unit, Carers NSW, Sydney.

Carers NSW
Level 18, 24 Campbell Street
Sydney NSW 2000
Ph: 02 9280 4744
Fax: 02 9280 4755
Email: contact@carersnsw.asn.au

© 2010 Carers New South Wales Inc.

Contents

ACRONYMS	4
EXECUTIVE SUMMARY.....	5
SUMMARY OF RECOMMENDATIONS	6
INTRODUCTION.....	9
Carers in NSW	9
Key statistics on NSW carers	10
Carers service needs	10
Current policy context for carers in NSW	10
CARERS NSW RECOMMENDATIONS FOR NSW	12
1. ENACTING NSW CARER RECOGNITION LEGISLATION	13
2. MEASURING THE EFFECTIVENESS OF INTERVENTIONS FOR CARERS.....	15
Evaluation	15
Assessment.....	16
3. EARLY INTERVENTION AND IDENTIFICATION	18
4. BEST PRACTICE FOR REACHING HIDDEN CARERS.....	20
5. RESPITE.....	21
6. PROVIDING TARGETED SUPPORT.....	23
Dementia carers.....	23
Sandwich generation carers	24
Elder carers.....	25
GLBTI carers.....	26
Young carers.....	27
Mental health carers.....	28
7. CARERS LOW WORKFORCE PARTICIPATION	30
CONCLUSION	33
REFERENCES.....	34

Acronyms

ABS	Australian Bureau of Statistics
ACAT	Aged Care Assessment Team
ADHC	Ageing, Disability and Home Care, Department of Human Services NSW
AIHW	Australian Institute of Health and Welfare
CALD	Culturally and Linguistically Diverse
COAG	Council of Australian Governments
CRCC	Commonwealth Respite and Carelink Centre
CSTDA	Commonwealth State/Territory Disability Agreement
DAS	Dementia Advisory Services
DOHA	Australian Department of Health and Ageing
EACH	Extended Aged Care At Home
GLBTI	Gay, Lesbian, Bisexual, Transexual, Intersex
HACC	Home and Community Care
HRSCFCHY	House of Representatives Standing Committee on Family, Community, Housing and Youth
MDS	Minimum Data Set
MHCA	Mental Health Council of Australia
NCCP	National Carer Counselling Program
NGO	Non Government Organisation
NRCP	National Respite for Carers Program
ONI-N	Ongoing Needs Identification NSW
PINC	Person in need of care
SDAC	Survey of Disability, Ageing and Carers

Executive summary

Carers NSW, as the peak organisation for carers in NSW, welcomes the opportunity to make this submission to the NSW Government for consideration prior to the NSW State Budget 2010-11.

The year 2010 will mark the third year of implementation of the *NSW Carers Action Plan 2007-2012*, which has made considerable headway in recognising and supporting carers throughout NSW with its five key priority areas providing a strong foundation for working to support carers across the state.

Despite strong support for carers in NSW as part of the Action Plan, the release of *Who Cares...? Report on the inquiry into better support for carers* in April 2009 highlighted that there is still much more that can be done to ensure carers receive the services and support that they need.

Carers NSW believes that the NSW Government is well placed to take the lead on a number of key initiatives that are being discussed at a national level given the NSW experience of developing and implementing the *NSW Carers Action Plan 2007-2012*.

This submission emphasises an approach to providing support and services for carers which is effective. Carers NSW is aware that support and services for carers must be focused on evidence-based practice and must be targeted and appropriate for the diversity of carers across NSW.

Carers NSW is aware, as it was highlighted in the recent report by the Australian Institute of Health and Welfare *Australia's Welfare 2009* that:

policy makers face an ongoing challenge to ensure that suitable support is available to carers to continue to provide care, but also to help them fulfil other life roles. This is necessary to ensure an adequate supply of carers in an environment where there is likely to be an increasing demand for informal carers, but fewer people available to provide care (188).

This submission seeks to rise to this challenge by making recommendations for how existing support structures can be further developed and improved, as well as how effective interventions for carers can be further implemented across NSW. It also seeks to further the vision of Carers NSW which is that caring is accepted as a shared community responsibility and that all carers in NSW are recognised, valued and supported by the community and by governments.



Elena Katrakis
Chief Executive Officer
Carers NSW

February 2010

Summary of recommendations

The following is a summary of the recommendations made by Carers NSW as part of this submission.

Enacting NSW carer legislation

1. Carers NSW recommends that the NSW Government enacts the *Carers Recognition Bill 2010* to provide greater recognition and rights for carers in NSW.
2. Carers NSW recommends that the NSW Government endorses the *NSW Carers Charter*, scheduled in the proposed *Carers Recognition Act 2010*.
3. Carers NSW recommends that the NSW Government endorses the proposed Ministerial Advisory Council for Carers, scheduled in the proposed *Carers Recognition Act 2010*.

Measuring the effectiveness of interventions for carers

4. Carers NSW recommends that the NSW Government, in particular, the NSW Department of Health, ensures that key findings that require action from the evaluation of the *NSW Carers Action Plan 2007-2012* are clearly identified and are responded to appropriately with additional funding attached when required.
5. Carers NSW recommends the NSW Government funds the development of a standardised evaluation tool to measure the effectiveness of carer support interventions and makes this tool accessible to all organisations who deliver state funded programs to carers.
6. Carers NSW recommends that the NSW Government actively advocates for the implementation of a standardised assessment tool for carers at the Council of Australian Governments and provides funding for a full-scale implementation of a standardised assessment tool such as the ONI-N across all programs and services for carers in NSW.

Early intervention and identification

7. Carers NSW recommends that the NSW Government provides funding for research into early intervention for carers in order to gain a better understanding of how carers can be supported and outcomes for them improved.

Best practice for reaching hidden carers

8. Carers NSW recommends that the NSW Government provides funding for the development of a best practice model or framework for reaching hidden carers. This funding should include the development of a discussion/research paper, community consultations, the development of a model and promotion across the sector once the model is established.

Respite

9. Carers NSW recommends that the NSW Government increases its allocation of funding for respite for all carers in NSW.

10. Carers NSW recommends that the NSW Government funds education courses for carers about how to use respite and its benefits in order to increase carers utilisation of respite services.

Providing targeted support

11. Carers NSW recommends that the NSW Government increases funding for all services which support carers of people with dementia in high prevalence and rural and remote areas, specifically the Dementia Advisory Services and carer support groups, to ensure that these carers have access to the support that they need.
12. Carers NSW recommends that the NSW Government increases its funding for strategies that improve diagnosis of early onset or younger onset dementia, and also increases funding for the provision of appropriate care services.
13. Carers NSW recommends that the NSW Government funds research into the specific needs of sandwich generation carers in order to create an evidence-base to plan and implement specialised services for this group of carers.
14. Carers NSW recommends that the NSW Government increases its allocation of funds to services and programs that support elder carers such as Aged Care Assessment Teams and Home and Community Care.
15. Carers NSW recommends that the NSW Government funds the development of a promotional/awareness campaign targeting the population group most likely to become elder carers—women aged 25-54, about what supports are available and what to do in the event that they become a carer.
16. Carers NSW recommends that the NSW Government provides funding for the re-implementation of the GLBTI Carer Support Program in order to ensure that GLBTI carers have their need for targeted support met.
17. Carers NSW recommends that the NSW Government funds further research about the needs of GLBTI carers and how and where they access services.
18. Carers NSW recommends that the NSW Government through Ageing, Disability and Home Care, Department of Human Services NSW includes Carers NSW, as the peak organisation for carers in NSW, in key advisory bodies to identify priorities, define programs and target services to better support young carers in NSW.
19. Carers NSW recommends that the NSW Government funds the development of a Young Carer Companion Card as part of the existing Companion Card Scheme in NSW.
20. Carers NSW recommends that the NSW Government increases funding overall for services to mental health carers in line with the 15 key issues raised in the *Adversity to Advocacy report card*.

Carers low workforce participation

21. Carers NSW recommends that the NSW Government provides additional funding to ensure all carer support programs are able to extend services to employed carers,

and that more respite programs and places are made available to assist working carers maintain their paid employment.

22. Carers NSW recommends that the NSW Government, in particular the NSW Office of Industrial Relations, provides funding for training for carers who have left the paid workforce as a result of their caring role.
23. Carers NSW recommends that the NSW Government, in particular the NSW Office of Industrial Relations explores opportunities, as suggested in the *Taking Care: Mature Age Workers with Elder Care Responsibilities* research report, to amend legislation as required for all carers in NSW to have the right to request flexible work arrangements regardless of age or relationship status.
24. Carers NSW recommends that the NSW Government requests that the Commonwealth Government through the Council of Australian Governments amends the *Fair Work Act 2009* and the *National Employment Standards* to include the right for all carers to have the right to request flexible work arrangements regardless of age or relationship status.

Introduction

The question *what does effective intervention for carers in NSW look like?* guides this submission. Carers NSW believes that with an increased emphasis on evidence-based practice that interventions for carers in NSW can be more strategic and targeted. As Williams and Owen (2009) suggest “there is ample scope for improving the service system as well as the evidence base for promoting effective interventions” (38).

This submission identifies seven key issues that require further consideration and strategies for how the NSW Government can provide further support for carers in NSW in 2010-11. These include enactment of carer recognition legislation, standardised assessment and evaluation, early intervention and identification of carers, developing best practice for engaging hidden carers, making respite services for carers more accessible, targeting specific groups of carers and helping carers to increase their workforce participation. Emphasis here is also placed on the need for further development of an evidence-base through NSW specific research about carers.

These strategies are in line with the *2006 NSW State Plan* which recognises that it is important to make sure that carers have access to more information and training opportunities. These strategies also build on what is already in place in the *NSW Carers Action Plan 2007-2012*, and last year carers were included as a population group in the Healthy Communities initiative of the *2009 NSW State Plan*.

Underpinning the Carers NSW Budget Submission 2010-11 is the recommendation that the NSW Parliament adopt the proposed NSW carers legislation – *Carers Recognition Act 2010*, incorporating the *NSW Carers Charter* – currently before the NSW Parliament. The introduction of this proposed legislation is timely, considering the Commonwealth Government’s response to the Better Support for Carers Inquiry that it would introduce national carer recognition legislation and a national carer recognition framework in 2010 that will be informed by a review of existing relevant state and territory legislation and policy.

Carers in NSW

A carer is 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 estimated to be approximately 750,000 (ABS, 2004) carers. However, new figures identified through the ABS General Social Survey 2006 suggest that there could be as many as 1,199,000 carers in NSW, or 11.6% of the total NSW population (Edwards et al, 2009, p.5). See table 1 below.

Australian Bureau of Statistics has undertaken the 2009 Survey of Disability, Ageing and Carers, although findings are to be released later this year. As the previous SDAC was in 2003, it is likely that the 2009 SDAC statistics on the number of carers in Australia are likely to be closer to the corrected data in table 1 below.

Carers exist in all communities, including amongst Aboriginal communities, those of cultural and linguistically diverse backgrounds, amongst GLBTI communities, and throughout metropolitan, regional and rural NSW.

Table 1: Number and proportion of carers in NSW according to location

Carers Location	Total no. in NSW	Proportion of population in NSW	Proportion of population in Australia
Major cities	847,000	11.3%	11.0%
Inner regional	259,000	12.5%	12.1%
Outer regional	87,000	12.9%	11.2%
Remote	6,000	11.3%	9.0%
Very remote	1,000	11.3%	9.1%
Total	1,199,000	11.6%	11.2%

Source: 2006 Census of Population and Housing estimates corrected for undercount using estimates from the General Social Survey 2006 (Edwards et al. 2009, 5)

Key statistics on NSW carers

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

- Approximately one-third of all carers in Australia live in NSW
- 40% of primary¹ carers cared for a partner, 29% for a child, 32% for other (eg sibling, parent)
- Women aged 45-54 years were the largest single group of carers
- 45% of primary carers provided 40 hours or more care per week on average
- 78% of primary carers lived with the person they supported
- 75% of carers were of workforce age although 45% were not in the workforce
- 55% of primary carers relied on a government allowance or pension as their principal source of income (ABS, 2004).

Carers service needs

The *Carers NSW Survey 2008* identified that:

- 34% of carers surveyed were not using services
- The main services used were Home and Community Care 14% and Commonwealth Respite and Carelink Centres 14%, followed by Aged Care Assessment Team 9%
- Of all services carers would like to receive 24% wanted respite, 15% carer support groups, 14% counselling, 13% community care services and 11% education and training
- When asked what would make caring easier 17% stated respite, 10% stated education and training and 10% counselling (Carers NSW, 2009a).

Current policy context for carers in NSW

The *NSW Carers Action Plan 2007-2012* provides the key policy context for the planning and development for working with carers in NSW. The five main priority areas identified through the Action Plan are:

1. Carers are recognised, respected and valued

¹ A primary carer is someone who takes on the main caring responsibilities of a care recipient. ABS 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. Hidden carers are identified and supported
3. Services for carers and the people they care for are improved
4. Carers are partners in care
5. Carers are supported to combine caring and work.

Currently, NSW Health is developing an evaluation framework for the Action Plan and Carers NSW looks forward to the release of the evaluation results.

The *Who Cares...? Report on the inquiry into better support for carers* was released in April 2009. The report identified six main areas that illustrate the day-to-day challenges faced by carers, these include lack of recognition of carers contribution to society and an absence of a national approach to meeting their needs, access to information about supports, services and assistance, financial stress, disadvantage and the cost of care, dissatisfaction with community care systems, lack of choice in workforce participation and education and their overall poor health and wellbeing (HRSCFCHY, 2009).

The *Who Cares...?* report identifies that carers have diverse information needs and that increased access to information, education, training, family and carer advocacy, case management and care coordination services are required (HRSCFCHY, 2009). Barriers to accessing information for carers included an overly complex and fragmented service system, limited time of carers, language and unawareness of rights to services and the lack of availability of information in specific service settings, such as Centrelink (HRSCFCHY, 2009).

The Commonwealth Government's response to the inquiry's recommendations in October 2009 was disappointing in some areas. The failure of the response to address key issues relating to carers in the workforce, education and training for carers and specialised support for young carers is of particular concern to Carers NSW and the National Network of Carers Associations.

As NSW has the largest number of carers in Australia, a key action in the report for carers in NSW is the implementation of a National Carer Recognition Framework and National Carers Recognition Legislation both to be introduced in 2010.

Carers NSW recommendations for NSW

This submission makes recommendations based upon Carers NSW identification of gaps in services and supports for carers across NSW. While there are seven areas that have been chosen to expand upon in detail and make comprehensive recommendations about in the submission, there are issues that Carers NSW continues to support and advocate for in order to improve the quality of life of carers and the people that they support. Of particular concern to Carers NSW is that people with a disability, their families and carers are well supported and have access to appropriate, timely care. Issues include:

Implementation of a National Disability Long Term Care and Support Scheme

Carers NSW supports the implementation of a National Disability Long Term Care and Support Scheme to ensure the lifelong care of people with a disability, and looks forward to the Productivity Commission's inquiry outcomes.

Improvement of the Program of Appliances for Disabled People

Carers NSW is part of the PADP Community Alliance and continues to advocate for improvements and additional funding for PADP.

Implementation of the IMPACT Services principles

Carers NSW is on the IMPACT Services working group and recommends that the IMPACT principles are implemented as part of reform of Home and Community Care Services in NSW as a shift towards enablement, a wellness approach and restorative approach.

An urgent increase in the availability of supported accommodation options for people with a disability

In line with recommendations made as part of the *Who Cares...?* report, Carers NSW supports the continued funding and commitment to an urgent increase in the availability of supported accommodation options to provide choice for people with a disability, their families and carers.

1. Enacting NSW carer recognition legislation

KEY ISSUES

- NSW has the largest number of carers in Australia, or 11.6% of its population.
- NSW is one of the three states in Australia not to have adopted a Carers Recognition Act, although a Private Member's Bill – the *Carers Recognition Bill 2010* – was announced in December 2009 in the NSW Legislative Assembly.
- The Commonwealth Government is introducing national carers recognition legislation in 2010 that will complement state and territory carer legislation.
- The Commonwealth Government is introducing a nationally consistent carer recognition framework in 2010 that will build on and complement state and territory carer policies.

THE EVIDENCE

The National Network of Carers Association has been advocating for national carer legislation for several years, and at a state level carers NSW has also been advocating for this legislation over many years.

In its 2010-11 budget submission Carers Australia states that:

...often the one constant in a person's life who is in need of health and community care is the family carer. They manage complex medications regimes, give physiotherapy on a daily basis, provide emotional support and monitor changes in conditions, particularly in relation to mental health ... The National Health and Hospital Reform Commission coined the phrase about carers as the 'invisible health workforce' in their final report. They acknowledged the vital role of carers in improving the health and wellbeing of people needing care (Carers Australia, 2010).

Carers say they often feel ignored by health professionals and discounted as a member of the care planning and management team, despite their significant role in improving outcomes for the person they care for. In 2005, it was estimated the replacement cost of this care with paid care was \$30.5 billion nationally, and the cost to replace this care in NSW would be \$10 billion (Access Economics, 2005). With an ageing population and the increasing incidence of disability it is expected that the replacement cost of this paid care would be even higher in 2010.

Unlike Queensland, Western Australia, South Australia, Northern Territory and the Australian Capital Territory, NSW has no carer recognition legislation. The proposed Private Member's Bill, if passed, will bring NSW in line with other states and territories in having legislation that recognises and supports carers, and which will provide NSW carer legislation for the proposed Commonwealth legislation to build upon.

It is true that carers were recognised by the NSW Government through its introduction of the *NSW Carers Action Plan 2007-2012*, the *Mental Health ACT 2007* and the inclusion of carers in the *2009 NSW State Plan*, Healthy Communities initiative. The proposed Act builds upon these beginnings and is a significant step forward.

Importantly for carers, the adoption of the Bill will also acknowledge their vital contribution to society, the people they care for, and the economy.

The introduction of national carer recognition and a national carer recognition framework were two significant and key recommendations in the *Who Cares...?* report, and were agreed to by the Commonwealth Government in its response to the report. These two recommendations will be introduced by the Commonwealth Government in 2010, and consultations about their development are commencing.

If there is no NSW carers recognition legislation that can inform, or assist build, their development, Carers NSW believes carers in NSW may be disadvantaged by the national carer recognition legislation, and national carer recognition framework.

STRATEGIES FOR ACTION

- **NSW Government to introduce a Carers Recognition Act to acknowledge the vital contribution of carers, and to inform national carer legislation**

Carers NSW believes that a Carers Recognition Act should:

- recognise the valuable contribution of carers to our society and to the people they care for
- recognise the benefit, including the social and economic benefit, provided by carers to the community
- provide for the interests of carers to be considered in decisions about the provision of services that impact on the role of carers
- identify and address specific needs of families with children and young people who are carers
- deliver culturally appropriate services of Aboriginal and Torres Strait Islander carers and carers from culturally and linguistically diverse backgrounds.

The enactment of the *Carers Recognition Bill 2010* would also establish a *NSW Carers Charter* and a Ministerial Advisory Council for Carers. The Charter will be a set of principles for all agencies who work with unpaid family carers. It will ensure carers are seen as co-clients with needs in their own right and entitled to their own assessment.

In its response to the *Who Cares...?* report, the Commonwealth Government also stated that work is being undertaken to ensure that carers are recognised in relevant Commonwealth legislation and policy. For example, it stated that its *Charter of Rights and Responsibilities for Community Care* recognises that services to the care recipient need to be delivered in a way that respects the person's family, representative and informal care arrangements. The Charter became a legal instrument on 1 October 2009 and applies to Australian Government funded aged care packages which operate under the *Aged Care Act 1997* (Cth).

The proposed Ministerial Advisory Council for Carers would be appointed by two co-chair Ministers, and the Advisory Council would report to these Ministers and work to advance the interests of carers and to promote compliance by NSW Government agencies with the *NSW Carers Charter*, and also provide general advice to the Ministers relating to carers. Other jurisdictions, such as Western Australia, have established similar advisory councils.

RECOMMENDATION 1

Carers NSW recommends that the NSW Government enacts the Carers Recognition Bill 2010 to provide greater recognition and rights for carers in NSW.

RECOMMENDATION 2

Carers NSW recommends that the NSW Government endorses the NSW Carers Charter, scheduled in the proposed Carers Recognition Act 2010.

RECOMMENDATION 3

Carers NSW recommends that the NSW Government endorses the proposed Ministerial Advisory Council for Carers, scheduled in the proposed Carers Recognition Act 2010.

2. Measuring the effectiveness of interventions for carers

KEY ISSUES

- Currently there is no evaluation framework in place to measure the effectiveness of all interventions for carers in NSW.
- Evaluation of carer services is ad hoc and also does not generate consistent data about carers in NSW.
- There are multiple assessment methods and tools used across programs for carers which means that carers often have to be assessed a number of different times for different programs and there is no consistent way to collect data about carers in NSW.

THE EVIDENCE

Evaluation

There are many strategies used throughout NSW to support and engage carers, but how many of them are proven to be *effective*? Eagar et al. (2007) undertook a large scale literature review and meta-study of what support interventions were effective for carers. The term or quality of effectiveness in this context took into account whether an intervention impacted on carers in a number of ways including whether it:

- Relieves negative feelings associated with caring
- Prevents or relieves depression
- Maintains or helps to create subjective wellbeing
- Improves quality of life and level of satisfaction with the caring role
- Increases the carers ability to care and their knowledge
- Increases the carer's competence.

Effective intervention, in this context, implies that support and services for carers must have clearly identifiable positive outcomes that benefit carers. Measuring effectiveness is closely linked with the purpose or goal of the intervention for carers (Eagar et al., 2007). Effective intervention also requires building an evidence-base and using research to guide the implementation of services.

While the NSW Health Department is currently developing an evaluation framework for the *NSW Carers Action Plan 2007-2012*, there is no other method or process for standardised evaluation of carer services in NSW. The delivery of services for carers in NSW is spread across HACC, the Carers Program and federally funded programs such as Commonwealth Respite and Carer Centres (CRCC). While data is collected through the HACC Minimum Data Set for example, it does not assess the effectiveness of carer services and support interventions.

This translates into a system of evaluation which is fragmented and does not allow for a consistent approach to the evaluation of carer services. As Eagar et al. (2007) states:

It is clear from the review of the literature and current practice in Australia that there are opportunities to harmonise the use of key questions relevant to carers and their support needs in national surveys and routine data collections. This work would support the progressive development of a common language of carer support and more standardised approaches to information sharing, in order to reduce the problems created by agencies and organisations continually reinventing similar but non-comparable ways of collecting information (77).

In line with an approach to carer services and intervention which emphasises effectiveness, using a standardised evaluation tool becomes increasingly important.

STRATEGIES FOR ACTION

- **Taking action on the outcomes of the evaluation of the *NSW Carers Action Plan 2007-2012***

Carers NSW believes that the evaluation of the *NSW Carers Action Plan 2007-2012* will provide a foundation for further movement towards effective intervention with carers and looks forward to seeing the outcome. In addition, Carers NSW believes that any evaluation of the Action Plan must have clearly identifiable actions for any gaps in support for carers identified through the evaluation process.

RECOMMENDATION 4

Carers NSW recommends that the NSW Government, in particular, the NSW Department of Health, ensures that key findings that require action from the evaluation of the NSW Carers Action Plan 2007-2012 are clearly identified and are responded to appropriately with additional funding attached when required.

- **NSW to take the lead in development of standardised evaluation tool for NSW**

Carers NSW believes that all state funded carer programs should include a standardised evaluation tool for measuring the effectiveness of intervention for carers. This tool could be developed using the current evaluation framework for the Action Plan as well as from research centres such as the University of Wollongong's Centre for Health Service Development work about effective intervention.

Moreover, an standardised evaluation tool could be further developed through new and innovative projects such as ADHC's *The Better Practice Project* which is leading reform in HACC in NSW and is focused on evidence-based practice as well as implementing a framework for evaluation from the onset of the project. The Action Plan evaluation could also lead the development of a standardised evaluation tool for carers in NSW by using it as a baseline framework to inform a more generic tool.

RECOMMENDATION 5

Carers NSW recommends the NSW Government funds the development of a standardised evaluation tool to measure the effectiveness of carer support interventions and makes this tool accessible to all organisations who deliver state funded programs to carers.

Assessment

The *Who Cares...?* report recommended the expansion of a nationally consistent assessment process based on Carer Eligibility and Needs Assessment-Revised (CENA-R) questionnaire, across federal and state and territory governments in order to reduce the number of assessments required for carers to receive services (HRSCFCHY, 2009).

In the Commonwealth Government's response to this recommendation it was marked as *agree to further consider* and it was stated that the Commonwealth Government will seek agreement through the Community and Disability Services Ministers' Conference for further consideration as part of the National Disability Agreement by the end of 2011. The Commonwealth Government also stated that it will further consider extending the consistent assessment approach to other programs within its responsibility (Commonwealth Government, 2009).

However, the Commonwealth Government's response means that action will not be taken to improve the standardisation of assessment for carers until the end of 2011 and it sits only within the priorities of the National Disability Agreement.

Carers NSW believes that there is an urgent need to improve the standardisation of carer assessment in NSW across all service areas including Mental Health, Ageing and Disability. Carers NSW believes that a standardised assessment tool will greatly improve how support for carers is provided and will enable a more evidence-based and targeted approach to funding and planning specific types of services for carers.

STRATEGY FOR ACTION

- **NSW to take the lead in implementation of standardised assessment**

Carers NSW believes that the implementation of a standardised assessment for carers service needs will provide a baseline of data about carers and lead to improved outcomes and measurement of what carers needs are and how, or, if they are being met.

Carers NSW believes that the NSW Government is in a prime position to take the lead in implementing a standardised assessment tool for carers. The 2011 timeframe proposed by the Commonwealth Government's response to the *Who Cares...?* report is disappointing and delays any real action from taking place. Carers NSW suggests that the NSW Government consider more direct action in regards to the implementation of standardised assessment on a national level for carers by introducing it as an agenda item at the Council of Australian Governments.

In addition, Carers NSW recommends that the NSW Government takes the lead in this area through a serious consideration of how a standardised assessment tool for carers could be implemented across NSW. Carers NSW is aware that ADHC uses the Ongoing Needs Identification tool–NSW (ONI-N) as part of the HACC *Hunter Access Point* to assess a client's functional capacity and need for services. For example, ADHC reported as part of the *Hunter Access Point Newsletter* that through the *Access Point* a total of 16,077 assessments had been completed between March 2008 and October 2009 (ADHC, 2009).

Carers NSW recognises that the success and further expansion of the *Access Point Project* in the Hunter will affect how and if the ONI-N is implemented as a standardised assessment tool across NSW as part of HACC. Carers NSW believes that the ONI-N can be easily utilised to assess carers needs and document a carer's profile. Eagar and Owen's (2002) suggestion in the *NSW ONI Guidelines* states that if the carer themselves face significant issues a separate ONI can be completed for the carer.

Given that the ONI-N has been utilised quite extensively through the *Hunter Access Point* Carers NSW believes that the NSW Government should consider implementing it as an assessment tool across all programs that provide services to carers, particularly the Carers Program administrated by NSW Health.

RECOMMENDATION 6

Carers NSW recommends that the NSW Government actively advocates for the implementation of a standardised assessment tool for carers at the Council of Australian Governments and provides funding for a full-scale implementation of a standardised assessment tool such as the ONI-N across all programs and services for carers in NSW.

3. Early intervention and identification

KEY ISSUE

- There is currently no formal emphasis on early intervention with carers and very little evidence about what early intervention may look like for carers in NSW.

THE EVIDENCE

While there is an emphasis on identifying hidden carers in NSW (Priority Two of the Action Plan), there are few examples of approaches or strategies for early intervention with carers. In fact, intervention with carers is often ad hoc and relies on the carer's ability to successfully navigate their way through the maze of services or for a service provider to identify the carer and provide some support (HRSCFCHY, 2009).

Early intervention is an approach that seeks to put the right supports in place early so that better outcomes are achieved in the long-term. Early intervention is also often used as a strategy to prevent crisis from occurring. There is, however, little evidence about what early intervention might look like when applied to carers at the beginning of their caring role.

Carers NSW found through the development of the *Carer Life Course Framework* (Pagnini, 2005) that carers require specific interventions at certain phases of their caring journey or life course. However, carers are not always engaged or identified upon the commencement of their caring role and this has possible implications for outcomes for carers in the long-term. For example, it is vital that young people providing care are identified and supported at the earliest possible stage. For young carers, in particular, early intervention greatly assists in reducing the negative impacts caring may have and which may arise from their caring role (Carers ACT, 2008).

Carers NSW believes that the potential benefits of early intervention for carers are:

- Prevention of crisis and carer burn out
- Better outcomes for the carer and care recipient
- Increased perceptions and experience of support
- Limits the carer becoming 'hidden'
- Improved relationship between the carer and care recipient
- Increased carers ability to 'cope' with the caring role
- Carers have more choice about their caring role and care support
- Limited impact on carers health and wellbeing.

It is these potential benefits that makes further research about strategies and approaches to early intervention with carers so important.

Unfortunately, evidence also indicates the low uptake of aged and community care support services by carers, and other eligible recipients. The first annual HACC report, *Home and Community Care Program 2007-08 Annual Report*, was released last year. It indicated that less than half (47.1%) the target population accessed HACC services – NSW (48.1%) had the third highest access, behind Victoria (56.3%) and South Australia (67.8%). Eighty per cent of NSW HACC clients who reported they had a carer lived with the carer (DoHA, 2009).

The *Carers NSW Survey 2008 Report* indicated that of 654 carer respondents only 34% accessed support services, and only 28% of care recipients accessed them (Carers NSW, 2009a).

An earlier survey by SANE Australia in 2007 revealed that less than half (46%) had accessed carer support services of any kind (SANE Australia, 2007).

STRATEGIES FOR ACTION

- **Research on early intervention**

Carers NSW believes that early intervention would place emphasis on a timely approach to service delivery for carers with the aim of improving outcomes for the caring relationship. Early intervention could also encourage the establishment of appropriate support structures that may help to prevent crisis situations from occurring and increase a carer's experience and perception of support from the onset of their caring role.

Carers NSW believes that further research on what early intervention might look like for carers, as well as its impacts, would help create an evidence-base for when intervention is most appropriate for carers. Such research could also establish how the perception of support from the beginning of the caring role can influence the caring experience overall and determine at what points carers seek support.

RECOMMENDATION 7

Carers NSW recommends that the NSW Government provides funding for research into early intervention for carers in order to gain a better understanding of how carers can be supported and outcomes for them improved.

4. Best practice for reaching hidden carers

KEY ISSUES

- Carers are considered to be hidden carers if they do not identify themselves as a carer or prefer not to disclose their role to others; and, or, they do not appear in statistics and data relating to carers (HRSCFCHY, 2009).
- There are a number of strategies used across the health and community sectors to engage hidden carers but there are no documented models or frameworks for best practice. The *Who Cares...?* report states that identification as a carer is the first step in accessing supports and services, and in NSW hidden carers are a priority of the *NSW Carers Action Plan 2007-2012*.

THE EVIDENCE

Priority Action Two in the *NSW Carers Action Plan 2007-2012* states that *hidden carers are identified and supported*. This part of the Action Plan takes into account engaging with specific carer groups such as CALD carers and Aboriginal carers as well as carers who are not using services and who are not identifying themselves as carers.

Evidence included in 3. Early intervention and identification above indicates the low access to services of carers (as well as the people the care for) and this may also reflect the incidence of hidden carers who chose to remain unidentified to some service providers.

At the Carers NSW 2009 Biennial Conference a number of presentations were made about working with hidden carers, in fact, Carers NSW is aware of a number of different strategies employed across the sector to engage hidden carers. However, apart from at conferences and meetings there is no formal process for identifying a best practice model for working with hidden carers in NSW and developing expertise across the sector.

Carers NSW also believes that improved identification of hidden carers is likely to be reflected in improved data carer data to inform government policy, programs and planning in relation to carer support and services.

STRATEGY FOR ACTION

- **Development of a hidden carers best practice model**

Carers NSW believes that the creation of a best practice model for hidden carers would provide a useful tool to provide community and health workers supporting carers with the know how to most effectively engage with these carers.

RECOMMENDATION 8

Carers NSW recommends that the NSW Government provides funding for the development of a best practice model for reaching hidden carers. This funding should include the development of a discussion/research paper, community consultations, the development of a model and promotion across the sector once the model is established.

5. Respite

KEY ISSUES

- Carers are using more respite but funding for respite has decreased.
- Carers require support and education to access respite.

THE EVIDENCE

When Carers NSW consulted with carers in 2008 and 2009, nearly every carer stated that they wanted more respite. Respite also featured in the *Who Cares...?* report. Of all services mentioned in the Better Support for Carers Inquiry the two repeatedly mentioned as both critically important and in short supply were respite and in-home assistance (HRSCFCHY, 2009).

The availability of respite both planned and emergency was an issue expressed by many carers. In addition, the affordability and flexibility of respite were perceived as barriers to accessing this service type. It is noted that respite services often meet the needs of the service system and not the carer or care recipient. Often respite is not available for those with high support needs or the only option for respite is a residential care facility which is not considered an appropriate option by carers and care recipients (HRSCFCHY, 2009).

The recent progress report for the Commonwealth State/Territory Disability Agreement on specialist disability services found that funded respite services registered the highest growth in service users relative to target population. In 2007-08, 31,500 people used CSTDA-funded respite services compared with 20,500 in 2003-04, corresponding to an increase from 96 respite users per 1,000 target population in 2003-04 to 137 per 1,000 in 2007-08. Over the same period, government expenditure per respite service user fell by 16% in real terms. Data on hours of respite received show a downward trend from an average of 12.1 per respite user per week in 2003-04 to 10.5 hours per week in 2007-08 (AIHW, 2009b).

The *Home and Community Care Program 2007-08 Annual Report* indicated that the highest average hours of service to clients by assistance type was for centre-based day care (130 hours) followed by respite care (86 hours). Note: the report stated that the average hours of care are a rough measure of service provision and do not reflect the experiences of individuals, eg some clients receive services throughout the entire year and others for only short periods (DoHA, 2009).

The recent report by Alzheimer's Australia released in June 2009 *Respite Care for people living with Dementia: It is more than just a short break* demonstrated that respite may be better utilised by carers if they have received education about it. The evaluation conducted by Alzheimer's Australia found that when carers attended an education course that included information about using respite 95% of carers felt that they would be comfortable using respite compared to 43% prior to the course (Alzheimer's Australia, 2009a). In addition, the use of respite more than doubled from 25% of carers who were using respite at the beginning of the course to 56% at the end of the course (Alzheimer's Australia, 2009a). What is most striking about this evidence is what a carer cited as the benefits of this education "...the course had helped give them 'permission' to use respite services" (Alzheimer's Australia, 2009a, 22).

STRATEGIES FOR ACTION

- **NSW funding for respite**

The evidence suggesting that government funding for respite per service user decreased in real terms while increased availability is identified by carers as a high need for their caring

role is alarming. Carers NSW believes that respite is an essential service for carers and that funding for respite in NSW must be provided according to the need for this service. In the light of the AIHW findings regarding respite usage under the HACC and CSTDA programs, Carers NSW recommends that the NSW Government increases its allocation of funding in NSW to align with demand, and the identified need by carers.

RECOMMENDATION 9

Carers NSW recommends that the NSW Government increases its allocation of funding for respite for all carers in NSW.

- **Education courses for carers about using respite**

As found by the Alzheimer's Australia study, carers need to be supported and educated to use respite. While the Alzheimer's Australia report is particular to carers of people with dementia, it provides direct evidence that education about respite may increase carers capacity to utilise it. It may also help, as cited above, give carers permission to use this service.

RECOMMENDATION 10

Carers NSW recommends that the NSW Government funds education courses for carers about how to use respite and its benefits in order to increase carers utilisation of respite services.

6. Providing targeted support

KEY ISSUES

- Carers need tailored and targeted support to meet their diverse needs.
- Carer population groups such as carers of people with dementia, sandwich generation carers, elder carers GLBTI carers, young carers and mental health carers all require specific action to have their needs considered in service planning and delivery.
- Dementia prevalence in Australia and NSW is predicted to increase significantly.

THE EVIDENCE

Dementia carers

Research and reports released on dementia prevalence and the growing need for carers of people with dementia by Access Economics and Alzheimer's Australia in 2009 demonstrate an urgent need for increased consideration and support for this group of carers.

In NSW in 2009, there are an estimated 84,000 people with dementia, 24,000 of which were new cases (Access Economics, 2009b). This number is predicted to increase to 341,000 people by 2050 (Access Economics, 2009b).

Access Economics (2009a) reported that family carers may be the only source of care for many people with dementia, with 37% of people with dementia receiving no formal care. In addition, they estimate the cost of replacing carers with paid care at \$5.5 billion per annum (Access Economics, 2009a).

The needs of carers of people with dementia are acute, in that, the characteristics of the condition make the caring role especially challenging (Access Economics, 2009a). Moreover, it is emphasised that in both international and Australian studies that flexible support, information and respite services, together with workplace and community understanding are essential supports for family carers of people with dementia (Access Economics, 2009a). Of the carers surveyed by Access Economics 31% stated caring had a negative impact on their physical health, 53% on their mental and emotional wellbeing and 55% on their lifestyle (Access Economics, 2009a).

These carers, when given a choice valued home support services such as shopping, transport and cleaning the most. Respite provided daily or for an extended period was also valued by these carers. A community centre offering counselling, recreational activities, education and information services was also a service type that carers of people with dementia would like to be made available to them (Access Economics, 2009a).

The *Projections of dementia prevalence and incidence in NSW: 2009-2050* (Access Economics, 2009b) also demonstrates the areas of NSW which have a higher prevalence of dementia and where more support will need to be provided. The top 10 areas in 2009 include Tweed, Port Macquarie, Myall Lakes, Gosford, Bega, Wyong, South Coast, Oxley, Strathfield and The Entrance. The Area Health Service with the highest rate of dementia prevalence was North Sydney/Central Coast and the ADHC region with the greatest prevalence was Metro South.

An emerging issue in relation to dementia is early onset or younger onset dementia. Carers NSW repeatedly has inquiries from very distressed carers and family members who cannot get access to dementia services and care packages as the person with dementia is not eligible for these as they are too young, or the person with dementia has specific needs that are not met by mainstream dementia services. Another difficulty for people with early onset

dementia is being correctly diagnosed to allow them and their carer and families to be directed to appropriate services, if they are available. Working carers also have difficulty in getting services to support them continue to work full-time to meet mortgages and other financial commitments, and many report that the cost of care services, if they can access them, is so high that this means they are required to use any savings or retirement funds (Carers NSW, 2009b and information provided to Carers NSW by carers).

STRATEGIES FOR ACTION

- **Increased funding and support for carers in high dementia prevalent areas of NSW**

Dementia is a national health priority and, through the National Dementia Initiative, governments have started to address its increasing prevalence (Access Economics, 2009a). Given that we know what areas of NSW are currently, and are going to be, areas of high incidence of dementia a more targeted approach based on this knowledge can be implemented.

Increased support for dementia carers across the whole of NSW is, and will continue to be, an essential part of service provision to carers across the state. Carers NSW believes it is important that additional funding is provided to increase the expertise of service providers across NSW, but particularly in the areas where dementia is most prevalent. However, it should also be noted that although areas and towns in western NSW are not areas of greatest prevalence they are rural and remote areas that are already poorly serviced.

Carers NSW supports Alzheimer's Australia NSW in their recommendation for continued support and expansion of Dementia Advisory Services (DAS). DAS are a valuable early intervention resource for people living with dementia, their family and carers and help promote dementia awareness. DAS workers also provide training, information and referrals, link people to assessment and support services and assist carers with home management strategies.

The expansion of DAS in 2010-11 should include increasing all of the current part-time positions to full-time to meet increasing demand. In addition, further funding for support groups for carers of people with dementia in high prevalence and emerging high prevalence areas will also be an important part of creating social support for these carers. Any additional funding should also be used to ensure that culturally appropriate services for Aboriginal carers and CALD carers of people with dementia are available across NSW.

RECOMMENDATION 11

Carers NSW recommends that the NSW Government increases funding for all services which support carers of people with dementia in high prevalence and rural and remote areas, specifically the Dementia Advisory Services and carer support groups, to ensure that these carers have access to the support that they need.

RECOMMENDATION 12

Carers NSW recommends that the NSW Government increases its funding for strategies that improve diagnosis of early onset or younger onset dementia, and also increases funding for the provision of appropriate care services.

Sandwich generation carers

The term 'sandwich generation' applies to carers who have both child and adult care responsibilities. The majority of these carers are women. While the number of women in this situation is unknown, and currently may only represent a small percentage of the carer

population, the increase in the age of women having children and the ageing population will mean that this particular group of women carers will also increase (Baird et al., 2009).

The research suggests that there is a gap in our knowledge about this group of carers and what their specific needs are. This highlights the need for further identification of these types of carers and how services can better engage with them. Caring for two or more people potentially increases a carer's experience of isolation as well as the intensity of their caring responsibilities.

STRATEGIES FOR ACTION

- **Further research about the needs of sandwich generation carers**

Given that sandwich generation carers are an emerging group of carers with dual caring responsibilities it is essential that the health and community service systems are able to identify their specific needs and address them. To do this, more research about this emerging group of carers needs to be undertaken.

RECOMMENDATION 13

Carers NSW recommends that the NSW Government funds research into the specific needs of sandwich generation carers in order to create an evidence-base to plan and implement specialised services for this group of carers.

Elder carers

The needs of carers of older people differ from those who care for children (Baird et al., 2009). Elder care is a gendered issue in Australia: it is conducted overwhelmingly by women relatives of elderly care recipients. These women are in their peak working years of 35-54 years (Baird et al., 2009).

In an elder care situation the intensity of the role increases over time and can involve a role reversal between parent and child (Baird et al., 2009). Issues affecting elder carers include:

- That the beginning stages of the caring role are the most intense and may require the carer to have greater absences from work
- Elder care needs often arise unexpectedly and are difficult to plan for.

In addition, this group of carers is disadvantaged by the *Fair Work Act 2009* which excludes them from the right to request flexible work in order to combine caring and work.

This particular group of carers is the fastest growing group of carers in Australia. Particular interventions will be required in order to assist these carers to coordinate the care of the person in need of support.

STRATEGIES FOR ACTION

A significant part of supporting elder carers will be assisting them to remain in paid employment or assisting them to re-enter the workforce. These issues will be addressed in Section 7 of this submission which focuses on carers workforce participation.

- **Funding for increased support of elder carers**

Increased funding for services that support elder carers in NSW is essential. While currently programs such as HACC and ACAT provide support to people who are frail aged and their carers these programs in most cases have extensive waiting lists. Carers NSW has continually heard from elder carers who are still waiting for an Aged Care Assessment Team

to come to their home or are waiting for a HACC service to become available. Carers NSW believes that to provide the appropriate support to elder carers the NSW Government must increase its allocation of funding to programs such as HACC and ACAT to ensure waiting lists are minimised and services delivered to carers who are in need of them.

RECOMMENDATION 14

Carers NSW recommends that the NSW Government increases its allocation of funds to services and programs that support elder carers such as Aged Care Assessment Teams and Home and Community Care.

- **Promotional/awareness raising for elder carers**

Catering to the needs of elder carers requires a separate and specific policy approach. It also requires an emphasis on early intervention and care coordination. Carers NSW believes that it may be beneficial to develop a promotional and awareness raising campaign aimed at women aged 35-54 years to provide information on what to do if you find yourself in a caring role and what supports are available.

RECOMMENDATION 15

Carers NSW recommends that the NSW Government funds the development of a promotional/awareness campaign targeting the population group most likely to become elder carers—women aged 25-54, about what supports are available and what to do in the event that they become a carer.

GLBTI carers

Gay, Lesbian, Bisexual, Transgender and Intersex (GLBTI) carers are some of the most hidden carers in the community and they require support and services which foster their full inclusion. Often GLBTI carers face challenges because of:

- Discrimination and marginalisation
- Equity of access to all services
- Recognition of their caring relationships, for example, many of the GLBTI rely on informal friendship networks
- Absence of family support
- Higher incidences of drug use and depression
- Social isolation
- They are unaware or do not assume that mainstream services may be able to offer them support
- The language used to describe services and support is not inclusive.

In addition, in the recent study released by Alzheimer's Australia *Dementia, Lesbians and Gay Men* it suggested that many lesbian and gay seniors became adults in a time when homosexuality was a source of societal discrimination (Alzheimer's Australia, 2009b). It also stated that:

Many daily activities and conversations don't require people to make a statement about their sexuality. But when lesbians and gay men begin to interact with services and support systems, this can become an issue (Alzheimer's Australia, 2009b, 8).

This report also identifies that there are many different types of caring relationships involving gay and lesbian seniors including, same-sex partnerships, community networks, a gay or lesbian adult child providing care for a lesbian or gay parent and a heterosexual person caring for a senior who is gay or lesbian (Alzheimer's Australia, 2009b). In addition to the various types of caring relationships gay and lesbian seniors are more likely to live alone than the general population (Alzheimer's Australia, 2009b).

Generally, awareness of this group of carers is quite low and many do not access services. Previously NSW Health funded ACON to deliver the GLBT Carer Support Program for two years from 2005 to 2006 in the South East Sydney Illawarra Area Health Service region. It is Carers NSW's understanding that GLBTI carers were so hidden and hard to reach that there were not enough carers engaged to continue running the program. This, however, does not mean that GLBTI carers do not require continued support and services.

Carers NSW is aware that often a GLBTI carer will not feel comfortable accessing mainstream services such as support groups for carers because they face discrimination as a result of their same-sex relationship with the care recipient. Carers NSW heard from carers who are often the only person in a support group with a same sex partner and do not feel able or comfortable to share their story with the group. This suggests that some services such as support groups would benefit from being specific to the GLBTI community, and also the need for initiatives to raise service provider awareness of, and training in, provision of GLBTI carer sensitive and appropriate services.

STRATEGIES FOR ACTION

- **Re-implementation of the GLBTI Carer Support Program**

Carers NSW believes that the GLBTI Carer Support Program should be funded in order to provide services such as support groups, advocacy and referral for GLBTI carers. The re-implementation of such a program will allow for GLBTI carers to have their need for support met within an environment they feel comfortable.

RECOMMENDATION 16

Carers NSW recommends that the NSW Government provides funding for the re-implementation of the GLBTI Carer Support Program in order to ensure that GLBTI carers have their need for targeted support met.

- **Undertake further research about the needs of GLBTI carers**

Currently there is a limited evidence-base that informs policy and practice with GLBTI carers. There is currently research about gay and lesbian seniors and their caring situations undertaken by Alzheimer's Australia and ACON, however there are still gaps in our knowledge about the specific needs of this group of carers. Carers NSW believes further research about GLBTI carers and how and where they access services is needed in order to be able to provide effective support services to this group.

RECOMMENDATION 17

Carers NSW recommends that the NSW Government funds further research about the needs of GLBTI carers and how and where they access services.

Young carers

In NSW, there are estimated to be 90,200 young carers aged under 25 living in NSW, or 4% of all people under 25 years (ABS, 2004).

A young carer is a child or young person under 26 years who provides support for a family member with a long-term illness, disability, mental illness, alcohol or drug dependency. They usually have more responsibilities than other young people their age. Young carers most at risk are those caring for parents, particularly sole parents. In some cases young people are caring on their own with little or no help.

Caring at a young age can have an impact on an individual's educational, social and emotional life, as well as have implications for their physical development, the quality of childhood and opportunities for the future.

The NSW Government supports young carers through funding to Carers NSW for its Young Carer Program; and Carers NSW is encouraged that Ageing, Disability and Home Care Department of Human Services has increased its focus on the best way to develop policies and services to support young carers in NSW.

STRATEGY FOR ACTION

- **Carers NSW provides expert advice to NSW Government and agencies on young carer issues**

Currently, Carers NSW has input into national young carer initiatives through its membership of ANYCAT (Australian National Young Carers Action Team) and other consultative mechanisms, but it believes that its membership of key advisory groups that advise NSW Government and agencies on policy, and define targets and services for young carers is essential to ensure that adequate expert advice and consultation is achieved.

RECOMMENDATION 18

Carers NSW recommends that the NSW Government through Ageing, Disability and Home Care, Department of Human Services NSW includes Carers NSW, as the peak organisation for carers in NSW, to key advisory bodies that identify priorities, define programs and target services to better support young carers in NSW.

Carers NSW has had feedback from young carers about their difficulty in accessing the NSW Companion Card. It has long been an issue that young carers are not recognised in their caring role. Especially when caring for an older sibling or parent, it is often assumed that because they are young, they are the ones being 'cared for'. Issues have arisen where young people accompanying an older sibling or parent (who they care for) are not allowed the same 'carer' privileges that other carers enjoy, such as free entry to particular venues, or transport.

STRATEGY FOR ACTION

- **NSW implements a Young Carer Companion Card**

In order to address this issue of recognition Carers NSW believes that young carers would benefit from having their own Young Carer Companion Card as part of the current NSW Companion Card Scheme.

RECOMMENDATION 19

Carers NSW recommends that the NSW Government funds the development of a Young Carers Companion Card as part of the existing Companion Card Scheme in NSW.

Mental health carers

In 2009, the Mental Health Council of Australia released the *Adversity to Advocacy report card* which reports the results of a national survey of mental health carers. The report documents 15 key issues found through the survey. The report card suggests that there is still a lot to be done to improve the quality of life and services to mental health carers.

STRATEGY FOR ACTION

- **Ensure current research on mental health carers informs practice**

Carers NSW believes that key findings and recommendations of the report need to be further consulted in the planning and implementation of support and services for mental health carers in NSW.

RECOMMENDATION 20

Carers NSW recommends that the NSW Government increases funding overall for services to mental health carers in line with the 15 key issues raised in the Adversity to Advocacy report card.

7. Carers low workforce participation

KEY ISSUES

- Carers often have limited choice about the need to reduce or end paid employment to undertake their caring role, and once their caring role has concluded only small numbers of carers are returning to work.

THE EVIDENCE

The *NSW Carers Action Plan 2007-2012* Priority for Action Five states that *carers are supported to combine caring and work*, however, more direct action is required in this area in order to ensure carers can continue to work and care if this is what they choose as well as re-enter the workforce upon the cessation of their caring role.

The Taskforce on Care Costs, in its 2007 report *The Hidden Face of Care* found that carers represent an under-utilised workforce resource: 44% of the carers surveyed choose a role below their skill level because it gave them flexibility they needed to balance work and caring responsibilities (TOCC, 2007). This represents a considerable loss in productivity for national and state economies. Some significant issues that carers report as barriers in accessing and staying in paid employment are:

- Lack of quality alternative care for the person they support
- Poor recognition from employment service providers
- Lack of flexible working arrangements
- Lack of understanding from colleagues and co-workers.

Access Economics reported that around 36% of primary carers who were unemployed or not in the labour force expressed a desire to return to work, especially on a part-time basis. Similarly they found the opportunity cost of time devoted to informal care, measured as a reduction in paid employment, is estimated to be \$4.9 billion (Access Economics, 2005).

The NSW Office of Industrial Relations released research in 2009 about mature aged carers and workforce participation. This research indicates that the workforce will change as Australia's population ages by impacting the number of workers who also have elder care responsibilities (Baird et al., 2009). This reflects and reinforces the need for employers and workforce policy to adapt to the changing demographics of the Australian community.

There is also an alarming finding that once carers leave the workforce to undertake caring responsibilities they often do not re-enter at the same level or at all (Baird et al., 2009). Adverse impacts of caring on labour force participation include:

- Changing jobs
- Reducing work hours
- Refusing promotion
- Not returning to earlier patterns of work when the caring relationship ends (Baird et al., 2009).

Carers NSW knows that many carers who are not in paid employment want to work and that barriers to full participation in the workforce include lack of affordable, alternative care arrangements and flexibility in work hours.

In addition, a recent scoping of Strategic Carers Action Network (SCAN) members by Carers NSW demonstrated that while the other four Priorities for Action of the Action Plan were considered in their work with carers, Priority for Action Five was not a key focus. This

suggests that health and community organisations require further support to engage and provide services to working carers.

STRATEGIES FOR ACTION

Carers NSW supports both the recommendations and the proposal for further research made in the *Taking Care: Mature Age Workers with Elder Care Responsibilities* project, conducted by the Women and Work Research Group at the University of Sydney and commissioned by NSW Industrial Relations. In addition, Carers NSW believes that the following strategies can be implemented to support employed carers as well as assist them to re-enter the workforce.

- **Increased services and service flexibility for employed carers**

Carers NSW found that service providers often struggle to engage with employed carers due to a lack of resources to provide services at times when employed carers could access them. Service providers need to be supported and properly resourced to be able to provide flexible hours of operation which make it easier for employed carers to access services.

Carers NSW believes that it would be of great benefit for employed carers if other carer services funded through HACC and the NSW Carers Program were funded to have flexible hours of operation to increase access for working carers. In addition, extended day respite places and programs for working carers in NSW should be a priority for the NSW Government.

Currently Carers NSW is trialling the extension of its Carer Counselling Program and the Carer Line up to 8.00pm three nights a week to improve access to these services for working carers, in particular. The trial is funded until 30 June 2010, and is funded by the Australian Department of Health and Ageing through the National Respite for Carers Program. Findings will inform Carers NSW of future program requirements.

RECOMMENDATION 21

Carers NSW recommends that the NSW Government provides additional funding to ensure all carer support programs are able to extend services to employed carers and that more respite programs and places are made available to assist working carers maintain their paid employment.

- **Support to re-enter the workforce**

Carers need support to re-enter the workforce once their caring role has ceased. Carers NSW believes that the NSW Government has a role to play in assisting carers to re-enter the workforce by funding the subsidisation of additional vocational training to do so.

RECOMMENDATION 22

Carers NSW recommends that the NSW Government, in particular the NSW Office of Industrial Relations, provides funding for training for carers who have left the paid workforce as a result of their caring role.

- **Adapt NSW Legislation: The right to request flexible work**

The *Who Cares...?* report in Recommendation 40 states:

That section 65(1) of the *Fair Work Act 2009* be amended to extend the right to request flexible working arrangements to all employees who have recognised care responsibilities, including those caring for adults with disabilities, mental illness, chronic illness or who are frail aged.

Carers NSW was disappointed when the NSW Government recently adopted the *Fair Work Act 2009* as the National Employment Standard (NES) in s65 of the *Fair Work Act 2009*

excluded the right of all carers to request flexible working arrangements. The Act only applies this right to a parent with a child with a disability under 18 years.

In spite of the adoption of the Act, Carers NSW would like to see the NSW Government take a pro-active approach to ensuring that all carers have the right to request flexible working conditions. For instance, Baird et al. suggest that there is a more direct role to be played by the states and territories:

It appears therefore, that using anti-discrimination legislation, the NSW State government could act to provide workers with caring responsibilities for adults with better access to flexible working than is currently available by way of anti-discrimination laws. Models exist on which to build. Victoria, the UK and New Zealand have all recently created a right for an employee to seek to alter their work arrangements to help combine caring and employment (47).

Carers NSW agrees with Baird et al. that there is more room for innovative solutions and possible changes in the legislation to ensure that all carers in NSW have the right to request flexible work.

RECOMMENDATION 23

Carers NSW recommends that the NSW Government, in particular the NSW Office of Industrial Relations, explores opportunities as suggested in the Taking Care: Mature Age Workers with Elder Care Responsibilities research report, to amend legislation as required for all carers in NSW to have the right to request flexible work regardless of age or relationship status.

RECOMMENDATION 24

Carers NSW recommends that the NSW Government requests that the Commonwealth Government through the Council of Australian Governments amends the Fair Work Act 2009 and the National Employment Standards to include the right for all carers to have the right to request flexible work arrangements regardless of age or relationship status.

Conclusion

Carers NSW would like to thank the NSW Government for the opportunity to make this pre-budget submission for 2010-11. Carers NSW believes that 2010-11 presents an opportunity to improve and increase support and services to carers in NSW, and nationally, and looks forward to the NSW Parliament implementation of the *Carers Recognition Act 2010* as well as increased funding for targeted and effective support for carers across NSW.

References

- Access Economics (2005) The Economic Value of Informal Care, Access Economics Report for Carers Australia, Canberra
- Access Economics (2009a) Making Choices Future dementia care: projections, problems and preferences, report prepared for Alzheimer's Australia, Canberra
- Access Economics (2009b) Projects of dementia prevalence and incidence in NSW: 2009-2050, report prepared for Alzheimer's Australia, Canberra
- Ageing, Disability and Home Care, Department of Human Services NSW (2009) Hunter Access Point Newsletter, Issue 5, www.ncoss.org.au/mail/HACC/091208-Hunter-Access-Point-Newsletter-Nov-09.pdf
- Ageing, Disability and Home Care, Department of Human Services NSW (2009) The Better Practice Project, INFORMATION SHEET 1, Sydney
- Alzheimer's Australia (2009a) Respite Care for People Living with Dementia "It's more than just a short break" Discussion Paper 17, Canberra
- Alzheimer's Australia (2009b) Dementia, Lesbians and Gay Men, Paper 15, Canberra
- Australian Bureau of Statistics (2004) 2003 Survey of Disability, Ageing and Carers (SDAC) Summary of Findings, Australian Bureau of Statistics, Canberra
- Australian Department of Health and Ageing (2009) Home and Community Care Program – 2007-08 Annual Report, Canberra
- Australian Institute of Health and Welfare (2009a) Australia's Welfare 2009, Canberra
- Australian Institute of Health and Welfare (2009b) Disability support services 2007-08: national data on services provided under the Commonwealth State/Territory Disability Agreement, Canberra
- Baird M et al. (2009) Taking Care: Mature Age Workers with Elder Care Responsibilities, Women and Work Research Group, University of Sydney, Sydney
- Carers ACT (2008) Response to Inquiry into the Early Intervention and Care of Vulnerable Children in the ACT, Canberra
- Carers Australia (2010) Don't wait: Our future is now, Federal Budget Submission, January 2010, Canberra
- Carers NSW (2009a) 'What Carers Want?' Carers NSW Survey 2008 Report. Carers NSW, Sydney
- Carers NSW (2009b) Carers News February/March 2010, Sydney
- Commonwealth Government (2009) 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
- Eagar K and Owen A (2002) Ongoing Needs Identification in NSW Primary Health and Community Care: How and Why, Centre for Health Service Development, University of Wollongong
- Eagar K et al. (2007) Effective Caring: a synthesis of the international evidence on carer needs and interventions, Centre for Health Service Development, University of Wollongong
- Edwards B et al. (2009) The tyranny of distance? Carers in regional and remote areas of Australia, report prepared for Carers Australia by the Australian Institute of Family Studies, Canberra

House of Representatives Standing Committee on Family, Community, Housing and Youth (2009) *Who Cares...? Report on the inquiry into better support for carers*, Canberra

Mental Health Council of Australia (2009) *Adversity to Advocacy report card*, Canberra

NSW Health (2007) *NSW Carers Action Plan 2007-2012*, NSW Department of Health, Sydney

Pagnini D (2005) *Carer Life Course Framework: an evidence-based approach to effective carer education and support*, Carers NSW, Sydney

Pagnini D (2008) *Expansion of the Carer life Course Framework*, Carers NSW, Sydney

Ramsey L et al. (2007) *A National Approach to Assessing the Needs of Carers*, Centre for Health Service Development, University of Wollongong

Roberto, K and Jarrott, S (2008) *Family Caregivers of Older Adults: A life span perspective*, *Family Relations* 57(1)

SANE Australia (2007) *SANE Research Bulletin 5: Family Carers and Mental Illness*, available at: www.sane.org/images/stories/information/research/0701_info_rb4.pdf

Taskforce on Care Costs (2007) *The hidden face of care: combining work and caring responsibilities for the aged and people with a disability*, retrieved from www.toc.org.au

Wagner, D (2006) *Families, Work and an Ageing Population: developing a Formula That Works for the Workers*, *Journal of Ageing and Social Policy* vol. 18(3/4)114

Williams K and Owen A (2009) *A contribution to research and development in the carer support sector: Lessons on effective caring*, *Australian Institute of Family Studies Family Matters*, 82 pp38-46