



Getting on with the job

**Delivering on the NSW Government's
commitment to carers**

Carers NSW 2013-14 pre-budget submission

December 2012

About Carers NSW

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

Our vision is that all carers in NSW are recognised, valued and supported by the community and by governments. Our goal is for carers in NSW to have improved opportunities, choice and access to support that meets their needs and circumstances across their life span.

About Carers

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/or alcohol dependency, 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-a-day job with emotional, physical and financial impacts, with implications in terms of their participation in employment, education and community activities.

Across NSW, there are approximately 850,000 carers, comprising individuals as young as 8 years of age through to the very elderly.

Carers exist in all communities, including amongst Aboriginal communities, those of culturally and linguistically diverse backgrounds, amongst Gay, Lesbian, Bisexual, Transgender, Intersex communities, and throughout metropolitan, regional and rural NSW.

Carers NSW

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Introduction

In its first 18 months in government, the NSW Government has demonstrated a strong focus on delivering on its promises and getting on with the job. It has prided itself on making the tough decisions that are needed to ensure a stronger tomorrow for NSW.

Carers NSW welcomes and supports the NSW Government taking a responsible and forward looking approach. We think that this approach should apply to all of the challenges facing our state, not just the high profile ones like transport and infrastructure.

Other areas have also suffered from underinvestment in the past, and are long overdue for change to ensure a strong tomorrow for NSW. The 850,000 carers in NSW, who save the NSW Government around \$15 billion each year, would attest to the need for greater recognition, inclusion and support of carers. The sustainability of our health, disability and mental health sectors depends on the continued contribution of this 'invisible workforce'.

The NSW Government is on the record acknowledging the need to better support and recognise carers. In the words of the Hon. Andrew Constance, now Minister for Ageing and Disability Services:

We can test the heart of society by looking at the response of government to community needs and the recognition of carers. For too long in New South Wales we have failed in that duty. We have failed to recognise those who contribute in ways that we can only imagine... We cannot turn our backs on carers in New South Wales.¹

The NSW Government has started delivering on its commitment to carers. A lot of work has been done to date. The *Stronger Together II* commitments continue to be delivered, the NSW Mental Health Commission has been established, and important reforms are occurring in the disability sector with the introduction of person centred approaches and the National Disability Insurance Scheme launch site in the Hunter. More specific work for carers has also been undertaken, especially in relation to young carers and to the implementation of the NSW *Carers (Recognition) Act 2010*.

To date the NSW Government has been delivering on its promises. Carers NSW implores them to keep it up. Now is the time to take some tough decisions, and make the investment that is needed for carers to ensure that our state has a strong future. The future of NSW depends on improvements to the experience of caring. This submission will outline the next steps the NSW Government needs to take to build upon the work done so far, and to keep on delivering for carers.

About this submission

This submission outlines recommendations for funding allocation in the 2013-14 NSW State Budget, relating to six priority areas:

1. Carers and person centred approaches
2. Rural and regional carers
3. Carer advocacy services
4. Workplace support of carers
5. Whole of government approach to recognising, including and supporting carers
6. Young carers.

To date, the NSW Government has made important investments in each of these areas. This submission outlines the next steps that the NSW Government must take to build on existing work and advance in these areas.

The six priorities addressed in this submission are just some of the key challenges facing carers in NSW. In addition to these six areas, Carers NSW continues to advocate on a range of other critically important issues such as the need for better services and support for carers of people with a mental illness, carers of people with dementia, and older parent carers.

Summary of Recommendations

1. Carers NSW recommends that the Department of Family and Community Services fund the provision of information to carers to support their engagement in person centred approaches, including an online information portal, printed resources and information sessions.
2. Carers NSW recommends that the Department of Family and Community Services fund the development and delivery of training to carers to support their engagement with person centred approaches.
3. Carers NSW recommends that the Department of Family and Community Services ensure that all policies and procedures relating to the implementation of person centred approaches facilitate robust practices of carer recognition, inclusion and support.
4. Carers NSW recommends that all policies and procedures developed or revised for the implementation of person centred approaches be checked against the *NSW Carers (Recognition) Act 2010*.
5. Carers NSW recommends that Department of Family and Community Services fund the development and delivery of training to staff and service providers to support their ability to work with carers in a person centred system.
6. Carers NSW recommends that the introduction of person centred approaches be subject to rigorous evaluation which incorporates documentation of the experiences of carers, and empirical evidence of the outcomes for carers.
7. Carers NSW recommends that the NSW Government prioritise rural and regional access in all future funding allocation and service planning.
8. Carers NSW recommends that the Department of Family and Community Services take a targeted approach to implementing person centred approaches in rural and regional NSW to ensure that equitable outcomes are achieved for people with a disability and their families and carers in rural and regional NSW.
9. Carers NSW recommends that the NSW Government increase funding to the Community Transport program and Transport for Health.
10. Carers NSW recommends that the NSW Government commit to providing equitable access to information, education and other opportunities to carers in rural and regional areas.
11. Carers NSW recommends that the Department of Family and Community Services provide increased funding to Aboriginal organisations to provide individual advocacy to Aboriginal carers and Aboriginal people with a disability.
12. Carers NSW recommends that the Department of Family and Community Services facilitate the up-skilling of mainstream individual advocacy services to improve their outreach to and support of Aboriginal people with a disability and their carers.

13. Carers NSW recommends that the Department of Family and Community Services invest in targeted resources, strategies and funding to support the engagement of Aboriginal people in person centred approaches.
14. Carers NSW recommends that *NSW 2021: Plan to make NSW Number One* have a strong focus on improving outcomes for Aboriginal people and communities, particularly in rural and regional areas.
15. Carers NSW recommends that the NSW Government fund a NSW Carer Advocacy Program to provide carers with access to individual advocacy in their own right as carers.
16. Carers NSW recommends that the NSW Government create and promote best practice carer employment strategies.
17. Carers NSW recommends that the NSW Government establish a Carer Friendly Workplace Champions program to achieve cultural change in relation to work and caring responsibilities.
18. Carers NSW recommends that the NSW Government promote the business case for supporting carers in the workplace, as part of a Carer Friendly Workplace Champions program.
19. Carers NSW recommends that the NSW Government commission research on the business benefits of supporting carers in the workplace.
20. Carers NSW recommends that Carer Impact Statements be required for all policy development processes by public sector agencies that may impact on carers.
21. Carers NSW recommends that the Office for Carers develop consistent and comprehensive carer assessment tools for use across all sectors in NSW.
22. Carers NSW recommends that the NSW Government advocate for the use of consistent and comprehensive carer assessment tools in the National Disability Insurance Scheme.
23. Carers NSW recommends that the Department of Family and Community Services provides increased, recurrent funding to Carers NSW for Carers Week Grants and Carers Day Out.
24. Carers NSW recommends that the Department of Family and Community Services fund the development of a Young Carer Passport in partnership with the Department of Education and Communities.
25. Carers NSW recommends that the Office for Carers establish a Young Carer Champions project in schools and other interested education institutions, in partnership with the Department of Education and Communities.
26. Carers NSW recommends that the Department of Families and Community Services provide increased recurrent funding to the Young Carer Program to enable a significant expansion in scope and geographic reach.

27. Carers NSW recommends that the Department of Family and Community Services fund Aboriginal and CALD community organisations to provide services and supports to young carers from these communities.

1. Carers and person centred approaches

The NSW Government has commenced a significant reform process in the NSW disability sector, and is to be congratulated on its commitment to introducing person centred approaches, which have the potential to revolutionise the lives of people with a disability and their carers.

Carers play a critical role in the disability sector, and will be significantly affected by these reforms. The NSW Government must ensure that the principles of the *NSW Carers Charter* guide the implementation of person centred approaches to ensure that carers are recognised, included and supported and that carers, like people with a disability, can live their lives, their way. To do otherwise would squander an invaluable opportunity to revolutionise caring, and would undermine the effectiveness of the reforms for all concerned.

1.1 Supporting carers to understand and engage with person centred approaches

Carers will need information and support to understand person centred approaches, including person centred planning and individualised funding. Carers NSW experience delivering *Supported Living Fund* information sessions has confirmed that there is a diverse level of knowledge and understanding of person centred approaches amongst carers, and that carers will require varying levels of support to be able to understand and engage with person centredness.

The Carers NSW 2012 Carer Survey supports this experience, demonstrating that there are currently low levels of awareness and understanding of person centred approaches amongst carers. Only 40 per cent of respondents caring for a person using disability services had heard of person centredness, and just over half had heard of individualised funding.²

Carers NSW acknowledges the Consumer Development Fund as an important initiative, which will need to be built upon to ensure that all carers in NSW have access to the supports they need to understand and engage with person centred approaches.

Next step: Provide a suite of information on person centred approaches to carers

A suite of information relating to specific issues involved in person centred planning and individualised funding must be provided to carers, in varying levels of detail, and in a variety of formats, to ensure that the diversity of information needs is met. An online portal, a suite of printed resources, and face-to-face information sessions should be provided, about:

- what a person centred system is
- how person centred planning, funding and service delivery works
- the role of carers in person centred planning
- the rights of carers in person centred planning.

Information should be provided in a range of community languages, with resources also provided to enable the use of interpreters where necessary, including at information sessions.

Recommendation 1: Carers NSW recommends that the Department of Family and Community Services fund the provision of information to carers to support their engagement in person centred approaches, including an online information portal, printed resources and information sessions.

Next step: Provide carers with access to the training that they will need to engage in person centred approaches

Carers need opportunities to develop the skills that will facilitate their successful engagement in person centred approaches. Carers will need access to a range of training opportunities, delivered in various formats, relating to:

- concepts and principles of person centred approaches
- communication
- conflict resolution
- advocacy and self-advocacy
- person centred planning
- introduction to individualised funding
- budgeting and/or basic accounting
- computer skills.

Funding should be provided for the development of new training, but also to facilitate the development or continuation of existing training that is currently provided in the community, such as self-advocacy courses. A range of non-government organisations, including Carers NSW, already have expertise in the delivery of such training and would be well placed to provide this training to carers. Funding should also be available to carers to enable them to access other appropriate training of their choice, such as existing training courses provided by community colleges and other training organisations.

Recommendation 2: Carers NSW recommends that the Department of Family and Community Services fund the development and delivery of training to carers to support their engagement with person centred approaches.

1.2 Supporting, recognising and including carers in person centred approaches

Establishing person centred approaches that have the person with the disability *and their carer* at the centre will require robust practices of carer recognition and inclusion, and a strong culture of carer inclusiveness.

Next step: Provide strong policy directions and framework to support the recognition, inclusion and support of carers in person centred approaches

The need to recognise, include and support carers must be written into the policy directives and frameworks that support the implementation of person centred approaches, at both a strategic and a procedural level. For example, policies and procedures relating to person centred planning, assessment, and individualised funding arrangements should facilitate

robust practices of carer recognition, inclusion and support. New and revised policies and procedures should be systematically checked against the NSW *Carers (Recognition) Act 2010* to ensure this is consistently achieved.

Recommendation 3: Carers NSW recommends that the Department of Family and Community Services ensure that all policies and procedures relating to the implementation of person centred approaches facilitate robust practices of carer recognition, inclusion and support.

Recommendation 4: Carers NSW recommends that all policies and procedures developed or revised for the implementation of person centred approaches be checked against the NSW *Carers (Recognition) Act 2010*.

Next step: Train service providers and disability support workers to recognise, support and include carers in person centred approaches

Carers NSW is aware that education and training is necessary to support the implementation of carer related policy and directions, and to bring about the cultural change that is required to realise robust practices of carer recognition, inclusion and support. Training should be provided to those who will be employed in the person centred system in:

- carer awareness
- role of carers in person centred planning
- rights of carers in person centred planning
- working with carers (including and supporting carers as partners in care).

Recommendation 5: Carers NSW recommends that Department of Family and Community Services fund the development and delivery of training to staff and service providers to support their ability to work with carers in a person centred system.

Next step: Evaluation of outcomes for carers in person centred approaches

The evaluation of person centred approaches must address the outcomes for and experiences of carers, as well as those of people with a disability. Empirical evidence of the outcomes for carers will be critically important given that the introduction of person centred approaches and individualised funding could have positive and negative impacts on carers. For example, evidence from the United Kingdom illustrates that carers supporting recipients of individual budgets were extensively involved in helping the consumer to use an individual budget, and in financial management and care coordination, and that the management of paperwork and on-going support arrangements generated more work for carers.³ Documentation of the experiences of carers will also be critically important to evaluating and improving the implementation of person centred approaches.

Recommendation 6: Carers NSW recommends that the introduction of person centred approaches be subject to rigorous evaluation which incorporates documentation of the experiences of carers, and empirical evidence of the outcomes for carers.

2. Rural and regional carers

The NSW Government has made its commitment to rural and regional NSW clear. Andrew Stoner, Minister for Trade, Regional Infrastructure and Services, is on the record as stating that “regional communities lie at the heart of this Government's decision-making.”⁴

The NSW Government must ensure that regional communities are central to planning and decision making in all areas, including in relation to health, palliative care, mental health and disability services. In particular, the implementation of person centred approaches must be undertaken with a special focus on rural and regional areas to ensure the effectiveness of these reforms across NSW.

It is well established that people living in rural and regional areas face disadvantage. In 2012 the Australian Institute of Health and Welfare found that the further people live away from major cities, the less healthy they are likely to be.⁵ This is also true of carers. Carers living in outer regional and remote areas experience higher rates of disability and lower rates of employment than non-carers living in the same areas and carers in major cities.⁶ Rural and regional carers also experience increased financial hardship, poorer health and experience more stressful events than non-carers.⁷ Aboriginal people in rural and regional areas, many of whom have caring responsibilities, also need to be at the heart of the NSW Government's focus on rural and regional communities.

2.1 Equitable access to services and supports, including in person centred approaches

Rural and regional carers face significant challenges in accessing the services and supports they need, as well as information and other opportunities. Research has shown that rural and regional carers have less access to a range of essential services, including doctors, employment services, telecommunication services, Centrelink, banks and other financial institutions, disability services and Medicare.⁸ The challenges arising from distance have been demonstrated by a survey of Western Australian carers, who identified major difficulties in travelling away for appointments such as the cost of travel, the need to be away overnight, being unable to coordinate appointments and inconvenient appointment times.⁹

Next step: Prioritise rural and regional areas in service delivery and planning

The NSW Government must ensure that the need for equitable access in rural and regional areas is a priority in future service delivery and reforms, particularly in relation to the implementation of person centred approaches. Unless there are adequate and accessible services in rural and regional areas, people with a disability and their carers will not benefit from improved choice and control under person centred approaches. Individualised funding is of little use if the services and supports needed are not available to be purchased.

Recommendation 7: Carers NSW recommends that the NSW Government prioritise rural and regional access in all future funding allocation and service planning.

Recommendation 8: Carers NSW recommends that the Department of Family and Community Services take a targeted approach to implementing person centred approaches

in rural and regional NSW to ensure that equitable outcomes are achieved for people with a disability and their families and carers in rural and regional NSW.

Next step: Improve access to transport in rural and regional areas

The NSW Government must invest in improving public transport and transport infrastructure in rural and regional NSW and build upon the investment it has already made in Community Transport and health related transport. Funding for the Community Transport program was increased in the 2011-12 state budget, as was funding for Transport for Health. The NSW Government must continue to increase funding for these programs to reduce the transport disadvantage currently faced by people in rural and regional areas, and improve access to services and supports.

Recommendation 9: Carers NSW recommends that the NSW Government increase funding to the Community Transport program and Transport for Health.

Next step: Provide access to information and education opportunities to rural carers

Carers from rural and regional areas often miss out on opportunities to attend information sessions, conferences, training and other opportunities that are more readily available in metropolitan areas. Feedback from carers and the results of the Carers NSW 2010 Carer Survey suggest that this is an ongoing cause of concern and frustration.¹⁰ Information sessions, consultations and capacity building opportunities for carers, particularly in relation to the introduction of person centred approaches, must be made available to all carers in NSW, through the use of diverse delivery methods, through the provision of financial and other support to travel when necessary, as well as through opportunities in their local area.

Recommendation 10: Carers NSW recommends that the NSW Government commit to providing equitable access to information, education and other opportunities to carers in rural and regional areas.

2.2 Aboriginal carers in rural and regional areas

The NSW Government has demonstrated a promising commitment to improving outcomes for Aboriginal carers across NSW, through the funding of Aboriginal specific *Living Life My Way* consultations held around NSW, and through the work of the Ministerial Taskforce on Aboriginal Affairs. However, as the NSW Government must be well aware, this is just the beginning of the investment that needs to occur in order to improve outcomes for Aboriginal carers and their communities and to help 'close the gap'.

According to the Australian Bureau of Statistics, just over half of the estimated 10,600 Aboriginal carers in NSW live in regional areas.¹¹ Aboriginal carers in rural and regional areas may face a double disadvantage compared to other carers, being affected by the issues arising from their geographic location, as well as the barriers to access and other issues that may affect them as Aboriginal carers. The high prevalence of disability and disease experienced by Aboriginal people¹² would be exacerbated by the challenges of living in rural and regional areas, particularly for Aboriginal carers who are up to three times as likely as other carers to need assistance with core activities themselves.¹³

Carers NSW experience providing the *Support Coordination Program for Older Parent Carers* in western NSW, which has involved outreach work to communities such as Brewarrina, Bourke and Wilcannia, indicates that some Aboriginal carers have intensive caring responsibilities. The impacts of these responsibilities are often exacerbated by their limited access to financial and other resources, inadequate housing, a lack of available and appropriate services as well as other factors such as low literacy levels, poor health and wellbeing and exposure to violence. The extensive consultation work of the Aboriginal Disability Network, documented in its reports on the *Living Life My Way* consultations¹⁴ and the *Telling Like It Is* report¹⁵ demonstrate that the vast majority of Aboriginal people with a disability are currently outside the service system, and do not receive any support other than that provided by carers, families and kinship networks.

Next step: Individual advocacy for Aboriginal carers and people with a disability

The experience of Carers NSW in western NSW, and the reports of the Aboriginal Disability Network, demonstrate the need for increased access to individual advocacy for Aboriginal carers and people with a disability. It is important that targeted advocacy, with the capacity to provide complex and long term support be available, particularly in the context of the introduction of person centred approaches. Mainstream individual advocacy services need increased capacity to outreach to and support Aboriginal people.

Recommendation 11: Carers NSW recommends that the Department of Family and Community Services provide increased funding to Aboriginal organisations to provide individual advocacy to Aboriginal carers and Aboriginal people with a disability.

Recommendation 12: Carers NSW recommends that the Department of Family and Community Services facilitate the up-skilling of mainstream individual advocacy services to improve their outreach to and support of Aboriginal people with a disability and their carers.

Next step: Person centred approaches for Aboriginal people with a disability and their carers

The introduction of person centred approaches must deliver better outcomes for Aboriginal people with a disability and their carers, and give them choice and control in their lives. Given the high prevalence of disability in Aboriginal communities and low rates of service access, targeted resources, strategies and funding will be required to ensure that Aboriginal people have the opportunity to engage with and benefit from person centred approaches. The NSW Government should work with and be guided by Aboriginal communities and organisations, and build upon the results of the *Living Life My Way* consultations.

Recommendation 13: Carers NSW recommends that the Department of Family and Community Services invest in targeted resources, strategies and funding to support the engagement of Aboriginal people in person centred approaches.

Next step: Improving outcomes for all Aboriginal people in rural and regional NSW

In order to improve the situation of Aboriginal carers in rural and regional NSW, access to services, supports and resources in all areas of life must be improved. There is a need for significant and widespread improvements in relation to access to mainstream services and infrastructure such as health, housing, transport and education as well as specialist services such as respite and in-home care services. Improving outcomes for Aboriginal people and communities should be a focus of all NSW Government Departments and agencies, and should be a cornerstone of the *NSW 2021: Plan to make NSW Number One* ten year plan.

Recommendation 14: Carers NSW recommends that *NSW 2021: Plan to make NSW Number One* have a strong focus on improving outcomes for Aboriginal people and communities, particularly in rural and regional areas.

3. Carer advocacy services

The NSW Government has recognised the need of people with a disability for advocacy services, and funds the NSW Advocacy Program (disability) to ensure that this need is met. This program and the National Disability Advocacy Program are critically important services.

Carers also need access to individual advocacy services, but can only access advocacy funded through these and other programs when they are acting on behalf of the person they care for, not when they are acting on their own behalf. There are currently no funded individual advocacy services for carers in their own right, despite the fact that:

- carers access a range of services and supports
- carers are included in various policy programs and legislation as a population group with distinct needs
- carers are vulnerable to crisis, face risks to their own wellbeing, and are often unable to “achieve a positive service response or intervention through their own efforts”.¹⁶

The need for carer advocacy services has been recognised as a ‘pressing need’ by the *Who Cares...?* Report which recommended that the National Disability Advocacy Program be extended to provide formal advocacy for carers in their own right when this is required, and to provide family advocacy services which better recognise the role of carers providing individual advocacy on behalf of, and with, care receivers.¹⁷ The Australian National Audit Office (ANAO) has also recognised the need for carer advocacy services, and the anomalies that exist relating to carers’ access to the National Disability Advocacy Service, and also recommended that access be extended to carers.¹⁸

The reports on the *Living Life My Way* 2011 consultations prepared by Ageing, Disability and Home Care¹⁹, the NSW Council of Intellectual Disability²⁰ and the Aboriginal Disability Network²¹ all confirm the important role of individual advocacy services, especially in the context of the introduction of person centred approaches, which will make access to carer advocacy services more important than ever. Some carers will need the assistance of an advocacy service to ensure their own needs and rights are respected in the person centred planning process, and to deal with other challenges that may arise in the person centred and individualised funding environment.

Without the provision of carer advocacy services, the principles enshrined in the *NSW Carers Charter* cannot be upheld. Access to individual advocacy is crucial to the NSW Government upholding the Charter, particularly relating to the following principles:

- f) Carers are to be acknowledged and recognised as having their own individual needs within and beyond their caring role...
- j) Carers’ choices in their caring role should be supported and recognised, including the recognition of carers in the assessment, planning, delivery and review of services that impact on carers and their role as carers.
- l) Support for carers should be timely, responsive, appropriate and accessible.²²

Next step: Provide carers with access to individual advocacy services

The NSW Government must provide all carers in NSW with access to individual advocacy services, in their own right as carers, regardless of what sector or sectors they interact with.

The NSW Government could achieve this by allocating additional funding through the NSW Advocacy Program to a carer focused organisation or organisations such as Carers NSW. This would require amendments to the guidelines of this program, which currently stipulate that advocacy services are for people with a disability or families and carers seeking assistance on their behalf.²³

A better option would be for the NSW Government to establish a separate NSW Carer Advocacy Program, along similar lines to the existing NSW Advocacy Program, as a carer specific rather than disability specific advocacy program. This would ensure that access to advocacy is not limited to carers of people with a disability only.

Recommendation 15: Carers NSW recommends that the NSW Government fund a NSW Carer Advocacy Program to provide carers with access to individual advocacy in their own right as carers.

4. Workplace support of carers

The NSW Government has taken important steps towards improving workplace support of carers in the public sector through its implementation of the *NSW Carers (Recognition) Act 2010*. The Department of Families and Community Services has developed resources including Implementation Guidelines, and undertook to deliver a “public sector education road show” and to develop electronic modules regarding carers and the Act.²⁴ These positive steps need to be built upon to make a real difference to the ability of carers to work and care.

The ability of carers to work and care needs to be drastically improved. The 2009 Survey of Disability, Ageing and Carers (SDAC) found that the workforce participation rate of primary carers was only 42 per cent, compared to 68 per cent for the general population.²⁵ Caring is also associated with working fewer hours, having a more marginal attachment to the labour force, and working at a level that is not commensurate with skills and qualifications.²⁶ The Productive Ageing Centre has identified caring responsibilities as a significant barrier to employment participation for mature aged people.²⁷

For those carers who do remain in the workforce, balancing work and care can be a source of considerable stress. The *Australian Unity Wellbeing Index Survey* found that over one third of employed carers were concerned about losing their job because of their caring responsibilities.²⁸

Despite the significant need to improve workplace support of carers, the *Negotiating caring and employment report* found that relatively few Australian workplaces are aware of how to support employees with caring responsibilities, and that little is known about the needs and experiences of the carers themselves. While some workplaces have various flexible work provisions, the study found “substantial evidence that arrangements tend to be fragmented and access to them arbitrary”.²⁹ The NSW Government has an important role to play in rectifying this situation, to ensure that carers, the people they support, employers and the NSW economy can all benefit from the increased workforce participation of carers.

Next step: Create and promote best practice carer employment strategies

The NSW Government and public sector agencies need to create and promote best practice carer employment strategies to lead change in workplace support of carers. Best practice examples should be informed by and build upon the findings and resources of the *Valuing Unpaid Caring Work in Australia Research Project*³⁰ commissioned by the Australian Human Rights Commission. Best practice examples may showcase strategies such as:

- provision of carer leave entitlements (including through the retention or expansion of existing entitlements under the Public Service Award)
- flexible working arrangements
- carer networks
- information provision and referral to services
- changes to job design and workload allocation.

Recommendation 16: Carers NSW recommends that the NSW Government create and promote best practice carer employment strategies.

Next step: Establish a Carer Friendly Workplace Champions program

The NSW Government should engage employers in its efforts to improve workplace support for carers by facilitating a Carer Friendly Workplace Champions program. The *Experience+ Corporate Champions* program³¹, which aims to promote better practice in the employment of mature age people, is an example of a similar project.

A Champions program provides a number of benefits. It is a relatively low-cost approach which importantly engages other stakeholders. It would create an incentive for businesses to support the campaign through the opportunity to build and demonstrate their corporate social responsibility whilst also improving their ability to attract and retain employer with caring responsibilities. The NSW Government needs to engage other stakeholders and sectors if it is to achieve cultural change in the recognition of caring responsibilities by employers.

Recommendation 17: Carers NSW recommends that the NSW Government establish a Carer Friendly Workplace Champions program to achieve cultural change in relation to work and caring responsibilities.

Next step: Promote and develop the business case for workplace support of carers

The NSW Government needs to take a lead role in promoting the business case for supporting carers in the workplace. Supporting employees with care responsibilities can have a range of benefits, including:

- increased retention of staff
- reduced recruitment and retention costs
- increased productivity and performance
- reduced sick leave and absenteeism
- improved service delivery
- improved cost savings.³²

There is a paucity of evidence of the business case for supporting employees with caring responsibilities in the Australian context, which needs to be addressed through the commissioning of research to ensure that there is a strong, relevant and convincing business case for better supporting carers in the workplace.

Recommendation 18: Carers NSW recommends that the NSW Government promote the business case for supporting carers in the workplace, as part of a Carer Friendly Workplace Champions program.

Recommendation 19: Carers NSW recommends that the NSW Government commission research on the business benefits of supporting carers in the workplace.

5. Whole of government approach to recognising, including and supporting carers

The NSW Government needs to take a whole of government approach to recognising, including and supporting carers, guided by the results of the *NSW Carers Action Plan 2007-2012* evaluation, the *NSW Carers (Recognition) Act 2010*, and the NSW Carers Advisory Council.

The evaluation of the *NSW Carers Action Plan 2007-2012* and the development of the *NSW Carers (Recognition) Act 2010 Implementation Plan 2011-2014* and *Implementation guidelines for public sector agencies* are important first steps which need to be built upon to ensure real and significant improvements to carer recognition, inclusion and support across all NSW Government Departments and agencies.

Next step: Introduce Carer Impact Statements

The *NSW Carers (Recognition) Act 2010* establishes some obligations for public sector agencies, including that:

A public sector agency must consult with such bodies representing carers as the agency considers appropriate when developing policies that impact on carers.³³

The *Implementation Guidelines for Public Sector Agencies*³⁴ provides valuable information and advice to support compliance with this obligation. However, this could be strengthened through the adoption of Carer Impact Statements across all public sector agencies to ensure that responsibility for systematically considering the impacts on carers sits with the agency who would undertake thorough consideration of the potential impacts on carers, informed by the consultation they are obliged to undertake with bodies representing carers.

Recommendation 20: Carers NSW recommends that Carer Impact Statements be required for all policy development processes by public sector agencies that may impact on carers.

Next step: Develop and introduce consistent carer assessment

The principles of the *NSW Carers Charter* can only be realised if consistent and comprehensive carer assessment tools are developed and implemented across all relevant human service sectors, including in the disability, mental health and health sectors.

The *NSW Carers Charter* establishes that:

- b) Carers' health and wellbeing are to be given due consideration.
- c) The views and needs of carers and the views, needs and best interests of the persons for whom they care must be taken into account in the assessment, planning, delivery and review of services provided to persons who are cared for.
- d) Carers should be referred to, and made aware of, appropriate services to assist carers in their caring role. Such referrals should be made after an assessment of the needs of carers or as part of the assessment or provision of services to the person being cared for.

f) Carers are to be acknowledged and recognised as having their own individual needs within and beyond their caring role. This acknowledgement and recognition is to take into consideration Aboriginal or Torres Strait Islander culture, age, disability, religion, socio-economic status, cultural differences, gender identification and place of residence.³⁵

These principles can only be put into practice if carer assessment tools are developed and systematically implemented. There is no other way to ensure that the needs of carers are acknowledged and recognised, that carers are referred to the services they need, and that their health and wellbeing, views and needs are taken into account. The diversity of carer experiences means that the same caring responsibilities can have very different impacts on different individuals. To understand a carer's situation, a range of factors need to be taken into account, including:

- the intensity of the care they provide
- their capacity, life stage and health and wellbeing
- the existence of other life or care responsibilities
- the supports available to the carer in their role (formal and informal)
- the resources available to the carer
- their position on the carer journey or carer life course³⁶
- their preferences/choices.

A comprehensive carer assessment is the only way to fairly and accurately identify what a carer's views and needs are, and what caring role they are able and willing to take on. The *Implementation guidelines for public sector agencies* effectively demonstrate the case for carer assessment, recognising the need for carer's choices to be "included and recognised at all stages of service provision".³⁷ The Guidelines also recognise that "each carer's need for service will differ, and carers needs change over time, making assessment very important".³⁸

The introduction of person centred approaches and the launch of the National Disability Insurance Scheme (NDIS) in the Hunter makes the introduction of carer assessment more crucial than ever. Ideally, comprehensive carer assessment tools would be developed at a national level, in line with the recommendations of the Productivity Commission³⁹ and the *Who Cares...? Report on the inquiry into better support for carers*⁴⁰. Carers NSW is concerned that this recommendation is not being taken up in the implementation of the NDIS. Therefore it falls to the NSW Government to provide leadership to the Commonwealth and other states and territories, by developing and implementing carer assessment tools, and strongly advocating for their use in the NDIS.

Recommendation 21: Carers NSW recommends that the Office for Carers develop consistent and comprehensive carer assessment tools for use across all sectors in NSW.

Recommendation 22: Carers NSW recommends that the NSW Government advocate for the use of consistent and comprehensive carer assessment tools in the National Disability Insurance Scheme.

Next step: Provide recurrent funding to Carers Week programs

Carers Week is an important opportunity for the community, Governments and service providers to recognise and celebrate the important contribution of carers. The funded Carers Week programs, including the Carers Week Grants and the NSW Carer Awards, make a significant contribution to carer recognition in NSW. Carers NSW recognises the valuable contribution that the funding of these programs has made to date. It is crucial that the NSW Government continue to fund these activities, and that they are supported by all NSW Government Departments and agencies.

Each year an increasing number of Carers Week events are held (funded by Carers Week grants) generating media coverage and providing carers with much needed recognition, as well as an opportunity to attend an event in their local area or the Carers Day Out event in the Sydney CBD. In 2012, 338 applications for a Carers Week grant were made, compared to 214 in 2010, an increase of almost 60 per cent. Carers Week events are an important opportunity to reach new and hidden carers, with the majority of 2012 Carers Week Grant recipients stating that new carers had attended their activity, with some events attracting as many as 30 new carers.

The NSW Carer Awards Program also makes a significant contribution to carer recognition. The program is particularly effective at raising the profile of caring in the community through local media coverage which often provides considerable insight into the experiences and contribution of Carer Award recipients. According to Carers NSW media monitoring, in the month following the NSW Carers Awards in 2012 there were 337 print articles about carers, significantly above the monthly average of 250 articles.

To date, the funding for Carers Week grants has been awarded to Carers NSW annually through a submission process, from Ageing, Disability and Home Care. These arrangements limit Carers NSW capacity to strategically plan for Carers Week activities, to maximise the impact and effectiveness of this funding. The allocation of recurrent funding for Carers Week grants and other Carers Week initiatives such as the NSW Carer Awards Program, would embed these events, foster greater commitment to them in the community and by all NSW Government Departments and agencies, and would enable Carers NSW to significantly build upon and further strengthen these important programs.

Recommendation 23: Carers NSW recommends that the Department of Family and Community Services provides increased, recurrent funding to Carers NSW for Carers Week Grants and Carers Day Out.

6. Young carers and education

The NSW Government has made significant efforts to improve the identification and support of young carers in line with the *NSW Carers Charter* which establishes that:

g) Children and young people who are carers have the same rights as all children and young people.

h) Children and young people who are carers face additional difficulties and burdens and should be supported in overcoming these difficulties and burdens.⁴¹

The NSW Government, particularly the Department of Families and Community Services, has made an important investment in young carers, through their continued funding of the Carers NSW Young Carer Program and other initiatives including the *Identifying and Supporting Young Carers* website and eLearning tool and the Young Carer Leadership program.* It is vital that the NSW Government continues to improve the recognition and support of young carers to build upon work done to date, and expand this focus into the education system through the engagement of the Department of Education and Communities.

6.1 Young carers and the education system

The vast majority of young people attend educational institutions on a regular basis, and often encounter problems in their participation in education as a result of their caring responsibilities. Educational institutions, particularly schools, therefore present a critical opportunity for identifying and supporting young carers, both internally and through referral to external services and supports.⁴² In the words of one young carer:

I think that if someone had picked up in high school that I was a young carer and helped me to receive services earlier, I think it would have made a real difference to me maybe finding things to help me go to university while looking after mum and also to help me when I was doing my HSC.⁴³

Young carers commonly experience problems at school, including poor concentration, fatigue, absence from school and difficulty completing homework and assignments. These issues are often due to the young carer worrying about the person they care for, and their caring role impacting on their ability to complete their school work, and even get a full night's sleep. Research in Australia and the United Kingdom reveals that schools often fail to recognise young carers and support their needs in the education system. This means that the difficulties young carers face in education and other areas ultimately lead to poorer outcomes in education and employment compared to other young people.⁴⁴

The focus the NSW Government has taken on improving young carer identification and support in the disability sector now needs to be complemented with an increased focus on education. The Office for Carers needs to establish a robust partnership with the Department

* The Young Carer Leadership Program was delivered by Carers NSW in 2012, with funding from the NSW Government Department of Family and Community Services.

of Education and Communities to ensure that schools realise their potential as a central site for assistance and support for young carers and that the Department of Education and Communities is committed to upholding the *NSW Carers Charter*.

Next step: Introduce Young Carer Passports in schools

Young Carer Passports (also known as Young Carer Cards) have been implemented in numerous jurisdictions in the United Kingdom. The Young Carer Passport is a way for young carers to discretely inform their teachers that they are a young carer. It can contain general information about the impacts of being a young carer and refer the teacher to strategies that would support the individual needs of the young person. It could also refer to sources of further information and resources (including a nominated individual within the school who can provide information and advice). Showing the passport can be a means by which the young person can access the small considerations they need in order to better participate in education. These may include having opportunities to make private telephone calls, time-out to talk to a support person, or extra assistance and support with homework. A Young Carer Passport is a low-cost but potentially high impact initiative that can empower young carers and improve their identification and support in the school system.

An account from one young carer demonstrates the significant benefits that can arise when teachers know a student has caring responsibilities:

Yes, I just said to the teacher, oh, I've just been looking after my mum and she just hasn't been too well and I didn't even finish telling what her situation was and instantly she just, took me into her office and she actually put me on the phone to Abe, who's left now, and he just said, Oh, I need to come and see you and I need to come and see you now. Yes, he came down to my house the next day and sat down and we had a chat so that was good. It was incredible, it was so good and I think the circumstances – I was so broken, like 16 years old and even though it had only just been me caring for my mum for six years, it was my life that I'd been living with and facing such hardship.⁴⁵

Recommendation 24: Carers NSW recommends that the Department of Family and Community Services fund the development of a Young Carer Passport in partnership with the Department of Education and Communities.

Next step: Introduce Young Carer Champions in schools

The success of initiatives such as Young Carer Passports often depends on the existence of an individual within the school with an understanding of and commitment to the goals of the project. To support the adoption and use of Young Carer Passports and the utilisation of existing young carer resources, the appointment of Young Carer Champions in schools and other education institutions should be facilitated.

A Young Carer Champion would be a nominated teacher or other member of staff who works with both staff and students to raise awareness of young carers, and to implement strategies to support young carers such as the Young Carer Passport. They would be supported by the provision of existing resources and information, membership of a network of other Young Carer Champions, and access to information and advice from Carers NSW

and/or the Office for Carers. They would be an identified point of referral for young carers and staff who require more information or advice about young carers (and identified in Young Carer Passport if this was in place).

Following the successful implementation of the Young Carer Champions in schools, it should be extended to TAFEs and Universities, as research indicates that young carers struggle to manage their caring responsibilities with tertiary education, and would benefit from greater awareness and understanding of their caring role in these institutions.⁴⁶

Recommendation 25: Carers NSW recommends that the Office for Carers establish a Young Carer Champions project in schools and other interested education institutions, in partnership with the Department of Education and Communities.

Next step: Increased recurrent funding to the Carers NSW Young Carer Program

The Carers NSW Young Carer Program is currently funded by the Department of Families and Community Services to raise awareness and understanding of young carers within the education and disability sectors, health networks and wider community by:

- developing e-learning tools for teachers and lecturers in State-wide schools, colleges and universities
- developing materials that can be used State-wide in schools, such as DVD's
- running State-wide workshops and information sessions and attending team meetings for professionals in all the above areas
- developing materials specific to GP's and health settings, and delivering / distributing these State-wide
- developing links with local employers and employment agencies to raise their awareness of young carers, their particular needs and issues getting into and remaining in work.

The Carers NSW Young Carer Program aims to deliver these activities across NSW. However, the scope of what the program can achieve is currently limited by the amount of funding provided. With an increase in recurrent funding to the program, a significant expansion in scope and geographic reach could be achieved, for example, through the creation of Young Carer Project Officer positions in Carers NSW regional offices. The result would be a truly state-wide and comprehensive Young Carer Program.

Recommendation 26: Carers NSW recommends that the Department of Families and Community Services provide increased recurrent funding to the Young Carer Program to enable a significant expansion in scope and geographic reach.

6.2 Supporting young carers from CALD and Aboriginal communities

Young people from CALD and Aboriginal backgrounds are more likely to be carers than other young people. Rates of caring amongst Indigenous young people are twice that of other young people.

Young carers from CALD and Aboriginal communities may have different experiences to other young carers, due to different cultural values and a lack of culturally appropriate services. Young carers from CALD and Aboriginal backgrounds are also more likely to be 'hidden' carers who do not identify as carers and/or do not receive support.⁴⁷

Next step: Introduce specific services and supports targeting young carers from CALD and Aboriginal communities

Specific services and supports are needed to ensure that young carers from CALD and Aboriginal communities are identified and supported by schools, services and by their communities. Tailored responses to these young carers could be developed and delivered by CALD and Aboriginal community organisations. Not only would these organisations be best placed to understand and reach members of these communities, it would have the added benefit of engaging organisations and community members that may not be currently aware of or supporting carers, and would raise awareness of the need to support carers amongst these organisations and communities more broadly.

Recommendation 27: Carers NSW recommends that the Department of Family and Community Services fund Aboriginal and CALD community organisations to provide services and supports to young carers from these communities.

Conclusion

The NSW Government is on record acknowledging the importance of recognising, including and supporting carers. Given the Government's strong focus on keeping its promises, Carers NSW looks forward to the NSW Government continuing to deliver on its commitments to carers, particularly in relation to the six priority areas highlighted in this submission.

The future of this state depends on improvements being made to the experience of caring, especially through better carer recognition, inclusion and support. That is why the NSW Government must build upon the investments it has made to date to ensure a strong tomorrow for carers, and therefore, for NSW.

Endnotes

- ¹ Andrew Constance, *Parliamentary Debates (Hansard)*, Carers Recognition Bill 2010, p 22376, Sydney. March 12 2010.
- ² Carers NSW, *Carers NSW 2012 Carer Survey*, Sydney, 2012.
- ³ C Glendinning et al, *The Individual Budgets Pilot Projects: Impacts and Outcomes for Carers*, Social Policy Research Unit, University of York and Personal Social Services Research Unit, University of Kent, 2009.
- ⁴ Andrew Stoner, *Parliamentary Debates (Hansard)*, Regional NSW, p 8452, Sydney, 16 February 2012.
- ⁵ Australian Institute of Health and Welfare, *Australia's health 2012*, Australia's health no. 13, Cat. No. AUS 156, Canberra, 2012.
- ⁶ B Edwards, M Gray and J Baxter, *The Tyranny of Distance? Carers in regional and remote areas of Australia*, Australian Institute of Family Studies, Canberra, 2009.
- ⁷ R Winterton and J Warburton, *Models of care for socially isolated older rural carers: barriers and implications*, *Rural and Remote Health*, 11: 1678, 2011.
- ⁸ B Edwards, M Gray and J Baxter, *The Tyranny of Distance? Carers in regional and remote areas of Australia*, Australian Institute of Family Studies, Canberra, 2009.
- ⁹ Carers WA, *Carers of family and friends in country Western Australia*, Perth, 2011.
- ¹⁰ Carers NSW, *Carers NSW 2010 Carer Survey*, Sydney, 2010.
- ¹¹ Australian Bureau of Statistics, *Census of Population and Housing*, Canberra, 2006.
- ¹² Australian Bureau of Statistics, *Summary of findings: 2006 ABS Census of Population and Housing, the Health and Welfare of Australia's Aboriginal and Torres Strait Islander People*, Canberra, 2008.
- ¹³ Australian Bureau of Statistics, *Summary of findings: 2006 ABS Census of Population and Housing, the Health and Welfare of Australia's Aboriginal and Torres Strait Islander People*, Canberra, 2008.
- ¹⁴ Aboriginal Disability Network, *Living Life My Way Consultations with Aboriginal communities*, Final Report, Sydney, April 2012.
- ¹⁵ Aboriginal Disability Network, *Telling it Like it Is: a report on community consultations with Aboriginal people with disability and their associates throughout NSW, 2004-2005*, Sydney, 2007.
- ¹⁶ House of Representatives Standing Committee on Family, Community, Housing and Youth *Who Cares...? Report on the inquiry into better support for carers*, Canberra, 2008.
- ¹⁷ Ibid.
- ¹⁸ Australian National Audit Office, 'Administration of the Commonwealth State Territory Disability Agreement', the Auditor-General Audit Report, no. 14, Canberra, 2005.
- ¹⁹ Ageing, Disability and Home Care, *Living Life My Way*, Outcomes of statewide consultations, Sydney, 2011.
- ²⁰ NSW CID, *Living Life My Way Consultations with people with intellectual disability*, Final Report, Sydney, April 2012.
- ²¹ Aboriginal Disability Network, *Living Life My Way Consultations with Aboriginal communities*, Final Report, Sydney, April 2012.
- ²² *Carers (Recognition) Act 2010 (NSW)*
- ²³ Ageing, Disability and Home Care, *NSW Advocacy Program Guidelines (disability)*, Sydney, 2010.
- ²⁴ Correspondence from Ageing, Disability and Home Care in response to *Rebuild NSW Revolutionise Caring*, Carers NSW Budget Submission to the NSW Government 2012-13.
- ²⁵ Australian Bureau of Statistics, *Survey of Disability, Ageing and Carers 2009*, Canberra, 2010.
- ²⁶ Taskforce on Care Costs, *The hidden face of care: Combining work and care responsibilities for the aged and people with a disability*, Sydney, 2007.

-
- ²⁷ National Seniors Productive Ageing Centre, *Barriers to mature age employment*, Final report of the Consultative Forum on Mature Age Participation, Canberra, 2012.
- ²⁸ R Cummins et al, *The wellbeing of Australians – Carer Health and Wellbeing*, Australian Unity Wellbeing Index Survey 17.1 Special Report, Melbourne, 2007.
- ²⁹ C Thomson, T Hill, M Griffiths, and M Bittman, *Negotiating caring and employment*, Final Report for the Australian Research Council Linkage Grant Project, Social Policy Research Centre, University of New South Wales, Sydney, 2008.
- ³⁰ Australian Human Rights Commission, 'Valuing Unpaid Caring Work in Australia Research Project' [Online] Available at:
http://www.humanrights.gov.au/sex_discrimination/VUCW_australiaResearchPri/index.htm
- ³¹ Department of Education, Employment and Workplace Relations, *Experience plus*, [Online], Available at:
<http://www.deewr.gov.au/Employment/Programs/ExpPlus/Employers/Pages/CorporateChampionsNews.aspx>
- ³² Department of Health, *Recognised, valued and supported: next steps for the Carers Strategy*, United Kingdom, 2010.
- ³³ *Carers (Recognition) Act 2010* (NSW)
- ³⁴ NSW Government, *Carers (Recognition) Act 2010 Implementation Guidelines for Public Sector Agencies*, Sydney, 2012.
- ³⁵ *Carers (Recognition) Act 2010* (NSW)
- ³⁶ Deanna Pagnini, *Carer Life Course Framework: an Evidence-Based Approach to Effective Carer Education and Support*, for Carers NSW and NSW Health, Sydney, 2005.
- ³⁷ NSW Government, *Carers (Recognition) Act 2010 Implementation Guidelines for Public Sector Agencies*, Sydney, 2012, p 14.
- ³⁸ *Ibid*, p 9.
- ³⁹ Productivity Commission, *Disability Care and Support*, Report no. 54, Final Inquiry Report, Canberra, 2011, p 332.
- ⁴⁰ House of Representatives Standing Committee on Family, Community, Housing and Youth, *Who Cares...? Report on the inquiry into better support for carers*, Canberra, 2009.
- ⁴¹ *Carers (Recognition) Act 2010* (NSW)
- ⁴² Social Policy Research Centre, *Young carers: Social policy impacts of the caring responsibilities of children and young adults*, Final Report, University of NSW, Sydney, 2011.
- ⁴³ Carers Australia, *Bring it!*, Final Report of the Young Carers Forum 2008, Canberra, 2009.
- ⁴⁴ Carers NSW, *Young Carer Literature Review*, Sydney, 2012.
- ⁴⁵ Carers Australia, *Bring it!*, Final Report of the Young Carers Forum 2008, Canberra, 2009.
- ⁴⁶ *Ibid*.
- ⁴⁷ B Cass et al, *Young carers in Australia: understanding the advantages and disadvantages of their care giving*, Social Policy Research Paper No. 38, Australian Government Department of Families, Housing, Community Services and Indigenous Affairs, Canberra, 2009.