



Rebuild NSW Revolutionise caring

Carers NSW Budget Submission to
the NSW Government 2012-13

October 2011

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's 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.

Carers NSW
Level 18, 24 Campbell Street
Sydney NSW 2000
P: (02) 9280 4744
F: (02) 9280 4755
Email: contact@carersnsw.asn.au
© Carers New South Wales Inc.

Contents

Introduction	3
Summary of Recommendations	4
Ongoing priorities for carers	7
1. Prepare for the introduction of person centred approaches	9
2. Significantly increase accommodation options	12
3. Include carers in mental health reform	15
4. Improve the financial security of carers	18
5. Implement and promote the <i>Carers (Recognition) Act 2010</i>	21
6. Introduce carer advocacy services	24
7. Enable carers to work and care	26
8. Capitalise on the potential of Information and Communication Technology	30
Conclusion	32
Endnotes	33

Introduction

Caring in NSW is at last poised to undergo real and significant change. For too long, caring has come at a significant cost – physically, emotionally, financially, professionally, and socially. For too many years carers have been calling for better recognition, inclusion and support. Time and time again we have heard their stories of isolation, exclusion and suffering. Current reform agendas provide a rare opportunity to finally address the disadvantage and inequity currently wed to the caring role.

The NSW Government must seize this opportunity to revolutionise caring, and to secure the future of the state's health, aged care and community care sectors, which are so dependent on the contribution of carers. Critical reforms, currently occurring at both a state and federal level, have the potential to revolutionise the experience of caring, provided they are carried out in accordance with the role and needs of carers.

National reforms such as health reform, aged care reform, the introduction of a National Disability Insurance Scheme, the National Carer Recognition Framework, the establishment of a National Mental Health Commission and the development of a road map to mental health reform offer the potential for significant change for carers.

The reforms occurring in NSW are no less promising. The introduction of the *Carers (Recognition) Act 2010* and Carers Advisory Council, the move towards a person centred disability sector, the commencement of phase two of *Stronger Together*, the establishment of a NSW Mental Health Commission, implementation of national health reforms and the new direction provided by *NSW 2021* all offer a rare glimpse of hope for carers.

It is the responsibility of the NSW Government to ensure that carers benefit from these reforms, and that their potential to revolutionise the experience of caring in this state is realised. To do so, the NSW Government must:

- prepare carers for the introduction of person centred approaches
- significantly increase accommodation options
- include carers in mental health reform
- improve the financial security of carers
- implement and promote the *Carers (Recognition) Act 2010*
- introduce carer advocacy services
- enable carers to work and care
- capitalise on the potential of Information and Communication Technology.

The NSW Government must address these eight priority areas, and look to the *NSW Carers Charter* for guiding principles, to ensure that the direction of the NSW Government and the state and national reforms lead to systems, and a society, in which carers are recognised, included and supported. By 2021, NSW must be number one for all people, including carers.

Summary of Recommendations

1. Carers NSW recommends that the NSW Government funds 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 NSW Government funds the development and delivery of training to carers, to support their engagement with person centred approaches.
3. Carers NSW recommends that the NSW Government funds the development and delivery of training to disability staff and service providers to support their ability to work with carers in a person centred system.
4. Carers NSW recommends that the NSW Government significantly increases the number of supported accommodation places available in the second phase of *Stronger Together*.
5. Carers NSW recommends that Ageing, Disability and Home Care regularly communicates with all families on the Register of Requests for Supported Accommodation to assess eligibility, advise how long the anticipated wait for accommodation is and provide families with an appropriate level of support while waiting for these services.
6. Carers NSW recommends that the NSW Government responds to the needs and choices of people with a disability and their families in the roll out of supported accommodation places and the Supported Living Fund.
7. Carers NSW recommends that the NSW Government increases funding for mental health in NSW in line with the proportion of the health burden constituted by mental health.
8. Carers NSW recommends that carers are represented on the Mental Health Commission, through formal mechanisms including (but not limited to) carer representative positions.
9. Carers NSW recommends that funding be allocated to enable effective carer participation in the Mental Health Commission, including providing reimbursement for travel and accommodation costs, and remuneration for individuals engaged as carer representatives.
10. Carers NSW recommends that the NSW Government funds the development of online mental health initiatives targeted at carers.
11. Carers NSW recommends that the NSW Government funds the development and provision of education and information to raise awareness of the mental health needs of carers themselves.

12. Carers NSW recommends that the NSW Government advocates to the Commonwealth Government for changes to Centrelink application processes for the Carer Payment and Carer Allowance to improve access for carers of people with a mental illness.
13. Carers NSW recommends that the NSW Government considers increasing the Low Income Household Rebate.
14. Carers NSW recommends that NSW Trade and Investment ensures that adequate supplies of EPA vouchers are available for and accessible to carers.
15. Carers NSW recommends that NSW Trade and Investment extends eligibility for the Low Income Household Rebate to all recipients of the Carer Allowance.
16. Carers NSW recommends that the NSW Government reverses its decision to incorporate the 2009 pension increase into the calculation of public rents.
17. Carers NSW recommends that the NSW Government funds a multi-faceted awareness campaign to raise awareness of the *Carers (Recognition) Act 2010* and of the contribution and needs of carers, targeted at the general community and at public sector and human service agencies.
18. Carers NSW recommends that the NSW Government funds education for frontline staff of human service agencies and funded organisations on the *NSW Carers Charter* and its implementation.
19. Carers NSW recommends that the NSW Government establishes an annual reporting framework on the implementation of the Act.
20. Carers NSW recommends that the NSW Government provides increased, recurrent funding to Carers NSW for the NSW Carers Award Program, Carers Week Grants and Carers Day Out.
21. Carers NSW recommends that the NSW Government funds a NSW Carer Advocacy Program to provide carers with access to individual advocacy in their own right as carers.
22. Carers NSW recommends that the NSW Government advocates to the Commonwealth Government for the extension of the right to request flexible working arrangements to all carers, regardless of the age of the care recipient, their reason for requiring care, or their relationship to the carer.
23. Carers NSW recommends that the NSW Government funds a working carer awareness campaign, to support the development of carer-friendly workplaces within the public sector, and more broadly.
24. Carers NSW recommends that the NSW Government advocates to the Commonwealth Government for changes to activity limitations on the Carer Payment (the 25 hour rule).

25. Carers NSW recommends that the NSW Government increases access to affordable and flexible care and support services, including after-hours and in holidays, to enable carers to participate in the workforce.
26. Carers NSW recommends that the NSW Government makes the mainstreaming of telehealthcare a commitment in the NSW 2021 plan, so that it becomes a normal part of the infrastructure of support for all who require care and support from carers and/or formal services by 2021.
27. Carers NSW recommends that the NSW Government funds the piloting of a Respite Learning Portal in NSW, to gauge the efficacy of this model in NSW, and its potential in the future person centred system.

Ongoing priorities for carers in NSW

This submission highlights eight priority areas for the consideration of the NSW Government, and provides 27 recommendations to ensure that NSW is the number one state for carers. In addition to the areas covered in this document, there are other important issues that Carers NSW continues to advocate for, including:

Transport

Transport is critical to the wellbeing and connectedness of carers and the people they support. There is increasing evidence regarding the relationship between transport, disadvantage and social exclusion.¹ Transport is an enabling service, underpinning access to support services, employment, education and community participation. In light of this, the Inquiry into Services provided or funded by Ageing, Disability and Home Care recommended that the NSW Government “ensures community transport concerns are addressed, particularly the need to make the service more person-centered, as a priority...”.²

Carers NSW recognises that funding for Community Transport and for the Isolated Patients Travel and Accommodation Assistance Scheme was increased in the 2011-12 state budget. However, such is the need for improved and increased transport services that Carers NSW continues to advocate for further increases in funding to these programs.

Implementation of a National Disability Insurance Scheme

Carers NSW strongly supports the implementation of a National Disability Insurance Scheme (NDIS), as represented in our submissions to the Inquiry into Disability Care and Support. Carers NSW acknowledges that the NSW Government has been a strong advocate for an NDIS, and encourages the NSW Government to continue its efforts to ensure that people with a disability, including people with a psychiatric disability, and their carers have access to lifelong care and support.

Aids and Equipment Program

Timely access to equipment, aids and appliances is of fundamental importance to people with a disability and their carers. Carers NSW acknowledges the small increase in funding to the Aids and Equipment Program (also known as PADP) made in the 2011-12 state budget, but urges the NSW Government to further increase funding to this program, as called for by the PADP Community Alliance.

Recognition and support of the diversity of carers

Carers NSW recognises that carers come from all walks of life, cultural backgrounds and age groups. Carers NSW continues to recognise and advocate for diverse carer population groups, especially carers from culturally and linguistically diverse backgrounds, young carers, Aboriginal carers and Gay, Lesbian, Bisexual, Transgender and Intersex carers. Carers NSW advocates for services and supports that are accessible and appropriate for all carers, as well as for targeted interventions for specific population groups when necessary.

Carer representation

Carers NSW continues to strongly advocate for carer representation, particularly in new and emerging organisations, including Medicare Locals, Local Health Districts and the NSW Mental Health Commission. Carers NSW hopes to see the NSW Government take a proactive approach to ensuring that public sector agencies comply with their obligations under the *Carers (Recognition) Act 2010*, including the obligation relating to carer consultation.

The experience of Western Australia demonstrates that legislation alone is unlikely to lead to systematic carer representation. A review of the *Carers Recognition Act 2004 (WA)* identified that organisations experienced difficulty in identifying carers who could become involved at the policy development or strategic or operational planning level, and that carers experienced difficulties in becoming involved for a number of reasons including lack of time, training, confidence, inadequate respite or financial resources.³

It is vital that the NSW Government supports public sector agencies to comply with their obligations under the Act, and ensures that public sector agencies allocate adequate funding and resources to support carer representation.

1. Prepare carers for the introduction of person centred approaches

The introduction of person centred approaches in the NSW disability sector has the potential to revolutionise the lives of people with a disability, and their carers. Carers will be crucial stakeholders in a person centred system, and will be significantly affected by the decisions made by the person with a disability, particularly when they have implications for the support that carers provide. Carers, like people with a disability, should have the right to live life their way, and must be partners alongside the person they care for in a person centred system.

Carers NSW strongly supports the introduction of person centred approaches, and urges the NSW Government to begin developing the capacity of all stakeholders to support the roll out of this reform, including people with a disability, service providers and carers. Information and training to enable carers to understand and engage with person centred approaches should be made available as soon as possible, if carers are to be able to participate in the person centred system, and support the person they care for to do the same.

The evidence

Carers will need information and support to understand person centred planning, personalised funding, and personalised service delivery. Carers currently have varying levels of understanding of person centredness, and will require varying levels of support to be able to understand and engage with a person centred system. Some carers may require little support, and may already be well informed. Other carers may require more information and support in order to understand and adjust to the new ways of thinking and working that person centredness will bring.

Research from the United Kingdom (UK) suggests that the information and training that was made available to support the introduction of personalisation focused on service providers, to the exclusion of people with disabilities and carers.⁴ It is crucial that in NSW this situation is not repeated, particularly as research from the UK has also found that information is a precondition for choice, and that a lack of access to relevant information at the pre-choice stage can disadvantage individuals.⁵

An immediate commencement of the provision of information and training will not only give more carers more time to build their capacity to engage with and support person centred approaches, it will also improve their capacity to have their say in the development and design of person centred approaches in NSW, and to make informed representations to the consultation process committed to by the NSW Government.

Action required from the NSW Government

1. Ensure carers have access to the information they will need to understand and engage in person centred approaches

Carers will have diverse information needs. 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. Initially, an online portal, a suite of printed resources, and face-to-face information sessions should be provided, with information 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 NSW Government funds 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. Provide carers with access to the training that they will need to engage in person centred approaches

Carers need to begin developing the skills that will facilitate their successful engagement in a person centred system. Carers must have access to a range of training opportunities, delivered in various formats including face-to-face and online. The training needs of carers will vary considerably. Some of the key areas in which training should be developed and provided include:

- communication
- conflict resolution
- advocacy
- self-advocacy
- introduction to person centred approaches
- 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 NSW Government funds the development and delivery of training to carers, to support their engagement with person centred approaches.

3. Improve the ability of service providers and disability support workers to work with carers

The report on the *Living Life My Way* summit identifies the need for cultural change, highlighting that “attitudes and values impact on person centred behaviour”.⁶ This is particularly true in regards to the recognition, inclusion and respect of carers, and their role in a person centred system.

To create a person centred system where both the person with the disability and their carer are at the centre, robust practices of carer recognition and inclusion, and a culture of carer inclusiveness will be required. One way in which this can be achieved is by training 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).

Carers NSW has successfully developed and delivered the *Working With Carers Training Package* for Ageing, Disability and Home Care. Given this experience, and their role as the peak body for carers in NSW, Carers NSW is well placed to develop and deliver such carer training to disability staff and service providers to enhance their capacity to recognise, include and respect carers in the new person centred system.

Recommendation 3: Carers NSW recommends that the NSW Government funds the development and delivery of training to disability staff and service providers to support their ability to work with carers in a person centred system.

Carers NSW has made further recommendations in relation to person centred approaches in *Supporting carers to live life their way*, a submission to the NSW Government’s consultations on person centred approaches. The recommendations listed above are the most immediately pressing of a range of recommendations relating to carers and the introduction of person centred approaches.

2. Significantly increase accommodation options

I believe we are only at first base in a 10-step process; accommodation must be a driving issue in the next step, particularly to support ageing carers.

The Hon. Kevin Humphries, 11 May 2010⁷

The critical lack of accommodation for people with a disability and for people with a mental illness must be a priority for the NSW Government. New accommodation options and services to assist people to live independently must be made available immediately, to assist those already in crisis, and to prevent many more families from also reaching breaking point.

The success of person centred approaches and of a National Disability Insurance Scheme will be at risk if the critical shortfall of accommodation is not addressed.

The evidence

Accommodation was identified as the “most significant unmet demand and the greatest anxiety for families” by the Disability Investment Group in its 2009 report *The Way Forward*.⁸ This finding was reaffirmed by the final report of the Inquiry into Services provided or funded by Ageing, Disability and Home Care, which acknowledged that the shortage of supported accommodation is “one of the most significant issues facing the disability services sector”. Further,

The Committee acknowledges the ongoing fear and frustration experienced by many carers who are not supported to plan for the future accommodation needs of their children. A service system that requires carers to reach breaking point before it provides appropriate services and support is not sustainable for the families or the system and may act to increase pressure on the system in future years.⁹

Ageing, Disability and Home Care (ADHC) stated in its evidence to the Inquiry that there was an immediate need for 750 supported accommodation places and a need for another 1,000 places in the future,¹⁰ based on the NSW Register of Requests for Supported Accommodation.* It is encouraging then that the second phase of *Stronger Together* is to provide 1,750 new supported accommodation places by 2016. However the need for supported accommodation is much higher than the Register indicates, and therefore *Stronger Together* must deliver many more accommodation places than are currently planned.

In its submission to the Inquiry, ADHC admitted that “it is only recently that ADHC has begun capturing this information in a consistent and comprehensive way”, and that the Register *only* records those who need 24 hour support.¹¹ The need for accommodation is therefore much higher than the Register indicates.

* As of July 30 2010 1,729 people were on this register, 723 of whom were identified as willing to take up a place immediately.

Many more individuals will not be on the Register as they do not know it exists, or how to apply. There is a high degree of confusion and misinformation surrounding access to disability services in general, and to supported accommodation services in particular. Carers NSW is familiar with many cases where carers mistakenly believe the person they care for is on a waiting list for supported accommodation. A survey conducted in 2011 of Support Coordinators from the Support Coordination for Older Parent Carers Program found that only half of those who need or will need supported accommodation are currently on waiting lists.¹²

The Australian Institute of Health and Welfare (AIHW) estimates that around 10,000 people in NSW have unmet supported accommodation needs,¹³ an estimate dismissed by ADHC on the basis that the AIHW's methodology doesn't take "existing informal care supports" into account. Given what we know about the difficult circumstances of many families and carers, it would be erroneous to assume that those of the 10,000 people who do have "informal care supports" will not also need supported accommodation now or in the future.

Action required from the NSW Government

1. Increase the number of supported accommodation places

The NSW Government must increase the number of supported accommodation places to be provided in the second phase of *Stronger Together*. Given that supported accommodation was one of the few service areas in the first phase of *Stronger Together* in which targets were not met, these places must be a priority for implementation. Carers NSW agrees with the assessment of the Standing Committee on Social Issues that "phase two of Stronger Together provides an opportunity for supported accommodation unmet need to be addressed."¹⁴ The Committee recommended that the number of supported accommodation options increases as a priority through *Stronger Together* to meet the need on the Register and the anticipated ongoing, growing demand.¹⁵

Recommendation 4: Carers NSW recommends that the NSW Government significantly increases the number of supported accommodation places available in the second phase of *Stronger Together*.

2. Improved support of people waiting for accommodation

The NSW Government must implement the other recommendations of the Inquiry into Services provided or funded by Ageing, Disability and Home Care, including the recommendations to improve communication with and support of people waiting for supported accommodation.

Recommendation 5: Carers NSW recommends that Ageing, Disability and Home Care regularly communicates with all families on the Register of Requests for Supported Accommodation to assess eligibility, advise how long the anticipated wait for accommodation is and provide families with an appropriate level of support while waiting for these services.

3. Provide people with the accommodation *they choose*

Finally, the NSW Government must give careful consideration to the way in which new supported accommodation places are rolled out. It is not enough that people have access to accommodation, they must have access to the accommodation and living arrangements of *their* choice that meets *their* needs. The introduction of person centred approaches in NSW will fail if people with a disability do not have a choice in where and how they live.

Recommendation 6: Carers NSW recommends that the NSW Government responds to the needs and choices of people with a disability and their families in the roll out of supported accommodation places and the Supported Living Fund.

3. Include carers in mental health reform

The NSW Government pledged to reform mental health services in the lead up to the 2011 election. By establishing the NSW Mental Health Taskforce, the first step towards honouring this commitment has been taken. It is of the utmost importance that the NSW Government succeeds in bringing about real and significant change to the NSW mental health system. This reform process must be informed by the principles of the *NSW Carers Charter*. Carers must be recognised, included and supported, in both the reform process and the resulting system.

The NSW Government must have as a priority:

- improving mental health services (thereby improving the situation of carers)
- improving the representation and participation of carers in the mental health system
- addressing the mental health needs of all carers.

The evidence

Carers play a critical role in the care and support of people with a mental illness. In the wake of deinstitutionalisation and in the absence of adequate community care services, carers have been forced to step in and fill the gap, carrying what the Burdekin report described as an “enormous and unreasonable burden of care”.¹⁶

Caring for a person with a mental illness in the current mental health system has significant physical, emotional, financial and social impacts, which is unsurprising given that carers of people with a mental illness spend an average of 104 hours caring per week.¹⁷ The findings of the *2010 Mental Health Carers Survey* illustrate some of these impacts. Nearly three-quarters of respondents to this survey reported their health was worse as a result of their caring role.¹⁸ A third of respondents were taking anxiety medication, and nearly 40 per cent were taking antidepressants.¹⁹ The survey also captured the financial burden of caring. It found, for example, that almost a third of respondents spent a median fortnightly amount of \$200 on the care recipient.²⁰

The needs of carers more broadly, as a population group with mental health needs of their own, must also be considered in the reform of mental health services. Carers need accessible, affordable mental health services. Research by the Australian Institute of Family Studies (AIFS) found that carers experience high rates of mental health problems,²¹ and are at a significantly higher risk of depression than the general population.²² The 2007 *Australian Unity Wellbeing Index Survey* found carers to have the lowest collective wellbeing of any known population group, and an average stress rating that is classified as moderate depression.²³

Carers NSW staff witness firsthand the mental health issues experienced by many carers. The Carer Line frequently receives calls from carers experiencing high levels of stress and anxiety. Several calls from carers expressing suicidal thoughts are received each week.

Action required from the NSW Government

1. Improve and increase mental health services

The NSW Government must act to ensure that the quantity and quality of services for people with a mental illness are greatly improved. Recent developments in mental health, including increased funding and a commitment to reform at a national level are encouraging. However, these changes do not negate the need for significant improvements in NSW. Carers NSW acknowledges the significant funding allocated to mental health in the 2011-12 NSW budget, but is also aware that this represented a decrease compared to the amount spent in 2010-11. The NSW Government must continue to increase funding to mental health, to a level which matches the proportion of the health burden that it represents.

Recommendation 7: Carers NSW recommends that the NSW Government increases funding for mental health in NSW in line with the proportion of the health burden constituted by mental health.

2. Ensure carer representation on and to the NSW Mental Health Commission

The NSW Government must continue to ensure that carers are represented on the NSW Mental Health Commission. This would align with the *NSW Carers (Recognition) Act 2010*, and comply with a range of national policies which identify carer participation as a priority, including the *National Standards for Mental Health Services*, *National Mental Health Strategy*, and the four *National Mental Health Plans*.²⁴ The importance of mechanisms for carer participation was also highlighted by the 2006 *Crisis to community* report.²⁵

Both the New Zealand Mental Health Commission (NZMHC) and the Western Australia Mental Health Commission (WAMHC) have ensured representation and participation of carers. The NZMHC has consumer and family participation as a priority.²⁶ The WAMHC Advisory Council sets a benchmark, as five of its 12 members have caring experience.²⁷

Carers NSW was pleased to note that at least one member of the NSW Mental Health Taskforce has caring experience, and that a Consumer and Carer Working Group has been established. The Mental Health Commission must build on these foundations by establishing multiple carer representative positions on all advisory committees. Mechanisms for carer representation must be developed to ensure the systematic representation and participation of carers at all levels of the Commission and its operations.

Recommendation 8: Carers NSW recommends that carers are represented on the Mental Health Commission, through formal mechanisms including (but not limited to) carer representative positions.

The participation and representation of carers on the Mental Health Commission will require funding. Funding must be allocated to enable effective carer (and consumer) participation. Time, financial hardship, transport, caring responsibilities and the need for training and support have all been identified as barriers to carer participation.²⁸ To enable effective

participation, and to ensure that individuals are not disadvantaged by their participation, they must be adequately resourced.

Recommendation 9: Carers NSW recommends that funding be allocated to enable effective carer participation in the Mental Health Commission, including providing reimbursement for travel and accommodation costs, and remuneration for individuals engaged as carer representatives.

3. Concerted action to improve the mental health of carers

In order to address the significant mental health needs of carers, demonstrated by the AIFS research²⁹ and other studies, the NSW Government must take concerted action. Carers need access to affordable, accessible mental health services, including both traditional and online services. The mental health need of carers should not be excluded from the current wave of e-mental health services and supports, evident in the recent announcement of a national e-mental health strategy. Online mental health initiatives developed in NSW should cater for and be targeted at carers, as well as other population groups.

Recommendation 10: Carers NSW recommends that the NSW Government funds the development of online mental health initiatives targeted at carers.

The NSW Government must also act to increase awareness of the mental health needs of carers, by funding the development and provision of education or information for health professionals and service providers. This could be achieved by funding an appropriately qualified organisation, such as Carers NSW. This initiative would support the ability of public sector agencies and agencies funded by the NSW Government to uphold principles of the *NSW Carers Charter*, particularly that “Carers’ health and wellbeing are to be given due consideration”.³⁰

Recommendation 11: Carers NSW recommends that the NSW Government funds the development and provision of education and information to raise awareness of the mental health needs of carers themselves.

4. Improve access of carers of people with mental illness to income support

Carers NSW constantly receives complaints from carers of people with a mental illness regarding the difficulty of accessing the Carer Payment and Carer Allowance. Carers of people with a mental illness often find that the application process for the Carer Payment and Carer Allowance is focused on physical assistance and does not recognise the nature of the care and support that people with a mental illness require. This is an issue that also commonly affects carers of people with an acquired brain injury.

Recommendation 12: Carers NSW recommends that the NSW Government advocates to the Commonwealth Government for changes to Centrelink application processes for the Carer Payment and Carer Allowance to improve access for carers of people with a mental illness.

4. Improve the financial security of carers

All too often we heard of the many financial challenges that carers are facing. I am alarmed at the number of instances of carers being so financially stricken that Government will be required to step in to deal with some of their hardship. In particular we heard of an instance of people's great concern about an increase in electricity prices. I do not want to hear more stories such as those I heard at Bathurst recently where carers are doing it so tough that they are unable to turn on the heating in their homes because of the increase in electricity prices. I flag that because it is vital that both the State and the Commonwealth look closely at the costs of providing care and, importantly, that they look at the impact of some utility price rises on carers.

The Hon. Andrew Constance, 11 May 2010³¹

The NSW Government must address the financial disadvantage and stress experienced by carers, as the Minister for Ageing and Disability Services so persuasively argued in the NSW Parliament last year. This is an increasingly critical issue for carers in the current context of increasing pressures on the cost of living, such as the increases in utility prices described by the Premier Barry O'Farrell as a "king hit to families".³²

The evidence

Carers face significant financial disadvantage and financial stress, as has been established by a significant body of research. Caring is associated with lower income levels, lower rates of labour force participation, and higher rates of dependence on government income support. Caring for just one year can lead to long term financial disadvantage.³³

Carers are particularly vulnerable to the pressure of increasing costs of living and increasing utility prices. There is clear and manifold evidence as to the difficulties carers face in meeting their costs, and the stress that this generates:

- carers are twice as likely to worry that their income will not be sufficient to meet their expenses³⁴
- around 30 per cent of families receiving carer benefits experience difficulty in paying utility bills (compared to 14.6 per cent of the general population)³⁵
- carers have higher poverty rates and an increased risk of financial stress³⁶
- over half of respondents to the *Carers NSW 2010 Carer Survey* reported having to borrow money as a result of their caring role.³⁷

The financial disadvantage associated with caring was also acknowledged in the 2004 Senate Community Affairs Committee Inquiry into poverty and hardship,³⁸ and the *Who Cares...? Report of the Inquiry into better support for carers*.

The importance of improving the financial situation of carers is supported by several key policy documents at a state and federal level. The *National Carer Strategy* includes the economic security of carers as a priority, and this is supported by the ninth principle of the

*Statement for Australia's Carers.*³⁹ The *NSW Carers Charter* states that “Carers should have the same rights, choices and opportunities as other Australians”, which should include the right to financial security.⁴⁰

Action required from the NSW Government

1. Reduce the impact of rising utility prices

The NSW Government must act to improve the financial situation of carers in NSW by alleviating the impact of utility price rises on carers, many of whom are already struggling to meet these costs.

The NSW Government has recently amended energy rebates for low income households by replacing the Energy Rebate with the Low Income Household Rebate. However, the June 2011 report of the Independent Pricing and Regulatory Tribunal (IPART) highlights the likely impact of price increases, and recommends that the NSW Government ensures the supply of sufficient Energy Accounts Payment Assistance (EAPA) scheme vouchers, and undertakes a review of assistance measures.⁴¹

Carers NSW is concerned that the \$200 rebate available through the Low Income Household Rebate scheme will be insufficient to counter the rising costs of utilities for carers who are already under significant financial strain, and that carers may not be aware of or have access to the EAPA vouchers that they need.

Recommendation 13: Carers NSW recommends that the NSW Government considers increasing the Low Income Household Rebate.

Recommendation 14: Carers NSW recommends that NSW Trade and Investment ensures that adequate supplies of EAPA vouchers are available for and accessible to carers.

Carers NSW is also concerned that limiting eligibility of this scheme to holders of the Pensioner Concession Card, Gold Card or Health Care Card may exclude some carers who experience financial stress due to the high costs of their caring role but who do not meet eligibility criteria for these cards. Income levels are only one side of financial stress for carers, who have been found to experience financial stress rates twice that of their income poverty rate,⁴² due to the high costs incurred by caring. Therefore eligibility should be extended to all recipients of the Carer Allowance.

Recommendation 15: Carers NSW recommends that NSW Trade and Investment extends eligibility for the Low Income Household Rebate to all recipients of the Carer Allowance.

2. Retract rent increases for public housing residents

The NSW Government must reconsider its recent “tough decision” to incorporate the 2009 \$30 increase in the base rate for single pensioners in the calculation of subsidised public rents. In 2010, Premier O’Farrell (then Opposition Leader) described the Keneally government’s intention to include the pension increase in rent calculations as a “straight out tax grab... hitting the State’s most vulnerable, adding to the burden they are already

feeling...”.⁴³ Carers NSW agrees with this assessment, and is disappointed that carers living in public housing, many of whom already find their pension payments inadequate, will lose part of this increase. The increase was made in recognition of the financial pressures facing pensioners. Carers NSW notes that only two other states have taken this decision. The majority of Australia’s states and territories have respected the spirit in which the pension increase was made, and the very real need of those who received it.

Recommendation 16: Carers NSW recommends that the NSW Government reverses its decision to incorporate the 2009 pension increase into the calculation of public rents.

5. Implement and promote the *Carers (Recognition) Act 2010*

This legislation is a good start and the charter is a good start... However, unless the Carers (Recognition) Bill is backed up with services it will be nothing more than an empirical statement that—gee whiz—the Government has woken up. It needs to be far more than that.

The Hon. Brad Hazzard, 11 May 2010⁴⁴

I hope this bill will give some hope to carers, who get on with their work, day in and day out. I hope they understand that this is but a first step. In my capacity as the shadow Minister for Disability Services and Ageing, I am well aware of the frustration and degree of cynicism that exists in politicians and their response to issues that directly impact on the loved ones of carers and on them... I hope that the Parliament today, in a bipartisan way, will take that first step to rectify the injustice.

The Hon. Andrew Constance, 12 March 2010⁴⁵

In 2010 the *NSW Carers (Recognition) Bill* was enacted with bipartisan support from the NSW Parliament. This was a historic day for carers, and an important first step in the journey towards carer recognition in NSW.

The *Carers (Recognition) Act 2010* (the Act) enacts a *NSW Carers Charter* and establishes a Carers Advisory Council. The Act includes requirements that public sector agencies consult with bodies representing carers when developing policies that impact on carers, ensure that staff and agents have an awareness and understanding of the Charter, and develop internal human resources policies with due regard to the Charter. Human services agencies have additional obligations, including a requirement to report on their compliance with the Act in their annual reports.

In December 2010 the Carers Advisory Council was established in a significant step towards the implementation of this Act. However, there remains work to be done to ensure that the principles enshrined in the *NSW Carers Charter* are reflected in reality and that obligations under the Act are met.

The evidence

The experiences of other Australian states and territories with similar legislation are instructive. Western Australia introduced similar legislation in 2004 and conducted a comprehensive review of its effectiveness in 2008.⁴⁶ The review found that the Western Australian legislation had not been effective in achieving its objectives of increasing recognition of the role of carers and including carers in service planning. This was attributed to several factors, including the lack of an awareness-raising campaign and training of key personnel within relevant organisations, which has contributed to low awareness and understanding of the legislation, and continuing confusion around the term carer.⁴⁷

The experience of Western Australia is highly relevant to NSW, given that there is already evidence of low levels of awareness of the Act. Only 43 per cent of respondents to the *Carers NSW 2010 Carer Survey* had heard of the Act, which is particularly concerning given that around 80 per cent of respondents were members of Carers NSW, and would have received information about the Act through Carers NSW publications. Low levels of awareness are also apparent among public sector and human services agencies.⁴⁸

It is important that the NSW Government take action to support the implementation of the Act, and to alleviate the concerns of the Act's critics. Criticisms of the Act include that it is a "legislated pat on the back" or "legislative lip service", as it does not award carers legal status, rights or entitlements.⁴⁹ In the absence of legislated rights for carers, the NSW Government must take a pro-active approach to ensuring that the Act achieves its objectives and allay the doubts and cynicism that exist with regards to the significance of the Act.

Action required from the NSW Government

1. A proactive approach to implementation of the Act

The NSW Government must take a proactive approach to ensuring that public sector and human service agencies comply with their obligations under the Act. The experience of Western Australia indicates that legislation alone will not initiate the cultural change required to achieve real recognition for carers.

Recommendation 17: Carers NSW recommends that the NSW Government funds a multi-faceted awareness campaign to raise awareness of the *Carers (Recognition) Act 2010* and of the contribution and needs of carers, targeted at the general community and at public sector and human service agencies.

Recommendation 18: Carers NSW recommends that the NSW Government funds education for frontline staff of human service agencies and funded organisations on the *NSW Carers Charter* and its implementation.

2. Monitor and report on the effectiveness of the Act

The NSW Government must ensure that the implementation of the Act is monitored in a systematic and transparent fashion. The impact of the Act must be measured and reported on, to inform promotion of the Act, and to inform the review of the Act that is to be conducted in 2015.

The Honourable Andrew Constance and other Members of Parliament are quoted in Hansard acknowledging that the Act is "but a first step". The main criticisms of the Act to date have focused on the absence of legislated rights for carers. The United Kingdom first introduced carer legislation in 1995, and subsequently introduced two further Acts in 2000 and 2004, to provide carers with further, legislated rights.⁵⁰ Further legislation or amendments to the current Act may be required in NSW to ensure that carers have access to assessment and support. Monitoring and reporting on the effectiveness of the Act will enable a meaningful review of the legislation in 2015, and of the need to provide carers with legislated rights, including the right to assessment.

Recommendation 19: Carers NSW recommends that the NSW Government establishes an annual reporting framework on the implementation of the Act.

3. Allocate recurrent funding to Carers Week programs

Carers Week is an important event for carers, and makes a significant contribution to carer recognition in NSW. 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. In 2011, 340 applications for a Carers Week grant were made, compared to 214 in 2010, an increase of almost 60 per cent in one year. The diversity of applicants is also increasing, with grants awarded to increasing numbers of CALD, Aboriginal, older parent carer, dementia and grandparent carer specific groups.

The NSW Carer Awards Program also makes a significant contribution to carer recognition, particularly with the greater involvement of local councils and local communities through local award ceremonies. These Awards provide vital recognition to carers, as well as raising the profile of caring in the community, particularly through local media coverage.

To date, Carers NSW has been funded by ADHC to provide Carers Week grants. This funding has been awarded on an annual basis through a submission process, which limits Carers NSW capacity to strategically plan for Carers Week activities. The allocation of recurrent funding for Carers Week grants, and the other Carers Week initiatives such as the NSW Carer Awards Program, would embed these events, foster greater commitment to them in the community, and enable Carers NSW to significantly build upon and further strengthen these programs.

Recommendation 20: Carers NSW recommends that the NSW Government provides increased, recurrent funding to Carers NSW for the NSW Carers Award Program, Carers Week Grants and Carers Day Out.

6. Introduce carer advocacy services

Carers need access to individual advocacy services in their own right as carers. Carers NSW receives many calls from carers seeking individual advocacy. The difficulty of finding such assistance adds further distress to the situation they are seeking assistance with, on top of the usual stresses and demands of their caring role.

The needs of people with a disability for advocacy services are generally acknowledged and provided for, particularly through the NSW Advocacy Program (disability) and the National Disability Advocacy Program. Carers, however, only have access to advocacy funded through these programs when they are acting on behalf of the person they care for, not when they are acting on their own behalf.⁵¹ Carers also need access to individual advocacy services because:

- carers in their own right are service users
- carers access health, social and financial benefits and services
- 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”.⁵²

The introduction of person centred approaches in the NSW disability sector makes 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 issues and challenges arising in the person centred and individualised funding environment.

The evidence

The need for carer advocacy services was recognised by the *Who Cares...?* Report which acknowledged the “pressing need” for formal advocacy services for carers in their own right. The *Who Cares...?* Report 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.⁵³

The Australian National Audit Office’s (ANAO) report on the Administration of the Commonwealth State/Territory Disability Agreement (CSTDA) also identified the need for carer advocacy services, and the anomalies that exist relating to carers’ access to the National Disability Advocacy Program. ANAO recommended that FaHCSIA (then FACs):

...through consultation with other members of the NDA, establishes the eligibility criteria for advocacy services currently in place in the jurisdictions and, based on the findings from such an investigation, consider extending access to advocacy services to the families and carers of people with disabilities in any future CSTDA.⁵⁴

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.⁵⁵

Action required from the NSW Government

1. Provide carers with 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 funding under the NSW Advocacy Program to a carer focused organisation such as Carers NSW to provide advocacy services. 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.⁵⁶

Alternatively, a separate NSW Carer Advocacy Program could be established, 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 21: Carers NSW recommends that the NSW Government funds a NSW Carer Advocacy Program to provide carers with access to individual advocacy in their own right as carers.

7. Enable carers to work and care

The ability to combine caring and employment is crucial to the wellbeing of carers, and to the continued contribution of carers. This is an issue which will become increasingly critical, as more and more working Australians are faced with caring responsibilities. A 2007 survey of Australian workers revealed that 23 per cent of respondents expected to have caring responsibilities in the next five years.⁵⁷

The evidence

The negative impact of caring on labour force participation is well established. 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, and over half of primary carers had a government pension or allowance as their main source of income.⁵⁸ As well as withdrawal from the workforce, caring is associated with working fewer hours, a more marginal attachment to the labour force, and working at a level that is not commensurate with skills and qualifications.⁵⁹ 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.⁶⁰

Many carers who are out of the workforce want to work.⁶¹ For example, many participants in the *Carers Engagement Project* reported that they would like to be employed in paid work, or in full-time rather than part-time work, but that this would be “impossible” to achieve in conjunction with their caring role.⁶² Increasing the workforce participation of carers has benefits not only for carers, but also for their employers.

The NSW economy would also benefit from the increased participation of carers. As the Productivity Commission acknowledged in the *Disability Care and Support* final report, improving the workforce participation of carers would have “major benefits”, not least the better utilisation of some carer’s skills, including people with “highly valuable human capital (such as law, computing science or business skills)”. The Commission’s conservative modelling of an increase in carer participation in the workforce indicated a potential increase to GDP of around \$1.5 billion annually.⁶³ Access Economics have also identified the significant opportunity costs that arise from carers low workforce participation. In 2010 they estimated the opportunity cost of time devoted to informal care, measured as a reduction in paid employment, at \$6.5 billion annually.⁶⁴

Action required from the NSW Government

There are multiple, cost-effective solutions that the NSW Government can implement to improve the ability of carers to combine work with their caring responsibilities.

1. Advocate for changes to the *Fair Work Act 2009*

There is increasing evidence of the need for more flexible working arrangements for carers.⁶⁵ The *Negotiating caring and employment* report found that employed carers with access to at least one carer-friendly provision (special leave, permanent part-time work,

home based work, flexible start and finishing times) were less likely to leave employment than those with without access to any of these provisions.⁶⁶ According to research from the UK, flexible working arrangements benefit carers because they address the diversity of individuals' circumstances, rather than stereotyping them as problem employees. Flexible arrangements are responsive to individual circumstances, and reduce resentment about perceived preferential treatment.⁶⁷

Providing flexible carer friendly working arrangements also has benefits for employers, including improved productivity and employee morale, reduced levels of absenteeism, greater employee attraction and retention, decreased turnover costs and improved corporate image.⁶⁸ Evidence from the UK, where carers have the right to request flexible working arrangements, demonstrates that "there is extensive evidence of the business benefits of flexible and alternative working arrangements".⁶⁹

The Commonwealth Government has previously rejected the recommendation of the *Who Cares...? Report* to extend the National Employment Standards (NES) right to request flexible working arrangements to carers of children aged over 18 years of age. Carers NSW, the national Network of Carers Associations, and the Australian Human Rights Commission have all advocated for the extension of this right.

The Productivity Commission has recognised the need to extend the right to request in both the *Disability Care and Support* and the *Caring for Older Australians* reports. In the former, the Productivity Commission recommends:

The Australian Government should amend s. 65(1) of the Fair Work Act 2009 to permit parents to request flexible leave from their employer if their child is over 18 years old, but subject to an NDIS assessment indicating that parents are providing a high level of care.

After monitoring the impacts of this legislative change, the Australian Government should assess whether it should make further changes to the Act to include employees caring for people other than children.⁷⁰

The Commonwealth Government's position on this issue appears to have shifted since the rejection of the *Who Cares...? recommendation*. In Priority three of the recently released *National Carer Strategy*, the Commonwealth Government has committed to consulting with stakeholders on the expansion of the right to request flexible working arrangements, including to "employees caring for older Australians and those caring for a person with a serious long-term illness or disability."⁷¹

Recommendation 22: Carers NSW recommends that the NSW Government advocates to the Commonwealth Government for the extension of the right to request flexible working arrangements to all carers, regardless of the age of the care recipient, their reason for requiring care, or their relationship to the carer.

2. Raise awareness of the rights and needs of working 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”.⁷²

The *Carers (Recognition) Act 2010* includes an obligation for all public sector agencies to develop internal human resources policies with due regard to the *NSW Carers Charter*, so far as they may significantly affect the role of a member of staff of the agency as a carer.⁷³ However, it is unlikely that legislation alone will lead to improved support for working carers, given the findings of the *Negotiating caring and employment report*, and research from the UK which found that the successful implementation of carer friendly working arrangements and policies depended on several factors including the culture of an organisation, a program of cultural change and specialist support structures.

In order to ensure that the obligations for public sector agencies in regards to employed carers are met, and that workplaces beyond the public sector improve the support and flexibility they provide to carers, the NSW Government must raise awareness of the rights and needs of working carers, and the importance of supporting them. A working carer awareness campaign would assist with the cultural change that will be required in public sector agencies in order for them to comply with the Act. It would also encourage and enable other workplaces to better support carers, particularly if the business case for doing so is promoted, and advice provided as to how this can be achieved.

Recommendation 23: Carers NSW recommends that the NSW Government funds a working carer awareness campaign, to support the development of carer-friendly workplaces within the public sector, and more broadly.

3. Advocate for changes to activity limitations on the Carer Payment

Recipients of the Carer Payment are currently restricted to 25 hours per week of any combination of work, study and volunteering, including travel time to and from these activities. This is a significant barrier to workforce participation by carers, and has serious ramifications for the education of young carers. Carers NSW is aware of young carers who are routinely absent from school in order to remain eligible for the Carer Payment.

The flawed nature of the activity limitations on Carer Payments have long been established. In 2009 the Pension Review Report found that:

... further consideration should be given to more robust eligibility criteria which focus on the actual level of care provided, rather than the use of a cap on the number of hours of work.⁷⁴

The findings of the *Who Cares...? Inquiry* on this matter are clear.

...the Committee believes that the 25 hour rule appears to be arbitrary and unnecessarily restrictive. The Committee believes that the 25 hour rule is significantly counterproductive in terms of encouraging carers to combine caring with employment and/or education. Therefore, the Committee recommends restrictions on the number of hours that those on Carer Payment can work, volunteer or study should be eased.⁷⁵

The NSW Government must advocate for changes to the activity limitations on Carer Payment, particularly given the Commonwealth Government's stated commitment to a participation agenda.⁷⁶

Recommendation 24: Carers NSW recommends that the NSW Government advocates to the Commonwealth Government for changes to activity limitations on the Carer Payment (the 25 hour rule).

4. Ensure carers have access to affordable alternative care services (including after-hours and vacation services)

Carers participation in the workforce depends on their ability to access affordable, alternative care and support services for the person they support. The NSW Government must ensure that the implementation of the second phase of *Stronger Together* includes the roll out of affordable and flexible care services, including services that are available after-hours and in holiday periods.

Recommendation 25: Carers NSW recommends that the NSW Government increases access to affordable and flexible care and support services, including after-hours and in holidays, to enable carers to participate in the workforce.

8. Capitalise on the potential of Information and Communication Technology

The health, disability and aged care sectors have been slow to capitalise on the opportunities offered by Information and Communication Technology (ICT), particularly in comparison to other industries.

Since Carers NSW previous budget submission to the NSW Government, in which Carers NSW recommended the mainstreaming of telehealthcare,[†] there have been indications that the health sector is awakening to the potential of ICT. The Commonwealth Government has announced the development of an e-mental health strategy and an online mental health portal and Telehealth is now a priority for Medicare Locals.⁷⁷

Carers NSW would like to see the NSW Government become a leader in this field by supporting the mainstreaming of telehealthcare in NSW, and by making the most of the potential of ICT in other respects, such as through the trialling of an online respite portal.

The evidence

Telecare has considerable, manifold benefits, for care recipients, carers and for the systems that support them. Telecare has been shown to:

- enable people to stay in their homes for longer
- reduce the need for acute home care
- delay admissions to residential care
- reduce the number of unplanned hospital admissions
- reduce the number of delayed discharges from hospital.⁷⁸

Evidence from Scotland demonstrates that carers using telecare services experience:

- feeling more relaxed and less stressed
- more confidence about the safety and wellbeing of the care recipient
- more opportunity to get away from their caring situation and take a break
- feeling better supported in their caring role
- improvements in their relationship with the care recipient
- the ability to remain in paid employment (for some carers).⁷⁹

Telehealthcare also has the potential to deliver considerable savings to the NSW Government. According to the evaluation of the Scottish Government's National Telecare Development Programme, in 2007-08 (the first main year of operation) savings totalling

[†] According to Scotland's *National Telecare Development Programme*, telecare is the remote or enhanced delivery of health and social services to people in their own home by means of telecommunications and computerised systems and usually refers to equipment and detectors that provide continuous, automatic and remote monitoring of care needs, emergencies and lifestyle changes. Telehealth is the provision of health services at a distance using a range of digital technologies. Telehealthcare is the convergence of telecare and telehealth to provide a technology-enabled and integrated approach to the delivery of effective, high-quality health and care services.

£11.15 million were identified. In 2007-10 the likely savings were valued at around £43 million, an anticipated benefit to program funding cost ratio of 5:1.⁸⁰ Australian research supports this. Access Economics made the conservative estimate that steady state benefits to Australia from wide scale implementation of telehealth may be in the vicinity of \$2 billion to \$4 billion per annum.⁸¹

Telehealthcare is not the only opportunity afforded by ICT. The NSW Government must also look to the potential of other innovations, such as the Respite Learning Portal established in Canada.

Action required from the NSW Government

1. Mainstream telehealthcare in the aged care, disability and health sectors in NSW

The NSW Government in its efforts to position NSW as number one by 2021 must include telehealthcare. Given the manifold benefits that telehealthcare could have for carers and the people they support, it is vital that all carers in NSW, especially carers from rural and regional areas, have the option of taking up this technology.

Recommendation 26: Carers NSW recommends that the NSW Government makes the mainstreaming of telehealthcare a commitment in the NSW 2021 plan, so that it becomes a normal part of the infrastructure of support for all who require care and support from carers and/or formal services by 2021.

2. Pilot a Respite Learning Portal to gauge the efficacy of this model in NSW

A Respite Learning Portal⁸² that has been successfully implemented in Canada, provides a potential model for NSW to pilot. This model will be particularly relevant in the changing disability context, in which service provision is set to undergo significant changes, and in which people with a disability and their carers are to have more choices and control over the services they use.

The Respite Learning Portal was developed to provide a place for knowledge exchange for respite workers and families, and to enhance the quality of care that respite workers are able to provide. The Portal provides core online training courses, topical webinars, discussion boards, articles and resources. The Portal has proven to be a successful mechanism to reach respite providers, with around 1,000 people registering for the basic training each year.⁸³

Recommendation 27: Carers NSW recommends that the NSW Government funds the piloting of a Respite Learning Portal in NSW, to gauge the efficacy of this model in NSW, and its potential in the future person centred system.

Conclusion

The NSW Government has promised to rebuild NSW. In its efforts to do so, the Government must look to revolutionise the experience of caring in this state. NSW will not be number one if carers are not better recognised, included and supported. NSW will not be number one if the significant challenges and gross inequities faced by carers are not addressed.

This submission provides the NSW Government with eight priority areas to address in order to improve the wellbeing of carers, and as a result, the wellbeing of the people they support, the sustainability of our care systems, and the wellbeing of our community more broadly. The NSW Government must look to these eight priority areas, and with the *NSW Carers Charter* as its guide, ensure that the current reform agendas are capitalised upon to deliver real change and hope for carers. There has never been a more opportune time to revolutionise the experience of caring in NSW.

End notes

- ¹ K Rosier and M McDonald, *The relationship between transport and disadvantage in Australia*, Communities and Families Clearinghouse Australia Resource sheet, Melbourne, 2011.
- ² Standing Committee on Social Issues, *Services provided or funded by the Department of Ageing, Disability and Home Care Report*, Sydney, 2010.
- ³ D Murray et al, *Review of the Carers Recognition Act 2004*, Final Report, Western Australia, 2008.
- ⁴ S Dowling et al, *Person-centred planning in social care: A scoping review*, Joseph Rowntree Foundation, London, 2006.
- ⁵ K Baxter, P Rabiee and C Glendinning, *Choice and change: disabled adults' and older people's experiences of making choices about services and support*, Social Policy Research Unit, University of York, York, 2011.
- ⁶ NSW Government, *Living life my way*, Summit Report, Sydney, 2011.
- ⁷ K Humphries, 'Carers (Recognition) Bill 2010 Agreement in Principle', NSW Hansard, p 22376, 11 May 2010, Sydney, 2010.
- ⁸ Disability Investment Group, *The Way Forward – A New Disability Policy Framework For Australia*, Canberra, 2009.
- ⁹ Standing Committee on Social Issues, *Services provided or funded by the Department of Ageing, Disability and Home Care Report*, Sydney, 2010.
- ¹⁰ Ageing, Disability and Home Care, 'Submission to the Inquiry into services provided or funded by the Department of Ageing, Disability and Home Care', Sydney, 2010.
- ¹¹ Ibid
- ¹² Carers NSW, *Older Parent Carer Supported Accommodation Report* (unpublished), Sydney, 2011.
- ¹³ Australian Institute of Health and Welfare, *Current and future demand for specialist disability services*, Canberra, 2007.
- ¹⁴ Standing Committee on Social Issues, *Services provided or funded by the Department of Ageing, Disability and Home Care Report*, Sydney, 2010.
- ¹⁵ Ibid
- ¹⁶ Human Rights and Equal Opportunities Commission, *Human rights and mental illness: report of the National Inquiry into the Human Rights of People with Mental Illness*, Canberra, 1993.
- ¹⁷ Mental Health Council of Australia (MHCA) and Carers Australia, *Carers of people with mental illness project report*, Canberra, 2000.
- ¹⁸ MHCA, *Mental Health Carers Report 2010*, Canberra, 2010.
- ¹⁹ Ibid
- ²⁰ Ibid
- ²¹ Australian Institute of Family Studies, *The nature and impact of caring for family members with a disability in Australia*, research report no. 16, Melbourne, 2008.
- ²² B Edwards and D Higgins, 'Is caring a health hazard? The mental health and vitality of carers of a person with a disability in Australia', *Medical Journal of Australia*, Vol.190 No. 7, Sydney, 2009.
- ²³ R Cummins et al, *The wellbeing of Australians – Carer Health and Wellbeing*, Australian Unity Wellbeing Index Survey 17.1 Special Report, Melbourne, 2007.
- ²⁴ Tasmanian Department of Health and Human Services, *Mental Health Services Consumer and Carer Participation Review*, Hobart, 2009.
- ²⁵ Select Committee on Mental Health, *A national approach to mental health – from crisis to community*, Canberra, 2006.
- ²⁶ New Zealand Mental Health Commission, *Statement of Intent 2011-2015*, Wellington, 2011.
- ²⁷ Government of Western Australia Mental Health Commission of, Mental Health Advisory Council Member Profiles, http://www.mentalhealth.wa.gov.au/advisory_council/AdvisoryCouncilMemberProfiles.aspx
- ²⁸ Tasmanian Department of Health and Human Services, *Mental Health Services Consumer and Carer Participation Review*, Hobart, 2009.

-
- ²⁹ Australian Institute of Family Studies, *The nature and impact of caring for family members with a disability in Australia*, research report no. 16, Melbourne, 2008.
- ³⁰ *Carers (Recognition) Act 2010* (NSW)
- ³¹ A Constance, 'Carers (Recognition) Bill 2010 Agreement in Principle', NSW Hansard, p 22376, Sydney, 11 May 2010.
- ³² B O'Farrell, 'Premier announces three point plan to ease power price increase', media release, Sydney, April 14 2011.
- ³³ M Bittman, T Hill and C Thomson, 'The Impact of Caring on Informal Carers' Employment, Income and Earnings: a Longitudinal Approach', *Australian Journal of Social Issues* Vol.42 No.2, Sydney, 2007.
- ³⁴ R Cummins et al, *The wellbeing of Australians – Carer Health and Wellbeing*, Australian Unity Wellbeing Index Survey 17.1 Special Report, Melbourne, 2007.
- ³⁵ B Edwards et al, *The nature and impact of caring for family members with a disability in Australia*, Australian Institute of Family Studies, Melbourne, 2008.
- ³⁶ T Hill, C Thomson and B Cass, *The costs of caring and the living standards of carers*, Social Policy Research Paper no. 43, Social Policy Research Centre, Sydney, 2011.
- ³⁷ Carers NSW, *Carers NSW 2010 Carer Survey*, Sydney, 2010.
- ³⁸ Parliament of Australia Senate Community Affairs Committee, *A hand up not a hand out: Renewing the fight against poverty*, Canberra, 2004.
- ³⁹ Australian Government, *National Carer Strategy*, Canberra, 2011.
- ⁴⁰ *Carers (Recognition) Act 2010* (NSW)
- ⁴¹ Independent Pricing and Regulatory Tribunal Changes, *Changes in regulated electricity retail prices from 1 July 2011*, Final Report, Sydney, 2011.
- ⁴² C Thomson, T Hill, M Griffiths and M Bittman, *Negotiating caring and employment: Final report for the Australian Research Council Linkage Grant Program*, University of NSW, Sydney, 2008.
- ⁴³ B O'Farrell, 'NSW Libs & Nats to review Keneally Govt Pension rent grab', media release, Sydney, 20 September 2010.
- ⁴⁴ Brad Hazzard, *Parliamentary Debates (Hansard)*, Carers (Recognition) Bill 2010, p 22376, Sydney, 11 May 2010.
- ⁴⁵ A Constance, 'Carers (Recognition) Bill 2010 Agreement in Principle', NSW Hansard, p 22376, Sydney, 11 May 2010.
- ⁴⁶ D Murray et al, *Review of the Carers Recognition Act 2004: Final Report*, Western Australia, 2008.
- ⁴⁷ Ibid
- ⁴⁸ Anecdotal evidence from Carers NSW from conversations with public sector agency employees, including human resource departments.
- ⁴⁹ Working Carers Gateway, 'National Carer Recognition Bill tabled' [Online], Available at: <http://www.workingcarers.org.au/options/1106-national-carer-recognition-bill-tabled>, 2010.
- ⁵⁰ UK Department of Health, 'Carers legislation' [Online] Available at: http://www.dh.gov.uk/en/SocialCare/Carers/DH_079499, 2009.
- ⁵¹ Ageing, Disability & Home Care, *NSW Advocacy Program Guidelines (disability)*, Sydney, 2010.
- ⁵² House of Representatives Standing Committee on Family, Community, Housing and Youth *Who Cares...? Report on the inquiry into better support for carers*, Canberra, 2008.
- ⁵³ Ibid
- ⁵⁴ Australian National Audit Office, 'Administration of the Commonwealth State Territory Disability Agreement', the Auditor-General Audit Report, no. 14, Canberra, 2005.
- ⁵⁵ *Carers (Recognition) Act 2010* (NSW)
- ⁵⁶ Ageing, Disability & Home Care, *NSW Advocacy Program Guidelines (disability)*, Sydney, 2010.
- ⁵⁷ Taskforce on Care Costs, *The hidden face of care: Combining work and care responsibilities for the aged and people with a disability*, Sydney, 2007.
- ⁵⁸ Australian Bureau of Statistics, *Survey of Disability, Ageing and Carers 2009*, Canberra, 2010.

-
- ⁵⁹ Taskforce on Care Costs, *The hidden face of care: Combining work and care responsibilities for the aged and people with a disability*, Sydney, 2007.
- ⁶⁰ R Cummins et al, *The wellbeing of Australians – Carer Health and Wellbeing*, Australian Unity Wellbeing Index Survey 17.1 Special Report, Melbourne, 2007.
- ⁶¹ M Gray and B Edwards, 'Determinants of the Labour Force Status of Female Carers', in *Australian Journal of Labour Economics*, Vol. 12, No. 1, Perth, 2009.
- ⁶² MHCA, *Adversity to Advocacy*, Canberra, 2009.
- ⁶³ Productivity Commission, *Disability Care and Support*, Final Report, Canberra, 2011.
- ⁶⁴ Access Economics, *The economic value of informal care in 2010*, Canberra, 2010.
- ⁶⁵ A Page et al, *Taking care: Mature age workers with elder care responsibilities*, Women and Work Research Group, University of Sydney, Sydney, 2009.
- ⁶⁶ C Thomson, T Hill, M Griffiths, and M Bittman, *Negotiating caring and employment*, Final Report for the Australian Research Council Linkage Grant Project 2008, Social Policy Research Centre, University of New South Wales, Sydney, 2008.
- ⁶⁷ S Yeandle et al, *Who Cares Wins: the social and business benefits of supporting working carers*, Centre for Social Inclusion, Sheffield, 2006.
- ⁶⁸ House of Representatives Standing Committee on Family, Community, Housing and Youth *Who Cares...? Report on the inquiry into better support for carers*, Canberra, 2008.
- ⁶⁹ S Yeandle et al, *Who Cares Wins: the social and business benefits of supporting working carers*, Centre for Social Inclusion, Sheffield, 2006.
- ⁷⁰ Productivity Commission, *Disability Care and Support*, Final Report, Canberra, 2011.
- ⁷¹ Australian Government, *National Carer Strategy*, Canberra, 2011.
- ⁷² 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.
- ⁷³ *Carers (Recognition) Act 2010* (NSW).
- ⁷⁴ J Harmer, *Pension Review Report*, Department of Families, Housing, Community Services and Indigenous Affairs, Canberra, 2009.
- ⁷⁵ House of Representatives Standing Committee on Family, Community, Housing and Youth *Who Cares...? Report on the inquiry into better support for carers*, Canberra, 2008.
- ⁷⁶ J Gillard, 'The Dignity of Work' Address to the Sydney Institute, 13 April 2011, Sydney, 2011.
- ⁷⁷ Department of Health and Ageing, 'Medicare Locals: Guidelines for the establishment and initial operation of Medicare Locals', Canberra, 2011.
- ⁷⁸ Carers Scotland, *'A weight off my mind' Exploring the impact and potential benefits of telecare for unpaid carers in Scotland*, Edinburgh, 2009.
- ⁷⁹ Ibid
- ⁸⁰ Ibid
- ⁸¹ Access Economics, *Financial and externality impacts of high-speed broadband for Telehealth*, Canberra, 2009.
- ⁸² Ontario Ministry of Community and Social Services, 'The Respite Learning Portal', available at: <http://www.respitecourse.ca>.
- ⁸³ L Atkinson, 'The Respite Learning Portal: Supporting Quality Care through Knowledge Exchange', Paper at Festival of International Conferences on Caregiving, Disability, Ageing and Technology, Toronto, 2011.