

State of risk or state of opportunity?

The future of caring in NSW

**Carers NSW Budget Submission to the
NSW Government 2011 – 2012**

November 2010



About Carers NSW

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

The core work of Carers NSW is to:

- be the voice for carers in NSW
- undertake research, policy development and advocacy
- provide carer services and programs
- provide education and training for carers and services providers
- build capacity in the sector.

Carers NSW'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.

This submission was prepared by Alison Parkinson, Policy Officer, Carers NSW.

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

Executive Summary.....	4
Summary of Recommendations.....	5
On-going priorities for carers in NSW.....	8
Introduction.....	9
1. Carers of people with a mental illness.....	11
2. Supported Accommodation.....	14
3. Working Carers.....	17
4. Telehealthcare.....	20
5. Carer Recognition Legislation.....	22
6. Transport.....	25
7. NSW Carer Card.....	27
Conclusion.....	29
Endnotes.....	30

Executive Summary

Carers NSW, as the peak organisation for carers in NSW, welcomes the opportunity to make this submission to the NSW Government for consideration prior to the 2011 – 2012 NSW State Budget.

As we enter a new four year term of government, we are faced with a time of great risk and, we believe, a time of great opportunity.

We believe that NSW is at a turning point. 2010 has been a significant year for carers, with the passing of the Carers (Recognition) Act 2010 and the establishment of the NSW Carers Advisory Council. These significant first steps provide us with a solid foundation on which to improve the lives of carers. There has never been a better time to make fundamental changes to the provision of care in our community, and to improve the experiences and impacts of caring. We have the opportunity to address the significant costs of caring and to make caring sustainable in the future.

It has never been more urgent that we do so. As the NSW Government is well aware, NSW is facing serious threats to the sustainability of its health and care systems, Government finances, and the state of the economy. Carers are already the 'invisible health workforce' who underpin the health and care systems. As the capacity of these systems comes under pressure, the contribution of carers will be increasingly important. Yet the number of people available to care, and the disposition of people to do so, is falling. The costs of caring are so high that the NSW Government must ask itself who will care, and what will it cost those who do?

2011 will not just see the renewal of Government. This is also a time of policy and system renewal with health reform, the commencement of phase two of *Stronger Together*, and the renewal of other key policies including *New South Wales: A New Direction for Mental Health* and the *State Health Plan: Towards 2010*. The report of the *Inquiry into services provided or funded by the Department of Ageing, Disability and Home Care*, the *Mental Health Carers Report 2010*, and the *Stronger Together* consultations not only point to the great need for reform in NSW, they also show the NSW Government the way to better develop and deliver services and supports for carers and those they care for.

This submission highlights seven key opportunities that exist to make fundamental changes in 2011 – 12, to prevent crisis occurring in the future. There is no doubt as to the risks facing NSW, and that they are fast approaching. If we seize this opportunity to make caring a shared community responsibility, to recognise, support and value carers, and to give carers choice in their caring role, the future will be brighter for all – for carers, for the people they support, and for the state of NSW.



Elena Katrakis
Chief Executive Officer
Carers NSW

November 2010

Summary of Recommendations

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

Carers of people with a mental illness

1. Increase funding for mental health in NSW in line with the proportion of the health burden constituted by mental health.
2. Improve the quality, range and capacity of services and supports for people with mental illness, including appropriate accommodation options and social and vocational supports.
3. Improve the quality, range and capacity of services and supports for carers of people with a mental illness, including education, counselling and respite.
4. Advocate through the Council of Australian Governments for mental health reform on a national level and the inclusion of mental health in National Health and Hospital Reform (NHHR), as per the 12 recommendations of the NHHR Commission regarding mental health.
5. Advocate through the Council of Australian Governments for reforms to ensure better awareness of and access to Carer Payment and Carer Allowance for carers of people with a mental illness.

Supported accommodation

6. Urgently increase the number and variety of supported accommodation options available to people with a disability as part of *Stronger Together* phase two, in line with current and projected unmet need.
7. Expand and adapt existing accommodation models such as those delivered by the *Housing and Accommodation Support Initiative (HASI) for people with mental illness* program and the *Disability Housing and Support Initiative (DHASI)*.
8. Facilitate the realisation of cooperative-based accommodation models already developed in the community by carers and families, such as Ryde Area Supported Accommodation for the Intellectually Disabled (RASAID).

Working carers

9. Increase service flexibility, introduce after hours services and extend day-program hours to suit 9-5 working arrangements.
10. Develop and distribute clear and accessible information, advice and resources for public sector agencies and other employers on creating carer-friendly work places.
11. Implement commitments made to increasing carer workforce participation in *Towards 2030* and the *NSW Carers Action Plan 2007-12*.
12. Advocate through the Council of Australian Governments for an amendment to the *Fair Work Act 2009* to extend the right to request flexible working

arrangements to all primary carers, regardless of the age of the care recipient or relationship status.

13. Honour the commitments made to working carers in *Towards 2030* and the *NSW Carers Action Plan*.

Telehealthcare

14. Immediately initiate the mainstreaming of telehealthcare in NSW, so that it becomes a routine and normal part of the infrastructure of support for everyday life for all who require care and support from carers and/or formal services.
15. Invest in all aspects of telehealthcare, including services from the telecare and telehealth domains. Telehealthcare should be available for all population groups, complemented by initiatives targeted specifically at those who will benefit most, including carers, people with chronic conditions and their carers, older people and their carers and people from rural and regional NSW.
16. Advocate for the mainstreaming of telehealthcare Australia-wide, and for the changes necessary to support this, including the development of national guidelines and standards for the use of telehealthcare, and the legislative changes that may be necessary in respect to telehealth services in the Medicare Benefits Scheme.

Carer recognition legislation

17. Implement a multi-faceted awareness campaign to raise awareness of the NSW Carers (Recognition) Act 2010 (the Act) and of the contribution and needs of carers, targeted at the general community and at public sector and human service agencies.
18. Facilitate the implementation of the Act by public sector and human service agencies by providing clear and accessible information, advice and resources.
19. Support the operations of the NSW Carer Advisory Council and their capacity to meet their objectives by providing adequate levels of administrative, financial and human resources support.
20. Commit to a comprehensive evaluation of the Act in 2014, including a review of the need to establish legal status, rights and entitlements for carers.

Transport

21. Adopt a social transit agenda to sit alongside the existing mass transit agenda.
22. Significantly increase funding to community transport.
23. Ensure that transport planning is incorporated into all health planning in the reformed NSW health system.
24. Significantly increase funding to the Transport for Health program, to remove the burden of health transport from community transport.

25. Incorporate the provision of adequate, accessible transport into phase two of *Stronger Together*.

A NSW Carer Card

26. Investigate options for developing a Carer Card in NSW that is based on the Seniors Card model as a tangible way of improving carer recognition and support in NSW.

27. Implement a Carer Card administered in conjunction with the Seniors Card program by Ageing, Disability and Home Care, Department of Human Services NSW.

On-going priorities for carers in NSW

This submission identifies seven key opportunities that exist for the NSW Government to address future risk for carers and for NSW. The submission explores these opportunities and their potential benefits.

It is not possible to cover in detail all of the issues facing carers in NSW in this submission. There are other very significant issues which, although not discussed here, continue to be issues that Carers NSW supports and advocates for, including:

1. The implementation of a National Disability Long Term Care and Support Scheme

Carers NSW continues to support the implementation of a National Disability Long Term Care and Support Scheme to ensure the lifelong care of people with a disability, as represented in our submission to the Productivity Commission Inquiry into a Scheme.

2. Recognition and support of the diversity of carers

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

Carers NSW continues to recognise and advocate for diverse carer population groups, especially carers from culturally and linguistically diverse backgrounds, Aboriginal carers and Gay, Lesbian, Bisexual, Transgender and Intersex carers. Carers NSW advocates for appropriate and accessible services and supports and for targeted interventions for specific population groups.

3. Recognition and support of young carers

Carers NSW has a particular commitment to advocating for young carers. A young carer is a child or young person 25 years or under who provides support to a person with a disability, mental illness, drug and alcohol dependencies, chronic condition, terminal illness or who is frail. There are 90,200 young carers in NSW.¹ Young carers have significant need for services and support. 44 per cent of young carer respondents to the Carers NSW 2010 Carer Survey never feel supported in their caring role, and 44 per cent don't access formal services.²

Carers NSW continues to advocate for the need for the NSW Government to support young carers, including through policies of the NSW Department of Education and Training (DET). Carers NSW recommends that NSW DET identify and support young carers in the education system, and that a young carer leadership program be implemented in conjunction with the Carers NSW Carer Representative Program and other expert stakeholders.

Carers NSW also reiterates its recommendation that a DVD and web-based tool be developed to increase awareness of and support for young carers by the NSW education system, staff and peers. The success of other online resources such as *Inspire*³ and *Livewire*⁴ point to the potential effectiveness of a web-based tool for young carers.

Introduction

The state of NSW is entering a time of great risk. Our future, and the continued contribution of carers, depend on the action we take today. The combined effects of an ageing population, growing demand for health and disability services, a shrinking pool of potential carers and increasing fiscal and workforce pressures threaten the future viability of the 'state of opportunity'. It is not just the economy and the NSW Government who face significant long term risks. The people who call NSW home will also pay a price, particularly carers and the increasing number of people with care needs.

State of risk

We know that population ageing has significant long-term risks for the economy and the sustainability of government finances.⁵ By 2051 over a quarter of the population will be aged 65 and over.⁶ According to the 2010 Intergenerational Report, by 2050 there will be only 2.7 people of working age to support each Australian aged 65 years and over, compared to 5 working aged people per aged person today.⁷

Population ageing will be accompanied by increasing rates of disability and increasing numbers of people living with chronic physical and mental illnesses such as cardiovascular disease, diabetes, chronic obstructive pulmonary disease, depression, osteoarthritis and renal disease.⁸ Dementia prevalence will also increase dramatically. According to Access Economics, there will be 116,000 people with dementia in NSW by 2050, an increase of 490 per cent.⁹

These demographic changes will place upward pressure on expenditure in the health, disability and aged care sectors. On average, an older person in NSW uses hospitals at four times the rate of a younger person.¹⁰ The NSW Government has acknowledged that there is a risk that health care in NSW could become unaffordable for the government and for the community.¹¹ A similar situation exists in the disability sector. Growth in demand for specialist disability services has been estimated at 7.5 per cent per annum in real terms, which is significantly greater than the increases in government spending, which have not kept pace with demand.¹²

It is not surprising then that NSW faces a situation in which costs could significantly outstrip revenue by 2044. The *Long-Term Fiscal Pressures Report* shows a build up of expenditure pressures. Demographic factors account for around 40 per cent of the projected fiscal gap of 3.4 per cent of Gross State Product in 2044.¹³

Increasing importance of carers

Carers currently provide the majority of care in NSW. In 2010, the replacement value of the care they provide is estimated to exceed \$40 billion Australia-wide,¹⁴ which equates to approximately \$13 billion in NSW. Carers are truly the 'invisible health workforce' without whom the health, aged care and disability care systems could not function.¹⁵

The contribution of carers to NSW is critical. It costs less to provide a combination of informal care and community based formal care services than to provide institutionalised care,¹⁶ and it is the preference of many people with care needs to continue living in the community. The unpaid work of carers can only grow in importance as the number of people requiring care increases, and the capacity of the government to meet their need decreases.

Decreasing availability of carers

One of the most significant risks facing NSW is the projected decrease in the availability of carers. Just a 10 per cent reduction in informal care would translate into a 40 per cent increase in the need for formal services.¹⁷

It is estimated that the number of carers available will decrease in proportion to demand due to factors including increased female workforce participation, increased rates of relationship breakdown, smaller families and increased childlessness, greater mobility and dispersion of families, the increased number of single person households (particularly among elderly), and inter-generational disposition to care. For example, Access Economics have identified that by 2029 there will be a serious shortage of dementia carers, equivalent to 80 per cent of the current number of dementia carers.¹⁸

Risk for carers

Carers are at risk of serious disadvantage as a result of their caring responsibilities. Research by the Australian Institute of Family Studies found that carers experience high rates of mental health problems, poor physical health, employment restrictions, financial hardship and relationship breakdown.¹⁹ The 2007 Australian Unity Wellbeing Index Survey found carers to have the lowest collective wellbeing of any known population group, with the wellbeing of carers who live with the care recipient being the lowest ever recorded for a large group of people. The Survey found that carers have an average stress rating that is classified as moderate depression, are more likely to experience chronic pain than is normal and their wellbeing is more vulnerable to pain.²⁰

Caring also has serious consequences for economic and financial wellbeing. Carers have lower rates of participation in the workforce, lower rates of employment and those who are employed work fewer hours. Data from the Australian Bureau of Statistics (ABS) Survey of Disability, Ageing and Carers (SDAC) paints a bleak picture; labour market participation of primary carers was less than half that of the general population; 44 per cent of primary carers were living in low income households; and 57 per cent of primary carers reported a government pension or allowance as their main source of income.²¹

NSW Health has acknowledged the continuing and significant health gap between people with the worst and best health in the population, and the risks that this entails.²² In light of what we know about carer health and wellbeing, it would seem that carers are among those with the worst health in the population. If NSW hopes or expects carers to continue their contribution as the 'invisible health workforce' and for people to continue to take up this role, then action must be taken to reduce its costs.

State of opportunity

NSW is entering a time of great risk but it is also a time of great opportunity. Action can be taken now to avoid the approaching crisis, by improving the situation of carers and the provision of care in NSW now and in the future. The time is now for the 'state of opportunity' to seize this chance, by adopting the recommendations outlined here pertaining to seven key areas where the NSW Government can make a real difference: mental health, supported accommodation, working carers, telehealthcare, carer recognition, transport, and a NSW Carers Card.

1. Carers of people with a mental illness – transform services, transform lives

Mental health services in NSW need revolutionary improvement. Deinstitutionalisation, without adequate community care, has resulted in a new form of institutionalisation: homelessness and imprisonment.

Final Report of the Legislative Council Select Committee on Mental Health²³

Deinstitutionalisation of mental health services, coupled with under-resourcing and a failure to develop appropriate community care programs means carers have borne a significant load in supporting the care, safety and recovery of people with mental illness. Whilst this has occurred Australia-wide, it has been particularly evident in NSW, which has performed relatively poorly in the provision of mental health services.²⁴

The evidence of the impact on carers is overwhelming. In 1993 the ‘Burdekin Report’ found that:

- carers carry an ‘enormous and unreasonable burden of care’
- caring has adverse effects on their physical, emotional and mental health and imposes heavy financial strains
- carers are denied information and excluded from decisions concerning care and treatment.²⁵

Sadly this situation has changed little over the past two decades, as chronicled by the Mental Health Council of Australia (MHCA) in landmark reports in 2003,²⁶ 2005,²⁷ and 2009.²⁸ The latter, *Adversity to Advocacy*, focuses on the experiences of carers, and found that for many “there was the sense that nothing had changed or will change, and the sad stories will continue to stay the same.”²⁹ The recently released *Mental Health Carers Report 2010* records very little improvement since the release of *Adversity to Advocacy*.³⁰

The increasing focus on recovery in NSW mental health services poses an additional risk for carers. It is important that recovery oriented services do not result in a burden of additional responsibility for carers and families that are already struggling to cope with their existing caring roles.

The opportunity

We are at a tipping point for mental health... Not only can we no longer afford to do nothing, we now have the opportunity, capacity and momentum to deliver genuinely transformational change.

Professor Patrick McGorry³¹

In 2010 mental health has been the subject of unprecedented public discussion and sustained media coverage.³² The high profile advocacy of 2010 Australian of the Year Patrick McGorry, Get Up campaigns and the public resignation of National Advisory Council on Mental Health chairperson John Mendoza have contributed to a new momentum in mental health.

There is evidence of a cultural shift at a federal level. For the first time, Australia has a Minister for Mental Health, a Shadow Minister for Mental Health and a Greens spokesperson. This shift in priorities, long overdue, needs to be reflected at a state level, especially in NSW.

A great opportunity exists for NSW to provide leadership on this issue by addressing its relatively poor track record on mental health, and honouring the commitment made to mental health by the Lemming Government. The timing could not be better. Key policies on mental health including; the *NSW Community Mental Health Strategy 2007–2012*; *New South Wales: A New Direction for Mental Health (2006-2010)*; *NSW Aboriginal Mental Health and Well Being Policy 2006-2010*; and the *State Health Plan: Towards 2010* are all due for renewal. The successors to these policies must reflect the finding of the NSW Legislative Council Select Committee on Mental Health that mental health “is as important as physical health and deserves equal priority.”³³ As such, mental health funding must be increased to reflect the proportion of the health burden it represents.

The recently introduced NSW Carers (Recognition) Act 2010 can support the inclusion of families and carers in mental health, aided by an accompanying information and awareness campaign to reinforce the NSW Mental Health Act 2007’s provisions regarding the inclusion of carers. This is not just an opportunity to increase services, but also to improve their quality, including their capacity to inform, educate, support and include carers as partners in care.

The benefits

Reforming mental health will have huge benefits for people with mental illness, their carers, society, and Government. The benefits of having adequate, quality mental health services and supports are the same as having a quality health system: unquantifiable and unquestionable.

Increasing service capacity will reduce the burden on carers, and the number of carers who are sole care providers. Currently, many carers act as a substitute for formal services, providing on average 104 hours of care per week.³⁴ In the Carers NSW 2010 Carer Survey 41 per cent of carers of people with a mental illness did not have anyone who could help them and 41 per cent did not access formal services.³⁵ As well as ensuring that carers are not alone in their caring role, more services will also have a huge impact on the health and wellbeing of people with mental illness, around two-thirds of whom do not access services.³⁶

Carers of people with a mental illness will enjoy better health and wellbeing. Under the current system, their wellbeing is seriously compromised by their caring responsibilities. According to the *Mental Health Carers Report 2010*, 70.6 per cent of carers of people with mental illness experience worse physical and/or mental health as a result of their caring responsibilities.³⁷ A significant proportion of respondents reported taking various medications as part of their coping strategy. 27.8 per cent took sleeping pills, 31.9 per cent took anxiety medication and 37.1 per cent took antidepressants.³⁸ Carers NSW data relating to counselling services from July to December in 2009 demonstrate that the number of carers of people with a mental illness was significantly higher than other carer groups and was the highest for the period.

Improved outcomes for people with mental illness, alongside better access to financial support for both the carer and the person with a mental illness will improve

the financial situation of carers, and alleviate the negative impacts of low income and high financial costs. According to the *Mental Health Carers Report 2010* the median income of carer households was \$35,000 per annum, which is approximately half the median income for Australian households in 2007–08.³⁹ 27 per cent of respondents to this survey spent between \$100 and \$200 fortnightly to support the person they care for.⁴⁰ Despite the serious financial implications of caring for a person with a mental illness, Carer Payment and Carer Allowance are difficult for carers of people with a mental illness to qualify for, and there are still low levels of awareness of carers' entitlement to these allowances.⁴¹

Mental health services which inform, educate, support and include carers as partners in care will achieve better outcomes for all concerned. One of the greatest frustrations faced by carers are their negative experiences with mental health professionals, the common failure to consider them partners in care and their exclusion from the treatment process.⁴² Not only is this frustrating, it is dangerous, as vital knowledge and information are excluded from the assessment process, as are the people who will be supporting the recovery process.

Economic benefits will also arise from better mental health services, particularly early intervention and prevention services. According to Access Economics, the financial cost of mental illness in people aged 12-25 is \$10.6 billion a year, and the value of their lost wellbeing a further \$20.5 billion.⁴³ The benefits that would arise from greater health and participation of people with a mental illness, and therefore their carers, would more than compensate for the funding required to achieve these gains.

Carers NSW calls on the NSW Government to:

1. Increase funding for mental health in NSW in line with the proportion of the health burden constituted by mental health.
2. Improve the quality, range and capacity of services and supports for people with mental illness, including appropriate accommodation options and social and vocational supports.
3. Improve the quality, range and capacity of services and supports for carers of people with a mental illness, including education, counselling and respite.
4. Advocate through the Council of Australian Governments for mental health reform on a national level and the inclusion of mental health in National Health and Hospital Reform (NHHR), as per the 12 recommendations of the NHHR Commission regarding mental health.
5. Advocate through the Council of Australian Governments for reforms to ensure better awareness of and access to Carer Payment and Carer Allowance for carers of people with a mental illness.

2. Supported Accommodation – beyond crisis

Governments must support carers to plan for the future care needs of their sons and daughters. This must be a genuine partnership. Parents have the right to know that the person with a disability will be well cared for, that the planning has been done and that a crisis will not have to occur before transition into supported accommodation is offered.

We need the government to provide more group home placements for people with high needs. There needs to be a waiting list so that carers do not have to abandon their children at a respite centre in order to get them placed in a group home, which is what we are advised to do at present.

Responses to the Carers NSW 2010 Carer Survey

There is an increasing body of evidence that the NSW Government is failing to meet the accommodation needs of people with a disability. Although there are no definitive statistics publicly available as to the level of unmet need, the Australian Institute of Health and Welfare (AIHW) estimates that around 10,000 people in NSW have unmet supported accommodation needs.⁴⁴ As of July 30, 2010 there were over 1,729 people on the NSW Register of Requests for Supported Accommodation, 723 of whom are identified as needing a 24 hour supported accommodation place and willing to take up a place immediately.⁴⁵ The Disability Investment Group has identified that “of all disability services, the most significant unmet demand and the greatest anxiety for families relates to housing and accommodation”.⁴⁶

The NSW Government has committed to increasing the number of accommodation places from 180 new places in 2006/07 to a total of 990 additional places in 2010/11.⁴⁷ This response is underwhelming when considered in context. Thousands of places are needed, not hundreds. A significant increase in the levels of commitment and investment will be required to meet current and future demand for supported accommodation.

The opportunity

The mounting evidence of unmet need, whilst concerning, at least enables the NSW Government to identify and address the shortage. Submissions to the Productivity Commission Public Inquiry into Disability Care and Support; evidence to the NSW Parliamentary Inquiry into services provided or funded by Ageing, Disability and Home Care (ADHC), Department of Human Services; the recent report from the NSW Ombudsman regarding the failure of devolution in NSW; and the data available on young people in residential aged care centres provide comprehensive evidence of the critical shortage that exists, which is having impacts across the sector. The recent report of the *Inquiry into services provided or funded by the Department of Ageing, Disability and Home Care*⁴⁸ not only provides confirmation of the dire need for more supported accommodation, it also provides the NSW Government with recommendations as to how this issue can begin to be addressed.

The community is becoming increasingly aware of the shortage of accommodation, and its implications. The landmark *Four Corners* report ‘Breaking Point’,⁴⁹ the ‘Mad as Hell’ campaign⁵⁰ and the recent rally for phase two of *Stronger Together* are all contributing towards, and are indicative of, greater awareness and support in the

community of this issue. The NSW Government may be threatened by the attention that this issue is receiving. Alternatively, it can choose to capitalise upon the support that exists for this issue, and use it to support increased investment in supported accommodation.

The timing could not be better for the NSW Government to step up their commitment to supported accommodation. *Stronger Together* phase two is yet to commence, which provides an opportunity for the Government to incorporate greater capacity and greater choice into their plans, as well as investigating other paths to a faster and more effective roll-out.

Successful accommodation models already exist for the NSW Government to implement and/or expand. One example is the partnership-delivered model employed by the *Housing and Accommodation Support Initiative (HASI) for people with mental illness* program, which provides housing linked to clinical and psychosocial rehabilitation services for people with psychiatric disability.⁵¹ This model has been extensively evaluated, and there is strong evidence to support the success of this model.⁵² The *Disability Housing and Support Initiative (DHASI)* funded by ADHC under *Stronger Together* for people with an intellectual disability or an acquired brain injury is a similar program that could be expanded and/or adapted for other population groups. Fifty places in the program were created in the first two years of *Stronger Together*.⁵³

Accommodation models also exist in the community. Facilitating the implementation of models such as co-operative owned housing models that have already been developed by families and carers, is another way in which more accommodation that meets the need of the people concerned can be provided.* It is time for the NSW Government to work with these families to realise their plans.

The NSW Government can also look to supported living programs that have been developed in NSW and interstate. These programs provide a model for those individuals who could live in the family home or other existing accommodation if provided with the necessary services. Such options provide an opportunity for a quicker and less expensive roll-out of accommodation places as they do not require the development of physical infrastructure. Programs such as the *Waverley Community Living Program*,⁵⁴ the *Homes West Association Inc*,⁵⁵ and the *Uniting Care Disability Independent Living Skills Project*⁵⁶ need to be considered as models that may help to meet the urgent need that exists in the community for supported accommodation. Another important consideration is that individuals who continue to live supported in their existing family home or other existing accommodation can continue to be connected to their existing social and support networks in a familiar environment.

The benefits

Providing appropriate supported accommodation that meets the need of both carer and care recipient, long before crisis, will have huge benefits for the individuals affected, and potentially prevent great harm. For older parent carers in particular, the benefits would be tremendous. Carers need to be able to retire, to have their own aged care needs met, and to be able to enjoy some peace of mind. 44 per cent of

* For example, Ryde Area Supported Accommodation for the Intellectually Disabled (RASAIID), a group of 19 families who have developed plans for a clustered residential model for 20 residents. See www.rasaid.org.au/ for more details.

ageing carers in NSW have been caring for 30 years or more,⁵⁷ and many are aged in their seventies, eighties and nineties. It is unjust and unfair that after decades of caring for their child they should be plagued by worry for the future, and be asking the question that Carers NSW hears so often: “What will happen when I die?”

Access to supported accommodation when it is needed will also benefit people with a disability. Everybody, including people with a disability, has the right to a standard of living adequate for their health and wellbeing, including housing.⁵⁸ A planned transition to supported accommodation has better outcomes for both the carer and the person with a disability.⁵⁹ Transitioning at an earlier point in time, before crisis, also means that the carer can support the individual through the process, and that family and care relationships can continue.

Strong evidence of supported accommodation being provided to those who need it is also likely to alleviate the concern and stress experienced by carers and families, including those who may not yet require accommodation. Evidence of the capacity of the NSW Government to meet this need would improve the outlook of all carers, and give them some hope for the future. This need is recognised in the report of the *Inquiry into services provided or funded by the Department of Ageing, Disability and Home Care* which includes recommendations pertaining to waiting lists procedures, and the Register of Requests for Supported Accommodation.⁶⁰

Meeting unmet need for supported accommodation will also have benefits for the disability services system in NSW and for the NSW Government. The current levels of unmet need have implications beyond the individual, rendering the disability services system reactive and crisis driven,⁶¹ and compromising the principles on which *Stronger Together* is founded.

Ensuring access to supported accommodation will result in savings for the NSW Government, by ending the current unsustainable reliance on emergency accommodation and ‘last resort’ funding. In May 2010, at least 40 people had been accessing ‘last resort’ funding for more than 12 months after their families or carer could no longer cope and/or they were in danger of becoming homeless.⁶² At the end of February 2010, 136 people were receiving crisis funding through the emergency response program, up from 94 in October 2009. Emergency accommodation is significantly more expensive than full-time housing, costing \$180,000 a year, compared to \$130,000 a year.⁶³ This reliance on emergency services is an expensive symptom of the critical shortage of supported accommodation, and the crisis-driven approach of the service system. Its costs are not only financial, but also personal for those individuals who are inappropriately placed in emergency accommodation for extended periods of time.

Carers NSW calls on the NSW Government to:

1. Urgently increase the number and variety of supported accommodation options available to people with a disability as part of *Stronger Together* phase two, in line with current and projected unmet need.
2. Expand and adapt existing accommodation models such as those delivered by the *Housing and Accommodation Support Initiative (HASI) for people with mental illness* program and the *Disability Housing and Support Initiative (DHASI)*.

3. Facilitate the realisation of cooperative-based accommodation models already developed in the community by carers and families, such as Ryde Area Supported Accommodation for the Intellectually Disabled (RASAID).

3. Working Carers – making work, work.

...in the end looking after someone is almost a parental role, and it's not negotiable, you need to do it. It seems odd that we have all this stuff about looking after children and we just don't have any formal recognition for looking after the elderly. If you change the conversations that we are having about leave and work to as if it was a child, then you realise that there's something wrong. Because no one would ask you to give your child to someone else, or can't someone else go to the first day of school.

Working carer who cares for her elderly parents

Many carers are effectively forced out of the workforce due to a lack of alternative care options and flexible working arrangements. Exclusion from employment means that carers are denied the financial and social benefits that employment brings, including the capacity to save for retirement. Some carers continue working, but often work fewer hours in positions below their skill level with less responsibility and less pay.

In 2007, the Australian Human Rights Commission (AHRC) identified balancing paid work and family responsibilities as one of the biggest challenges facing Australia in the 21st century.⁶⁴ In *It's About Time* the AHRC made the case for a new framework to support a balance between paid work and family responsibilities; which recognises the changes in caring needs and responsibilities across a person's life cycle; addresses gender equality and shares unpaid and paid work better across the labour market and the community, and between individuals.

The opportunity

The NSW Government has the opportunity to build on growing momentum on work and family balance. There is now a greater understanding of the need for a balance between work and care, evident in the significant advances that have been made for parents with child care responsibilities. Key developments have been the introduction of a paid parental leave scheme, the incorporation of a right to request flexible working hours in the National Employment Standards, and the continued focus on child care, including the introduction of the Child Care Rebate.

Unfortunately, progress for working carers has been largely limited to parents with child care responsibilities. The importance and impact of other care responsibilities including the care of older people and adults with disabilities continues to be overlooked, despite the increasing prevalence of such responsibilities, and the increasing policy and media focus on the implications of an ageing population.

In the wake of the Paid Parental Leave Scheme and national and state carer recognition legislation, the NSW Government has a golden opportunity to extend these advances to all carers. The NSW Carers (Recognition) Act 2010 in particular provides the NSW Government with leverage on this issue. The requirements for public sector agencies to reflect the NSW Carers Charter in their internal human resources policies will improve the situation of 12 per cent of the workforce,⁶⁵ and provide an exemplar for the NSW Government to extend to all NSW employees.

This is also an opportunity to address the challenges facing the NSW economy. Our economy needs action, as demonstrated by the most recent Commsec *State of the States* economic ranking report, which ranked NSW last in the country.

In *Towards 2030 - planning for our changing population* the NSW Government acknowledges the importance of maintaining a strong economy in NSW to help negate the risks associated with an ageing population. As the plan states, “if overall economic growth rates are to be maintained then Government needs to focus on issues relating to workforce productivity and participation.”⁶⁶ The Government must implement the priorities committed to in 2008 under *Towards 2030*, especially those relating to workforce participation and carers (such as priorities 3.1.1[†] 3.1.5[‡] and 3.1.8[§]).

Finally, the impending commencement of phase two of *Stronger Together* provides a window to ensure that caring is more work-friendly. By introducing a focus on providing carers with affordable alternative care arrangements, with extended hours to suit working hours, the NSW Government can do its part to ensure that carers are not excluded from the workforce. It is not only up to employers to make work places more carer-friendly, the NSW Government must also make caring more work-friendly.

The benefits

Making caring more work-friendly, and work more carer-friendly, particularly for carers of adults, will have significant and manifold benefits for NSW.

Carers will experience significant, long lasting benefits from increased workforce participation and employment. Working provides a sense of social connectedness, purpose and achievement, as well as improving long term financial security, and reducing dependence on government benefits. Almost 40 per cent and 55 per cent of primary carers have government pensions as their main source of cash income.⁶⁷ Reducing this level of dependence is in the interest of carers, the community and governments.

Improving the ability of carers to remain in paid employment will also help to reduce gender inequalities in NSW, as caring and its impacts are highly gendered. Although only 54 per cent of carers are women, they represent 71 per cent of primary carers, and have more intense caring responsibilities.^{**} As women are more likely to be carers while of working age, the impact on their workforce participation and financial situation is very significant. We know that Australian women experience economic disadvantage, and that the face of poverty in the future will be “old, grey and female”.⁶⁸ Reducing the disadvantage facing carers will also reduce the disadvantage experienced by women. This is particularly pertinent in the context of an ageing

[†]3.1.1 Ensure public sector agencies encourage increased workforce participation by developing flexible approaches to employment, job redesign, job mobility, policies to recruit and retain staff, and new workforce models.

[‡] 3.1.5 Work with the business community to identify barriers to workforce participation and develop best practice solutions.

[§] 3.1.8 Implement strategies under the NSW Carers Action Plan 2007 – 2012 to:

- assist mature age workers to meet their caring responsibilities for ageing family members
- combine caring and work
- increase workplace flexibility for carers
- enhance the Working Carers Gateway website.

^{**} According to ABS SDAC 2003 data, 52 per cent of female primary carers provide 40 or more hours of care per week compared with 39 per cent of male primary carers.

population, in which nine out of ten frail older parents are cared for by women,⁶⁹ and the number of workers with frail older parents is increasing.

Keeping carers in the workforce will also benefit the economy, by reducing productivity losses and by improving labour force participation rates. Labour force participation is projected to fall by 7 per cent by 2044-45, creating a shortage of some 530,000 workers.⁷⁰ The productivity losses arising from carers leaving the workforce are also considerable, estimated at \$6.5 billion in 2010.⁷¹ There is also evidence of the benefits arising from carer workforce participation. According to National Disability Services, the benefit to the Australian economy would be \$32 billion if just 20 per cent of carers returned to work.⁷² Although this data relates to national figures, a significant proportion of these impacts would occur in NSW as NSW is home to around one-third of the nation's carers.⁷³

Carers NSW calls on the NSW Government to:

1. Increase service flexibility, introduce after hours services and extend day-program hours to suit 9-5 working arrangements.
2. Develop and distribute clear and accessible information, advice and resources for public sector agencies and other employers on creating carer-friendly work places.
3. Implement commitments made to increasing carer workforce participation in *Towards 2030* and the *NSW Carers Action Plan 2007-12*.
4. Advocate through the Council of Australian Governments for an amendment to the *Fair Work Act 2009* to extend the right to request flexible working arrangements to all primary carers, regardless of the age of the care recipient or relationship status.
5. Honour the commitments made to working carers in *Towards 2030* and the *NSW Carers Action Plan*.

4. Telehealthcare – today’s technology for tomorrow’s crisis

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. Telecare usually refers to equipment and detectors that provide continuous, automatic and remote monitoring of care needs, emergencies and lifestyle changes, using information and communication technology to trigger human responses, or shut down equipment to prevent hazards.⁷⁴

Telehealth is the provision of health services at a distance using a range of digital technologies.⁷⁵

There is accelerating convergence between telecare and telehealth 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.⁷⁶

The opportunity

The health, disability and aged care sectors are lagging behind other industries in their application of Information and Communication Technology (ICT). As acknowledged by the National Health and Hospital Reform (NHHR) Commission, telehealth is not yet used to its potential, despite numerous innovative projects having been trialled around the country.⁷⁷ This is not the case in other comparable nations, such as Canada, the United States and Scotland, who are currently reaping the benefits of making telehealth and telecare mainstream components of health and care services.

There has never been a better time for NSW to ‘mainstream’ telehealthcare. The infrastructure exists, and will be strengthened by the roll out of the National Broadband Network. The National E-health transition currently underway will also support the mainstream application of telehealthcare. The technology is available, and has been trialled in a variety of locations around the country, and internationally. A local industry is also in place, which, despite low domestic take up, is currently playing “a pivotal role in the global health e-revolution”.⁷⁸

The people of NSW are also ready for the telehealthcare revolution, as demonstrated by their keen uptake of ICT. According to the ABS Multipurpose Household Survey 72 per cent of Australian households had home internet access, 78 per cent of households had access to a computer and rates of internet access had quadrupled between 1998 and 2009.⁷⁹ In June 2010 66 per cent of Australians aged over 14 had broadband service in their homes.⁸⁰ Respondents to the 2010 Carers NSW Carer Survey showed an even more marked engagement with ICT. Despite the average age of survey recipients being 58 (with 34 per cent aged over 65) 76 per cent had access to the internet and 84 per cent had a mobile phone. However, only five per cent of respondents were currently using telehealthcare services.⁸¹

The benefits

The benefits of telehealthcare are manifold. It will not be a panacea for all the challenges facing our care systems, but it can assist NSW to mitigate the significant

risks posed by the demographic and workforce pressures discussed earlier. 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.⁸²

Telehealthcare can also save the NSW Government considerable amounts of money. Access Economics estimates that steady state benefits to Australia from wide scale implementation of telehealth may be in the vicinity of \$2 billion to \$4 billion dollars per annum, an estimate they acknowledge to be an underestimate.⁸³

The Scottish experience of telecare supports these findings. According to the evaluation of the Scottish Government's National Telecare Development Programme, in 2007 – 08 (the first main year of operation) savings totalling £11.15 million were identified. In 2007 – 2010 the likely savings were valued at around £43 million, an anticipated benefit to program funding cost ratio of 5:1.⁸⁴

The benefits to carers are also considerable. 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).⁸⁵

Telehealthcare will also have considerable benefits for rural and regional carers, although they are by no means the only population group who would benefit. Australian telehealth initiatives to date have often focused on rural and regional areas, in response to the challenges of delivering accessible services. According to NSW Health almost one quarter of people living in rural or regional areas will face difficulty accessing health care when they need it.⁸⁶ Service utilisation and health outcomes for rural and regional carers would be greatly improved through telehealthcare.

Carers NSW calls on the NSW Government to:

1. Immediately initiate the mainstreaming of telehealthcare in NSW, so that it becomes a routine and normal part of the infrastructure of support for everyday life for all whose require care and support from carers and/or formal services.
2. Invest in all aspects of telehealthcare, including services from the telecare and telehealth domains. Telehealthcare should be available for all population groups, complemented by initiatives targeted specifically at those who will benefit most, including carers, people with chronic conditions and their carers, older people and their carers and people from rural and regional NSW.
3. Advocate for the mainstreaming of telehealthcare Australia-wide, and for the changes necessary to support this, including the development of national guidelines and standards for the use of telehealthcare, and the legislative changes that may be necessary in respect to telehealth services in the Medicare Benefits Scheme.

5. Carer Recognition Legislation – Putting the Act into Action

Only legislation can begin the long journey towards equal opportunities for carers...Only legislation will ensure carers are seen as individuals entitled to and receiving support in their own right.

Laraine Toms, President, Carers NSW⁸⁷

On the passing of this bill departments and agencies must be calibrated to implement the charter to its fullest extent. There will need to be policy change, retraining and education, capacity building, process change and additional financial resources to support the charter and to ensure compliance with the charter. I would expect the Treasurer's upcoming budget to have specific line items to activate and support the implementation of the bill.

The Hon. Ian Cohen⁸⁸

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 NSW Carers (Recognition) Act 2010 (the Act) enacts a NSW Carers Charter and establishes a Carers Advisory Council. The Act also includes requirements that public sector agencies in NSW take action to reflect the NSW Carers Charter. They must 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.

Six months on the NSW Government has demonstrated commitment to implementing this legislation, particularly in regards to the establishment of the Carers Advisory Council. The NSW Government must take an equally conscientious approach to the implementation of the other components of the Act.

The opportunity

The fact that NSW was one of the last jurisdictions in Australia to enact carer recognition legislation provides NSW with a unique opportunity to effectively implement the Act. Western Australia, South Australia, the Northern Territory, Queensland and the Australian Capital Territory have already had carer recognition legislation for some time. Although this has been disheartening for carers in NSW, the advantage of this situation is that NSW can learn from the experiences of these jurisdictions and the relative effectiveness of their legislation.

Western Australia, for example, introduced similar legislation in 2004 and conducted a comprehensive review of its effectiveness in 2008.⁸⁹ This review provides clear guidance on the action required to effectively implement carer recognition legislation. Findings included that the Western Australian Act had not been effective in achieving its objectives of increasing recognition of the role of carers and including carers in service planning. This was attributed to several factors, including a lack of an awareness-raising campaign and training of key personnel within relevant

organisations, which has contributed to low awareness and understanding of the Act, and continuing confusion around the term 'carer'.⁹⁰

The experience of Western Australia is applicable to NSW. 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. This is particularly concerning when one considers that around 80 per cent of survey respondents were Carers NSW members, and thus would have received information about the Act. It is apparent that there are also low levels of awareness among public sector and human services agencies, their staff and contractors, who will therefore require assistance to understand, implement and promote the Act.⁹¹

The Act provides the NSW Government with the opportunity to provide true leadership on carer recognition. Some consider that legislation, such as this Act, which does not award carers legal status, rights or entitlements is a 'legislated pat on the back' or 'legislative lip service'.⁹² Although this does not have to be the case for NSW, in the absence of legislated rights for carers, the NSW Government must take a pro-active leadership role to ensure that the Act achieves its objectives.

The benefits

The 2009 *Who Cares?* Inquiry found that despite their significant contribution to society, many carers feel their role is still not understood or appreciated by governments or by the wider community, including the professionals and service providers who have significant and frequent interaction with them.⁹³ There does not seem to have been any significant progress since the Inquiry in this regard. In the Carers NSW 2010 Carer Survey 41 respondents made additional comments relating to the need for greater recognition of carers. Effectively implemented carer recognition legislation will meet this need.

Implementing carer recognition legislation will also have benefits for the NSW Government. Better recognition and inclusion of carers, particularly in service planning and human resource policies, will have positive outcomes for carers health, wellbeing and employment participation, and will make caring more sustainable. As our health and care systems depend upon carers, anything that makes this role easier for them has manifold benefits for the state and the NSW Government.

Further, providing leadership in this regard will enable the NSW Government to finally catch up with other Australian governments, and will progress their commitment to carers in the NSW Carers Action Plan. The NSW Government needs to prove to the carers of NSW that it is serious about recognising, supporting and valuing carers, and that it appreciates the critical contribution they make to the wellbeing of the people they care for, and of our society.

Carers NSW calls on the NSW Government to:

1. Implement a multi-faceted awareness campaign to raise awareness of the Act and of the contribution and needs of carers, targeted at the general community and at public sector and human service agencies.
2. Facilitate the implementation of the Act by public sector and human service agencies by providing clear and accessible information, advice and resources.

3. Support the operations of the Carer Advisory Council and their capacity to meet their objectives by providing adequate levels of administrative, financial and human resources support.
4. Commit to a comprehensive evaluation of the Act in 2014, including a review of the need to establish legal status, rights and entitlements for carers.

6. Transport – eliminating transport disadvantage in NSW

Travel demand is so diverse. The reasons we travel, the times we travel, the distances we cover and the modes we choose are influenced by so many different factors. The patterns of travel for the people of NSW are changing. *It is our job to understand these needs and plan for a transport system to support NSW into the future.*^{††}

Transport NSW in *Moving Together Corporate Plan 2010 – 2014*⁹⁴

Demand for transport is as diverse as the people of NSW. Unfortunately, this is not reflected in *Moving Together*, or in the *NSW State Plan*, which both focus squarely on transport for Sydney CBD-bound commuters. Another glaring oversight in NSW Government policy is the impacts of transport on health and wellbeing.

Transport is a social determinant of health, and a critical part of our lives. It is fundamental to ensuring access to work, education, health services and other essential civic and social opportunities.⁹⁵ Carers and the people they care for are vulnerable to transport disadvantage, which renders services inaccessible, entrenches social isolation and negatively impacts upon participation in employment and education and health and wellbeing.

The opportunity

The Cancer Council NSW (TCCNSW), Council of Social Service of NSW (NCOSS) and the NSW Community Transport Organisation (CTO) have released the findings of a study of community transport in NSW. *No Transport, No Treatment* provides the NSW Government with a timely insight into the increasing unmet need for transport to health services. NSW Health currently provides only 10 per cent of the funding for the 680,000 trips to health services provided by community transport each year.⁹⁶ It is clear that a cultural shift is required. The report recommends; increased funding for non-emergency health-related transport; allocation of resources to make health transport available to all; and the incorporation of transport planning into all health planning.⁹⁷

The NSW health system is currently undergoing significant changes. This era of reform, and particularly the creation of Local Health Networks (LHNs), could facilitate the implementation of these solutions. Planning for transport services can be embedded into health planning from the commencement of LHNs.

Combined Pensioners & Superannuants Association NSW (CPSA) have also released a report on transport disadvantage. *Closing the transport gap* addresses the transport needs of older people and people with disability, and the significant impacts of their transport disadvantage. CPSA proposes that the NSW Government adopt a social transit agenda to sit alongside its mass transit agenda, to address this disadvantage.

2011 will mark the beginning of a new era in NSW. Regardless of the results of the election in March, the beginning of a new four-year electoral cycle will provide the NSW Government with the opportunity to reassess and refocus key challenges facing NSW, including transport. It would be an ideal time to adopt a social transit agenda alongside the existing commuter-focused mass transit agenda.

^{††} Emphasis Carers NSW

The commencement of phase two of *Stronger Together* provides further opportunity for the NSW Government to look closely at the transport needs of people with a disability and their carers, to make a renewed commitment to community transport, and to incorporate the provision of transport services to users of respite, day programs and other disability services.

The benefits

The benefits of eliminating transport disadvantage will be widespread and significant, particularly for carers and the people they care for.

Older people and their carers (particularly those balancing work and care) will benefit from improved transport. Transport assistance is a critical need for older people, and was the second largest area of need for Aged Care Assessment Team clients in 2006-07.⁹⁸ According to SDAC 2003 showed 43 per cent of people in NSW over the age of 60 years needed assistance with transport. Assistance to these individuals was overwhelmingly provided by carers.⁹⁹

Better transport provision will not only reduce the transport responsibilities borne by many carers, it will also improve the accessibility and usefulness of services such as respite. The time, cost and stress involved in transporting the care recipient, whether it is crossing peak hour traffic in a metropolitan centre, or great distances in rural NSW, compromises service utilisation and the potential benefits of service use. A Western Australian study found that the key issues facing rural carers were not so much a lack of services, but rather access to services, due to travel time and distance, financial constraints and the physical management of the care recipient.¹⁰⁰ Providing transport will increase the utilisation and usefulness of disability services.

Better transport to health services will improve health outcomes for many, including rural carers. Use of health care services declines as the individuals' distance from the facility increases.¹⁰¹ According to NSW Health almost one quarter of people living in rural or regional areas will face difficulty accessing health care when they need it.¹⁰² Distance has been related to delays in treatment and increased mortality for some health problems.¹⁰³ Increased funding for health-related transport would reduce the number of people missing or delaying health appointments because of transport issues and would release existing community transport funding for other important transport roles.

Carers NSW calls on the NSW Government to:

1. Adopt a social transit agenda to sit alongside the existing mass transit agenda.
2. Significantly increase funding to community transport.
3. Ensure that transport planning is incorporated into all health planning in the reformed NSW health system.
4. Significantly increase funding to the Transport for Health program, to remove the burden of health transport from community transport.
5. Incorporate the provision of adequate, accessible transport into phase two of *Stronger Together*.

7. A NSW Carer Card – real recognition for carers

A Carer Card is a discount and benefits card for primary carers modelled on the successful Seniors Card scheme. Unlike the widely-promoted Companion Card, a Carer Card can be used by the carer in their own right, independent of the care recipient.

A Carer Card is an important act of symbolic and financial recognition of the value of carers to our society and of the personal and financial costs of caring. It would provide a range of benefits similar to that of the Seniors Card, including:

- concession fares on public transport (including private operated)
- discounts on goods and services from participating businesses, including holiday and leisure venues, and professional services
- concession entry to major community events such as the Sydney Royal Easter Show
- concession entry to public and cultural institutions.

A Carer Card could also be used within the health, community and aged care sectors to improve recognition of carers and facilitate their inclusion as partners in care. Health providers could provide card holders with access to bulk billing for services and to free annual health checks to maintain their own health and wellbeing.

The opportunity

Now is the time for NSW to introduce a Carer Card. In 2010 NSW took an important step towards recognising carers with the enactment of the NSW Carers (Recognition) Act 2010. Before the passing of this bill, NSW was one of only three Australian states and territories without carer recognition legislation. A year ago, in the Carers NSW 2009-10 pre-budget submission we urged the NSW Government to catch up with the rest of the country in this regard. This year we repeat that call, but in reference to a Carer Card. Victoria,¹⁰⁴ Queensland¹⁰⁵ and the Northern Territory¹⁰⁶ already have them. The time is right for NSW to follow through on their commitment to carer recognition and catch up with the leading states on this issue, by establishing a Carer Card.

The successful Seniors Card program provides both a model and an administrative framework for a Carer Card, which could 'piggy back' on the Senior Card program and be implemented and administrated by Ageing, Disability and Home Care. If eligibility is limited to primary carers who are residents of NSW (demonstrated through receipt of the Carer Payment and/or Carer Allowance or the declaration of a health professional), the pool of potential recipients would be less than 110,000.^{‡‡} The scope of the Carer Card would thus be considerably less than the Seniors Card, which had 985,000 members as of May 2010.¹⁰⁷ Considering the similar models of the Cards and the relatively small scale of the Carer Card, Carers NSW believes that the costs involved, including the cost of transport concessions, are relatively low and are outweighed by the benefits of the Card for NSW and for carers.^{§§}

^{‡‡} Calculation based on the number of primary carers in NSW aged under 65 in the *ABS 2003 Survey of Disability and Carers*. Many primary carers aged 60 and over would be eligible for the Seniors Card.

^{§§} In 2006 Carers NSW submitted a proposal for a Carer Card to the NSW Government. This contains more detailed analysis of the cost and implementation of the Carer Card.

The benefits

A Carer Card would provide tangible recognition for carers, and increase awareness of carers throughout the community. Individuals, community groups and businesses will all become more aware of the value and cost of caring. This will be of particular importance to hidden carers. Greater levels of awareness and recognition in the community will help some hidden carers to identify as carers and access services and support.

A Carer Card would also provide much needed financial relief for carers. In NSW over half of all primary carers rely on a government pension or allowance as their principal source of income.¹⁰⁸ Their median gross personal income is \$224 per week compared with \$401 for the total population.¹⁰⁹ Each week the Carers NSW Carer Line receives inquiries from carers about a NSW Carer Card. The discounts and concession fares provided by the card may not seem significant to some, but for carers who experience high financial stress and are forced to pass up many of life's luxuries and necessities, this assistance will be of great value.

Just as the Senior Card encourages older Australia's to enjoy more active and healthier lifestyles, so too may the Carer Card enable carers to achieve greater participation in the community, particularly in community events and in leisure and recreational activities. It is well established the carers are vulnerable to social isolation and social exclusion. By assisting carers to access these services and activities, their sense of connectedness to the community, and their emotional and physical wellbeing may improve.

Finally, the NSW Government would also benefit from the introduction of a Carer Card. The introduction of a Carer Card would further progress towards honouring the NSW Government's commitments to carers in the *NSW Carers Action Plan 2007-12* and the NSW Carers (Recognition) Act 2010.

Carers NSW calls on the NSW Government to:

1. Investigate options for developing a Carer Card in NSW that is based on the Seniors Card model as a tangible way of improving carer recognition and support in NSW
2. Implement a Carer Card administered in conjunction with the Seniors Card program by Ageing, Disability and Home Care, Department of Human Services NSW.

Conclusion

Carers NSW would like to thank the NSW Government for the opportunity to make this submission prior to the 2011 – 2012 NSW State Budget. Carers NSW hopes that the NSW Government will seize the opportunity that currently presents itself to address the future challenges faced by the state of NSW and its carers. We look forward to a brighter future for carers and for our state, where carers are recognised, valued and supported, where caring is a shared community responsibility, and where carers have the right to choice, including the right to choose (or not) to continue in their caring role.

Endnotes

- ¹ Australian Bureau of Statistics, *Survey of Disability, Ageing and Carers 2003*, Cat. No 4430.0, Canberra, 2004.
- ² Carers NSW, Carers NSW 2010 Carer Survey, Sydney, 2010.
- ³ Inspire Foundation, 'Inspire' website [online], available at: <http://www.inspire.org.au/>, 2010.
- ⁴ Livewire, 'Livewire - Connecting, Supporting and Empowering through Online Communities' [online], available at: <https://www.livewire.org.au/>, 2010.
- ⁵ Commonwealth Treasury, *Australia to 2050: future challenges*, Intergenerational Report 2010, Canberra, 2010.
- ⁶ NSW Department of Premier and Cabinet, *Towards 2030: planning for our changing population*, Sydney, 2008.
- ⁷ Commonwealth Treasury, *Australia to 2050: future challenges*, 2010.
- ⁸ NSW Department of Health, *Future Directions for Health in NSW – Towards 2025*, Sydney, 2007.
- ⁹ Access Economics *Projections of dementia prevalence and incidence in NSW: 2009 – 2050*, report for Alzheimer's Australia NSW, Canberra, 2009.
- ¹⁰ NSW Government, 'Submission to Productivity Commission Research Study into Economic Implications of an Ageing Australia', Sydney, 2004.
- ¹¹ NSW Department of Health, *Future Directions for Health in NSW*, 2007.
- ¹² Disability Investment Group, *The Way Forward – A New Disability Policy Framework For Australia*, Canberra, 2009.
- ¹³ NSW Treasury, *NSW Long Term Fiscal Pressures Report Budget Paper No. 6, 2006 2007 Budget Papers*, NSW Treasury, Sydney, 2006.
- ¹⁴ Access Economics, *The value of informal care in 2010*, report for Carers Australia, Canberra, 2010.
- ¹⁵ National Health and Hospital Reform Commission, *A Healthier Future for all Australians – Final Report of the National Health and Hospitals Reform Commission*, 2009.
- ¹⁶ Access Economics, *The value of informal care in 2010*, 2010.
- ¹⁷ Disability Investment Group, *The Way Forward*, 2009.
- ¹⁸ Access Economics, *Keeping dementia front of mind: incidence and prevalence 2009 – 2050*, report for Alzheimer's Australia, 2009.
- ¹⁹ 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.
- ²⁰ R Cummins et al, *The wellbeing of Australians – Carer Health and Wellbeing*, Australian Unity Wellbeing Index Survey 17.1 Special Report, 2007.
- ²¹ Australian Bureau of Statistics (ABS), *Survey of Disability, Ageing and Carers 2003*, Cat. No 4430.0, Canberra, 2004.
- ²² NSW Department of Health, *Future Directions for Health in NSW*, 2007.
- ²³ NSW Legislative Council Select Committee on Mental Health, *Final Report Mental Health Services In New South Wales*, 2002.
- ²⁴ Mental Health Council of Australia, *Not For Service: Experiences of Injustice and Despair in Mental Health Care in Australia*, Canberra, 2005.
- ²⁵ 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.
- ²⁶ G Groom, I Hickie & T Davenport, *Out of Hospital, Out of Mind! A report detailing mental health services in Australia in 2002 and community priorities for national mental health policy for 2003-2008*, Canberra, 2003.
- ²⁷ Mental Health Council of Australia, *Not For Service*, Canberra, 2005.
- ²⁸ Mental Health Council of Australia, *Adversity to Advocacy: The Lives and Hopes of Mental Health Carers*, Canberra, 2009.
- ²⁹ Ibid
- ³⁰ Mental Health Council of Australia, *Mental Health Carers Report 2010*, Sydney, 2010.
- ³¹ P McGorry, 'Open minds, improve services, transform Australia' [online], available at: www.patmcgorry.com.au, 2010.
- ³² P McGorry, 'Lives blighted by an unhealthy mindset', *The Australian*, Sydney, October 9, 2010.

-
- ³³ NSW Legislative Council Select Committee on Mental Health, Legislative Council Select Committee on Mental Health Final Report Mental Health Services In New South Wales, Parliamentary Paper no. 368, 2002.
- ³⁴ Mental Health Council of Australia and Carers Australia, *Carers of people with mental illness project report*, Canberra, 2000.
- ³⁵ Carers NSW, Carers NSW 2010 Carer Survey, Sydney, 2010.
- ³⁶ Australian Bureau of Statistics, *National Survey of Mental Health and Wellbeing: Summary of Results*, Cat No. 4326.0, 2008.
- ³⁷ Mental Health Council of Australia, *Mental Health Carers Report 2010*, Sydney, 2010.
- ³⁸ Ibid.
- ³⁹ Ibid.
- ⁴⁰ Ibid.
- ⁴¹ Mental Health Council of Australia, *Adversity to Advocacy*, 2009.
- ⁴² Ibid.
- ⁴³ Access Economics, *The economic impact of youth mental illness and the cost effectiveness of early intervention*, report for headspace Centre of Excellence in Youth Mental Health, 2009.
- ⁴⁴ Australian Institute of Health and Welfare, *Current and future demand for specialist disability services*, Canberra, 2007.
- ⁴⁵ Ageing, Disability and Home Care, 'Submission to the Inquiry into services provided or funded by the Department of Ageing, Disability and Home Care', 2010.
- ⁴⁶ Disability Investment Group, *The Way Forward*, 2009.
- ⁴⁷ Ageing, Disability and Home Care, *Stronger Together: A new direction for disability services in NSW 2006 – 2016*, Sydney, 2010.
- ⁴⁸ Standing Committee on Social Issues, *Services provided or funded by the Department of Ageing, Disability and Home Care Report*, Sydney, 2010.
- ⁴⁹ Australian Broadcasting Corporation, 'Breaking Point', *Four Corners*, 2010.
- ⁵⁰ Australians Mad as Hell [online] <http://australiansmadashell.com.au> 2010.
- ⁵¹ NSW Department of Health, *Housing and Accommodation Support Initiative (HASI) for people with mental illness*, Sydney, 2006.
- ⁵² K Muir et al, 'Housing and Accommodation Support Initiative Evaluation, Report III', *SPRC Report 2/07*, report prepared for NSW Health and Housing NSW, Sydney, 2007.
- ⁵³ Ageing, Disability and Home Care, 'Stronger Together: A report card for the first two years' Sydney, 2008.
- ⁵⁴ Waverley Council, 'Waverley Community Living Program' [online], available at: <http://www1.waverley.nsw.gov.au/commservices/disability/wclp.asp>, Sydney, 2010.
- ⁵⁵ Homes West Association Inc., 'Homes West Association Inc' [online], available at: <http://www.homeswest.org.au/>, Queensland, 2010.
- ⁵⁶ Uniting Care Disability, 'Independent Living Skills Project' [online], available at: http://www.unitingcaredisability.org.au/supported_living/independent_living_skills_project, Sydney, 2010.
- ⁵⁷ Australian Institute of Health and Welfare, *Current and future demand for specialist disability services*, Canberra, 2007.
- ⁵⁸ United Nations, *Universal Declaration of Human Rights*, Article 25.1, 1948.
- ⁵⁹ Cartwright and Parker, 2004, cited in Sue King et al, *Care to live or live to care? An insight into the experiences of ageing parent carers*, Sydney, 2010.
- ⁶⁰ Standing Committee on Social Issues, *Services provided or funded by the Department of Ageing, Disability and Home Care Report*, Sydney, 2010.
- ⁶¹ Victorian Advocacy League for Individuals with Disability Inc et al 'Submission to Inquiries into Supported Accommodation for those with Disability and Mental Illness', Victoria, 2010.
- ⁶² L Hall, 'Disabled children face years in crisis care' *Sydney Morning Herald*, Sydney, May 28 2010.
- ⁶³ Ibid.
- ⁶⁴ Australian Human Rights Commission, *It's About Time*, Sydney, 2007.
- ⁶⁵ Department of Premier and Cabinet, 'Public Sector Employment' [online], Available at: http://www.dpc.nsw.gov.au/public_sector_employment, September 8 2010.
- ⁶⁶ NSW Department of Premier and Cabinet, *Towards 2030*, 2008.
- ⁶⁷ Australian Bureau of Statistics, *Disability, Ageing and Carers: Summary of Findings 2004* Cat No 4430.0, 2004.

- ⁶⁸ M O'Halloran quoted in S Peatling 'Outdated welfare system hits carers', *The Sydney Morning Herald*, May 16 2010.
- ⁶⁹ Australian Bureau of Statistics, *Survey of Disability, Ageing and Carers 2003*, 2004.
- ⁷⁰ L Rolland cited in NSW Department of Premier and Cabinet, *Towards 2030: planning for our changing population*, Sydney, 2008.
- ⁷¹ Access Economics, *The Economic Value of Informal Care in 2010*, 2010.
- ⁷² National Disability Services, 'Submission to the Productivity Commission Inquiry into Disability Care and Support', 2010.
- ⁷³ Australian Bureau of Statistics, *Survey of Disability, Ageing and Carers 2003*, 2004.
- ⁷⁴ Joint Improvement Team, *National Telecare Development Programme in Scotland Glossary of Terms and Definitions* Scottish Government, Edinburgh, 2008.
- ⁷⁵ Ibid.
- ⁷⁶ Ibid.
- ⁷⁷ National Health and Hospital Reform Commission, *A Healthier Future for all Australians – Final Report of the National Health and Hospitals Reform Commission*, 2009.
- ⁷⁸ Australian School of Business, 'Medicine-To-Go: Stand By For the e-Health Revolution' [online], available at: <http://knowledge.asb.unsw.edu.au/article.cfm?articleid=1027>, 2010.
- ⁷⁹ Australian Bureau of Statistics, *Household Use of Information Technology, Australia, 2008-09* [online], available at: <http://www.abs.gov.au/ausstats/abs@.nsf/mf/8146.0>, 2008.
- ⁸⁰ Australian Communications and Media Authority, *Australia in the digital economy: The shift to the online environment*, Communications report 2009-10 series, 2010.
- ⁸¹ Carers NSW, *Carers NSW 2010 Carer Survey*, Sydney, 2010.
- ⁸² Carers Scotland, 'A weight off my mind' *Exploring the impact and potential benefits of telecare for unpaid carers in Scotland*, Edinburgh, 2009.
- ⁸³ Access Economics, *Financial and externality impacts of high-speed broadband for Telehealth*, Canberra, 2009.
- ⁸⁴ Carers Scotland, 'A weight off my mind', 2009.
- ⁸⁵ Ibid.
- ⁸⁶ NSW Ministry of Transport 2006 cited in TCCNSW, NOSS and NSW CTO, *No Transport, No Treatment*, Sydney, 2010.
- ⁸⁷ L Toms, 'Carers Recognition Bill' in *Carers News*, April/May, 2010.
- ⁸⁸ I Cohen cited in NSW Legislative Council, 'Carers (Recognition) Bill 2010 Second Reading', Hansard, May 12, 2010.
- ⁸⁹ D Murray et al, *Review of the Carers Recognition Act 2004: Final Report*, Western Australia, 2008.
- ⁹⁰ Ibid, p 4.
- ⁹¹ Anecdotal evidence from Carers NSW from conversations with public sector agency employees, including human resources.
- ⁹² Working Carers Gateway, 'National Carer Recognition Bill tabled' [Online], Available at: <http://www.workingcarers.org.au/options/1106-national-carer-recognition-bill-tabled>, 2010.
- ⁹³ House of Representatives Standing Committee on Family, Community, Housing and Youth *Who Cares...? Report on the inquiry into better support for carers*, Canberra, 2008.
- ⁹⁴ Transport NSW, *Moving Together Corporate Plan 2010 – 2014*, Sydney, 2010.
- ⁹⁵ State of Victoria, *Improving options and reducing barriers. Addressing transport disadvantage: A status report*, 2008.
- ⁹⁶ TCCNSW, NCOSS and NSW CTO, *No Transport, No Treatment: Community transport to health services in NSW*, Sydney, 2010.
- ⁹⁷ Ibid.
- ⁹⁸ Australian Institute of Health and Welfare, *Australia's Welfare 2009 series no. 9.Cat.no.AUS 117*, Canberra, 2009.
- ⁹⁹ Australian Bureau of Statistics, *Survey of Disability, Ageing and Carers 2003*, 2004.
- ¹⁰⁰ T Barrett, *Roughing it in the bush – carers in rural and remote Western Australia: their needs and experiences* University of Western Australia, Perth, 2005.
- ¹⁰¹ Queensland Health, 'Social Determinants of Health Transport Fact Sheet', Ipswich, 2003.
- ¹⁰² NSW Ministry of Transport 2006 cited in TCCNSW, NOSS and NSW CTO, *No Transport, No Treatment*, Sydney, 2010.
- ¹⁰³ Queensland Health, 'Social Determinants of Health Transport Fact Sheet', Ipswich, 2003.
- ¹⁰⁴ Victorian Government, 'Victorian Government Carer Card Program' [online], available at: <http://carercard.vic.gov.au/home>, Melbourne, 2010.

-
- ¹⁰⁵ Queensland Government, 'Carer Business Discount Card' [online], available at: <http://www.communityservices.qld.gov.au/community/carerbusinessdiscountcard/>, 2010.
- ¹⁰⁶ Northern Territory Government, 'NT Pensioner and Carer Concession Scheme' [online], available at: http://www.health.nt.gov.au/Aged_and_Disability/Subsidies/NT_Pencon_Scheme/index.aspx, 2010.
- ¹⁰⁷ NSW Government, Seniors Card Media Kit, Sydney, 2010.
- ¹⁰⁸ Australian Bureau of Statistics, *Survey of Disability, Ageing and Carers 2003*, 2004.
- ¹⁰⁹ Ibid.