

**Submission
No 3**

**FIFTH REVIEW OF THE EXERCISE OF THE FUNCTIONS
OF THE LIFETIME CARE AND SUPPORT AUTHORITY**

Organisation: Carers NSW

Date received: 29/10/2013

29 October 2013

The Director
Standing Committee on Law and Justice
Parliament House
Macquarie St
Sydney NSW 2000

Fifth Review of the exercise and functions of the Lifetime Care and Support Authority and Twelfth Review of the exercise and functions of the Motor Accidents Authority

Carers NSW welcomes the opportunity to provide a submission to the Fifth Review of the exercise of the functions of the Lifetime Care and Support Authority (LTCSA) and the Twelfth Review of the exercise of the functions of the Motor Accidents Authority (MAA).

Carers NSW is an association for relatives and friends supporting people with a disability, mental illness, drug or alcohol dependency, chronic condition, terminal illness or who are frail aged. The core work of Carers NSW is to:

- Be the voice of carers in NSW;
- Undertake research, policy development and systemic advocacy;
- Provide carer services and programs;
- Provide education and training for carers and service providers; and
- Build capacity in the sector.

Carers NSW has made submissions to several previous reviews of the LTCSA and MAA, many of which have been included in the final reports, and has been given several other opportunities to provide feedback to the LTCSA and MAA. This submission focuses on carer recognition, staff training, greater choice and control, carer support and carer employment and participation.

Carers NSW would like to thank the Standing Committee on Law and Justice for accepting our submission. For further information, please contact Sarah Judd, Policy and Development Officer, on
or _____.

Yours sincerely,

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Chief Executive Officer
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Carers NSW submission to the Fifth Review of the exercise and functions of the Lifetime Care and Support Authority (LTCSA) and Twelfth Review of the exercise and functions of the Motor Accidents Authority (MAA)

This submission will address the following address the following areas:

1. About carers
2. Carer recognition
3. Staff training
4. Greater choice and control
5. Carer support
6. Carer employment and participation
7. Conclusion

Summary of recommendations

Recommendation 1: Carers NSW recommends that the LTCSA and MAA take further steps to meet their obligations as public sector human service agencies under the NSW *Carers (Recognition) Act 2010*.

Recommendation 2: Carers NSW recommends that the LTCSA include carer awareness training in their skills development initiatives for attendant care workers and case managers.

Recommendation 3: Carers NSW recommends that the LTCSA's Case Manager and Attendant Care Finder tools be provided in alternative formats and languages in order to increase their accessibility to older people, people with disabilities and people from CALD backgrounds.

Recommendation 4: Carers NSW recommends that the LTCSA and MAA continue to implement the use of the term 'carer' in their publications and websites to recognise the support provided by family members.

Recommendation 5: Carers NSW recommends that the LTCSA and MAA produce, publish online and distribute information linking carers to services and support.

Recommendation 6: Carers NSW recommends that exceptions be considered to the non-payment of family members for LTCSS participants from Aboriginal and Torres Strait Islander and CALD backgrounds, and those living in rural and remote areas.

Recommendation 7: Carers NSW recommends that the LTCSA continue and expand its initiatives to support the carers and families of LTCSS participants.

Recommendation 8: Carers NSW recommends that the LTCSA and MAA explore flexible working practices to enable carers employed by the Authorities to balance work and care.

Recommendation 9: Carers NSW recommends that the LTCSA increase carer participation in the governance and direction of the Scheme, and introduce carer representative positions to the Advisory Council.

1. About carers

A carer is any person who provides informal care and support to a family member or friend who has a disability, mental illness, drug or alcohol dependence, chronic condition, terminal illness or who is frail. This includes friends and relatives supporting people who have acquired a spinal cord injury, brain injury, multiple amputations, severe burns or permanent blindness as the result of a motor accident.

There were nearly 850,000 carers in New South Wales (NSW) in 2009, which was 12 per cent of the NSW population at the time. Among these were more than a quarter of a million primary carers, the people providing the most informal assistance to an individual. Most primary carers lived in the same household as the main recipient of their careⁱ.

Carers are of particular importance for people who are reported as having a 'profound or severe core limitation', or in other words, who need help with communication, mobility and/or self-careⁱⁱ. For many of these people, family and/or friends provide critical day-to-day support in these areas, as well as practical domestic assistance, support with managing medications and coordinating services and supports, emotional care and support, and advocacy for the rights and recognition of the people they care for.

Of the 170,000 primary carers caring for someone with a profound or severe core limitation living in the same household in 2009, most dedicated 20 or more hours per week to caringⁱⁱⁱ. In 2010 Access Economics estimated that the financial cost of replacing the care provided by carers would be over \$40 billion for that year^{iv}.

The significant role that carers play in the lives of people injured in motor accidents was underlined by the Standing Committee on Law and Justice in its the report on the Fourth Review into the LTCSA, which acknowledged its "appreciation for the informal care arrangements that so often underpin rehabilitation."^v

2. Carer recognition

In Carers NSW submission and response to questions on notice for the Fourth Review of the LTCSA and MAA, we highlighted the significance of the NSW *Carers (Recognition) Act 2010* (the Act) to the two authorities. The Act requires that public sector human services agencies, including the LTCSA and MAA:

- Take all reasonable steps to ensure that their members of staff and agents are aware of, and understand, the NSW Carers Charter;

- Consult with bodies representing carers when developing policies that impact on carers;
- Consider the NSW Carers Charter in the development their human resource policies;
- Take all reasonable steps to ensure that the agency, members of staff and agents take action to reflect the principles of the NSW Carers Charter in their work; and
- Include a report on their compliance with the Act in their annual report.^{vi}

Carers NSW congratulates the LTCSA on its expression at its last review of support for the spirit of the Act, recognition of the Authority's obligations under the Act, commitment to advising all staff on the principles of the NSW Carers Charter and openness to continued ongoing consultation with Carers NSW^{vii}.

This response demonstrates a strong commitment to meeting the first two obligations listed, however, full compliance with the Act requires further action. Given that the 2012-13 Annual Report of the LTCSA has not yet been tabled at the time of submission, it is difficult for Carers NSW to evaluate the LTCSA's compliance with these obligations. However, we found no references in the available documentation (the 2011-12 Annual Report and the current LTCSA website) to indicate that full compliance has yet been achieved.

In the absence of the most recent Annual Report, Carers NSW therefore makes a number of recommendations in line with its 2011 response to the questions on notice from the Fourth Review of the LTCSA^{viii}. Carers NSW recommends that the LTCSA:

- Broaden its carer consultation and representation process beyond Carers NSW and other representative organisations to include carers directly;
- Review its internal human resources policies and their impact on employees with workplace responsibilities to better support employees with caring responsibilities;
- Pursue a range of initiatives to ensure that staff and agents not only understand the NSW Carers Charter, but also incorporate its principles into their work. Options previously suggested by Carers NSW were included in the report on the Fourth Review^{ix}; and
- Report on its compliance with the *NSW Carers (Recognition) Act 2010* in its annual reports.

In contrast to the LTCSA, the MAA has not, as far as we are aware, voiced an equivalent commitment to the Act. Carers NSW is disappointed that Act was not mentioned in the report of the Eleventh Review of the MAA. In the absence of the most recent Annual Report, Carers NSW hopes the MAA will demonstrate a commitment to meeting its obligations in future.

Recommendation 1: Carers NSW recommends that the LTCSA and MAA take further steps to meet their obligations as public sector human service agencies under the *NSW Carers (Recognition) Act 2010*.

3. Staff training

Competent, 'care aware'^x staff and service providers are critical in supporting the carers of participants of the Lifetime Care and Support Scheme (LTCSS). Carers NSW therefore

commends the LTCSA on its efforts to increase the skills base, competence and variety of attendant care workers and case managers, as reported in the 2010/11 and 2011/12 Annual Reports. The new panel of attendant care providers and the Approved Case Manager Initiative promise to increase the qualifications, specialist skills and professional accountability of the LTCSS workforce as well as provide greater choice to participants and better coverage of services across NSW^{xi}.

These outcomes are certainly in the interests of the carers and families of participants, as high quality care services and adequate choice promote productive and sustainable care arrangements that reduce the pressure on carers and families. This point was brought to the attention of Carers NSW earlier this year by a former carer who shared her experiences of caring for her husband. Although his spinal cord injury was the result of a work incident, and therefore beyond the scope of the LTCSS, her experiences effectively convey the significant implications of the quality of care workers on the daily life and wellbeing of carers and families.

Case study

Janette*'s husband Mario* became quadriplegic as a result of a workplace accident, and was subsequently entitled to lifetime nursing and attendant care through workers compensation. As Mario's care needs increased over time, the level of care he received also increased. However, the quality of care declined.

Initially, an effective routine involving specialised, experienced nurses had enabled Janette to continue working full time. Many of the newer care workers, however, did not have specialist skills or experience, and lacked the skills and confidence to competently perform basic tasks such as adjusting Mario in his wheelchair. As a result, Janette felt she had to constantly supervise the care workers, intervening where necessary to ensure his safety and comfort were maintained. The family's wellbeing also suffered from the pressure to constantly 'play host' and be polite and patient with the many strangers coming in and out of their home 24 hours a day, even when they demonstrated poor attitudes.

The supervisory role undertaken by Janette led her to stop working prior to retirement age. She rarely felt able to take a break or have time to herself. Janette also lacked confidence that the care workers would know what to do in a medical emergency, which meant that she could not leave the house for very long, or very often. When she did, she was unable to stop worrying that something would go wrong at home. However, she was afraid to change providers in case the family was left worse off.

The constant pressure caused by the lack of skills and poor attitudes of the care workers had a significant impact on Janette's own health and wellbeing, prompting concerns from her extended family. With more competent, personable workers, Janette believes that her caring role may have taken less of a toll on her.

* Not their real names

This case study also reflects to the importance of trust and rapport between care workers and carers. Quality of paid care is an important contributor to positive working relationships, as demonstrated above. However, carer recognition and awareness is also a key component. The NSW Carers Charter notes the importance of recognising the valuable

support and expertise carers contribute to the care of their family member or friend, and the need for service delivery to take into account the needs, views and best interests of carers. However, carer recognition and inclusion in disability services is often hindered by a lack of understanding of the importance of family and friends, and a lack of skills in collaboration and partnership with these parties among service providers and staff.^{xii}

Carers NSW submissions to previous reviews of the LTCSA have recommended education and training in carer awareness and support for staff and service providers associated with the LTCSS. This submission reiterates this recommendation, proposing that the workshop *Understanding and supporting carers* developed and delivered by Carers NSW, or other similar training, be delivered to attendant care workers and case managers as part of the current capacity building initiatives. Such training will equip staff and service providers to better understand and respond to the needs of carers, leading to better outcomes for LTCSS participants and their carers and families.

Recommendation 2: Carers NSW recommends that the LTCSA include carer awareness training in their skills development initiatives for attendant care workers and case managers

4. Greater choice and control

As Carers NSW noted in its submission to the last review of the LTCSA and MAA, the NSW Government is currently working towards a more person-centred disability system in NSW. Carers NSW is supportive of this transition and optimistic that this change will mean greater choice and control for people with disabilities and their families and carers. Carers NSW accordingly congratulates the LTCSA on their efforts towards increasing the choice and control of participants and carers in relation to the choosing of staff.

The online Case Manager and Attendant Care Finder tools reflect a person centred philosophy, are user friendly and will undoubtedly provide injured people and their families and carers more choice and control over the services they receive. However, Carers NSW cautions that some people, especially older people, people with disabilities and people from culturally and linguistically diverse (CALD) backgrounds, may need support and assistance in completing the tool, or alternative versions of the tool, such as in other languages.

Recommendation 3: Carers NSW recommends that the Case Manager and Attendant Care Finder tools be provided in alternative formats and languages to make choice and control accessible to older people, people with disabilities and people from CALD backgrounds.

Previous Carers NSW submissions have recommended that the term 'carer' be used in LTCSA and MAA publications and on their websites to help identify hidden carers, along with information linking carers to appropriate services and support. In the report of the Eleventh Review of the MAA, the Committee reported that the MAA had advised it was in the process of changing its language as part of the upgrading of its website, but was yet to publish information specifically directed to assist carers^{xiii}. Carers NSW congratulates the MAA on its active efforts to recognise carers through the language on their website.

However, despite acknowledgement of these recommendations in the review reports, Carers NSW is disappointed to note that there is still limited reference to, and information for, carers on the LTCSA and MAA websites, and that the references and information that do exist are difficult to find. We encourage the MAA and LTCSA to continue to change language in their website and publications where appropriate to better recognise carers and enable them to self-identify and find support.

Recommendation 4: Carers NSW recommends that the LTCSA and MAA continue to implement the use of the term 'carer' in their publications and websites to recognise the support provided by family members.

Carers NSW also recommends, in agreement with the Committee, that the MAA and LTCSA produce and publish information on their websites linking carers to appropriate services and support. Carers NSW, other non-government organisations and the Commonwealth Respite and Carelink Centres provide a range of services and supports for carers, including counselling and respite. The Department of Human Services also provides the Carer Payment and/or Carer Allowance to eligible applicants, but not all carers are aware of these opportunities for income support.

A simple web page or downloadable fact sheet with information about who carers are and the services and supports that exist could be extremely helpful for carers, especially those grappling with a recent accident and its implications for the person affected and their family. In addition to publishing this resource on the LTCSA and MAA websites, it could be distributed to prospective, new and existing families to provide better referral channels to existing services and supports.

Recommendation 5: Carers NSW recommends that the LTCSA and MAA produce, publish online and distribute information linking carers to services and support.

5. Carer support

Carers NSW is aware that, in addition to promoting other services and supports to carers, the LTCSA has some capacity to support carers directly. We applaud the commitment of the LTCSA to further exploring options for supporting families.

One key way in which the LTCSA has demonstrated a desire to support carers is in its carefully considered decision not to pay family members to provide attendant care services, other than in rare exceptional circumstances. The thorough consideration of the needs and interests of carers and families is evident in the LTCSA's justification of this decision in previous reviews and annual reports.

While Carers NSW agrees that paid attendant care is in the interests of carers, providing them with assistance and time to take a break from their caring responsibilities, we also recommend that exceptions continue to be explored in cases where paid family care may be more appropriate than bringing in external care workers. In the report of the Fourth Review, the Australian Lawyers' Alliance (ALA) put forward some potential exceptions where paying

a family member could be appropriate. Further, a case was cited of a carer in a remote location being paid to care:

“there is only one circumstance where because of the remote location in which the participant resides, the Scheme agreed to pay a family member as a carer. In that case, Mr Bowen explained, the carer was an employee of a care service provider in order to ensure that requirements were met to ensure the person could do the work both well and safely.”^{xiv}

In line with the above example, Carers NSW recommends that the option of payment be available to some carers, where, for location or other reasons this may be more appropriate, and where adequate training and workplace protections are available to the carer. For example, families from a culturally and linguistically diverse (CALD) or Aboriginal and Torres Strait Islander background, or families living in rural or remote areas of NSW where service choices may be limited, may require special consideration.

Recommendation 6: Carers NSW recommends that exceptions be considered to the non-payment of family members for LTCSS participants from Aboriginal and Torres Strait Islander and CALD backgrounds, and those living in rural and remote areas.

Although paid attendant care services are of great benefit to the carers and families of injured persons, the presence of paid care workers does not necessarily eliminate the large responsibility placed on the carer, as the case study in Section 3 demonstrates. Carers require other, more targeted support to maintain their health and wellbeing and sustain them in their caring role.

Carers NSW congratulates the LTCSA on its initiatives to support the carers and families of LTCSS participants, including its piloting of a program aimed at building family resilience and its consideration of a comprehensive family support program^{xv}. Carers NSW also welcomes the LTCSA’s contribution to the development of the Sargood Centre on the Northern Beaches as an important opportunity for families to be comprehensively supported along with their injured family member. Carers NSW recommends that, in addition to the services and supports that will be offered to families via LTCSS programs, the Centre be used as a ‘one stop shop’ for resources and information for carers, including referral to existing services and supports such as those offered by Carers NSW, the Department of Human Services and the Commonwealth Respite and Carelink Centres.

Recommendation 7: Carers NSW recommends that the LTCSA continue and expand its initiatives to support the carers and families of LTCSS participants.

6. Carer employment and participation

Carers NSW is pleased that, as part of their public sector reporting requirements, the LTCSA and MAA report on Equal Employment Opportunity (EEO) groups in accordance with key priorities identified in their respective EEO Plans. Carers NSW commends the concentration

on increasing the representation of women, Aboriginal and Torres Strait Islanders, people whose first language is not English and people with a disability, and points out that there are likely to be many carers represented in these groups. Carers are more likely to be female and to have a disability^{xvi}, people in Aboriginal and Torres Strait Islander communities are more likely to be carers than the general population^{xvii} and a large proportion of carers in NSW are from CALD backgrounds.^{xviii}

Carers NSW therefore recommends, in line with the obligations of public sector agencies under the *NSW Carers (Recognition) Act 2010*, that the LTCSA and MAA consider the needs of carers in their human resource policies and explore flexible workplace practices to enable carers who may be employed by the Authorities to balance work and care.

Recommendation 8: Carers NSW recommends that the LTCSA and MAA explore flexible working practices to enable carers employed by the Authorities to balance work and care.

Consistent with our previous recommendations and those of the Committee^{xix}, Carers NSW also highlights the importance of enabling LTCSA participants and their carers to participate in the Advisory Council and providing them with necessary support to do so. Carers NSW recognises the changes intended to facilitate consumer participation through the creation of positions for consumer representatives and recommends that similar steps be taken to increase carer participation, as carers are directly impacted by the operation of the LTCSA and should be recognised as key stakeholders.

Recommendation 9: Carers NSW recommends that the LTCSA increase carer participation in the governance and direction of the Scheme, and introduce carer representative positions to the Advisory Council.

7. Conclusion

Carers NSW thanks the Standing Committee on Law and Justice for the opportunity to provide a submission to the Fifth Review of the exercise and functions of the LTCSA and the Twelfth Review of the exercise and functions of the MAA. We acknowledge the efforts of both Authorities to implement previous recommendations by Carers NSW and the Committee aimed at increasing the recognition and support of carers, and eagerly await the expansion of these efforts in the future.

ⁱ Australian Bureau of Statistics 2012, *Disability, Ageing and Carers Australia: State tables for New South Wales*, Australian Bureau of Statistics, Canberra. The 2009 SDAC provides the most up-to-date state-wide data about people with disability and carers.

ⁱⁱ Ibid.

ⁱⁱⁱ Ibid.

^{iv} Access Economics 2010, *The economic value of informal care in 2010*, Report for Carers Australia. Access Economics, Canberra.

^v Standing Committee on Law and Justice 2011, *Fourth Review of the Lifetime Care and Support Authority and the Lifetime Care and Support Advisory Council*, Report 47, NSW Legislative Council, Sydney, p. 83.

^{vi} Ageing, Disability & Home Care (2012) *NSW Carers (Recognition) Act 2010: Implementation guidelines for public sector agencies*, NSW Government, Sydney.

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- ^{vii} Standing Committee on Law and Justice 2011, *Fourth Review of the Lifetime Care and Support Authority and the Lifetime Care and Support Advisory Council*, p. 80.
- ^{viii} Carers NSW 2011, *Carers NSW response to Questions on Notice from the Fourth Review of the LTCSA and LTCSAC*, NSW Legislative Council, Sydney.
- ^{ix} Standing Committee on Law and Justice 2011, *Fourth Review of the Lifetime Care and Support Authority and the Lifetime Care and Support Advisory Council*, p. 80
- ^x Care Aware National Carer Awareness Initiative, 2013, <http://careaware.com.au>
- ^{xi} Lifetime Care & Support Authority, 2011, *Lifetime Care and Support Authority Annual Report 2010-11*, NSW Government, Sydney, p. 13; Lifetime Care & Support Authority, 2012, *Lifetime Care & Support Authority of NSW Annual Report 2011-12*, NSW Government, Sydney, p. 9.
- ^{xii} Department of Human Services and Department of Education and Early Childhood Development (2011) *Family-centred, person-centred organisations: a guide for managers and governance bodies to support whole-of-organisation approaches to family-centred practice*, State Government of Victoria, Melbourne.
- ^{xiii} Standing Committee on Law and Justice 2011, *Eleventh Review of the exercise of the functions of the Motor Accidents Authority and the Motor Accidents Council*, Report 48, NSW Legislative Council, Sydney, pp. 52-53.
- ^{xiv} Standing Committee on Law and Justice 2011, *Fourth Review of the Lifetime Care and Support Authority and the Lifetime Care and Support Advisory Council*, p. 82.
- ^{xv} *Ibid*, p. 81.
- ^{xvi} Australian Bureau of Statistics 2012.
- ^{xvii} Australian Institute of Health and Welfare 2008, *The health and welfare of Australia's Aboriginal and Torres Strait Islander peoples 2008*, Australian Institute of Health and Welfare, Canberra, p. 69;
- ^{xviii} Carers Australia 2013, 'Culturally and linguistically diverse carers', <http://www.carersaustralia.com.au/about-carers/culturally-and-linguistically-diverse-carers>, viewed 29 October 2013.
- ^{xix} Standing Committee on Law and Justice 2011, *Fourth Review of the Lifetime Care and Support Authority and the Lifetime Care and Support Advisory Council*, p. 29.