



25 October 2011

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

Carers NSW response to Questions on Notice from the Fourth Review of the LTCSA and LTCSAC

Carers NSW thanks the NSW Legislative Council Standing Committee on Law and Justice for the opportunity to provide further information to the Fourth Review of the Lifetime Care and Support Authority (LTCSA) and Lifetime Care and Support Advisory Council (LTCSAC). This submission provides Carers NSW response to Questions on Notice received from the Committee.

Entry into force of the *Carers (Recognition) Act 2010*

- 1. In your submission you referred to the entry into force of the Carers (Recognition) Act 2010. In its answers to questions on notice, the LTCSA stated that it would 'ensure that all staff are advised of the NSW Carers Charter' and that it will continue to consult with Carers NSW on guidelines. What more do you think that the Authority should do?*

The *Carers (Recognition) Act 2010* (the Act) came into force in May 2010. Under section seven of the Act public sector agencies have the following obligations:

- (1) A public sector agency must take all reasonable steps to ensure that the members of staff and agents of the agency have an awareness and understanding of the NSW Carers Charter.
- (2) A public sector agency must consult with such bodies representing carers as the agency considers appropriate when developing policies that impact on carers.
- (3) A public sector agency's internal human resources policies, so far as they may significantly affect the role of a member of staff of the agency as a carer, are to be developed having due regard to the NSW Carers Charter.

Carers NSW is pleased that the LTCSA has taken steps to meet the first obligation, by committing to ensuring that all staff are aware of the NSW Carers Charter. Informing staff of the Charter is an important first step in ensuring that this obligation is met.

In addition to advising staff of the NSW Carers Charter, the LTCSA should consider how the Charter can be kept at the front of mind for staff, so that the principles of the Charter inform their work. Options for consideration by the LTCSA include:

- incorporation of the NSW Carers Charter into induction processes
- inclusion of the NSW Carers Charter on an equal footing with other key documents and standards
- provision of information about the role and needs of carers to assist staff to contextualise and understand the importance of the NSW Carers Charter
- prominent display of the NSW Carers Charter in all LTCSA workplaces
- facilitation of discussion about the NSW Carers Charter, through periodically recurring agenda items in staff meetings (where appropriate), or through articles in LTCSA newsletters or other publications.

Carers NSW acknowledges that the LTCSA has also established consultation practices which should ensure it complies with its second obligation under the Act. The LTCSA has sought feedback from Carers NSW and has included Carers NSW on advisory groups. Carers NSW hopes to continue to work with LTCSA in this capacity.

Although continuing to consult with Carers NSW may be sufficient for the LTCSA to comply with this obligation, Carers NSW suggests that the LTCSA look to improve the representation and participation of carers within the LTCSA, in the spirit of the NSW Carers Charter, particularly that "carers' unique knowledge and experience should be acknowledged and recognised".¹ The LTCSA should review its current consultation processes and identify opportunities for improving carer consultation and representation, including by developing formal structures for carer representation and participation.

In order to meet its third obligation under the Act, the LTCSA should review its internal human resources policies and their impact on employees with workplace responsibilities. The LTCSA should give consideration to the ways in which employees with caring responsibilities could be better supported. This could be through the provision of information about services and supports for carers, access to counselling services, and implementing carer-friendly practices such as flexible working hours. Providing training to management and staff regarding employees with caring responsibilities could also improve the support of employees with caring responsibilities, and their capacity to continue to balance work and care.

In its efforts to comply with the Act, the LTCSA should not look to merely meet its legal obligations under the Act. Instead, it should look to uphold the principles of the NSW Carer Charter and the spirit of the legislation as best as possible, and where appropriate, go beyond its legal obligations to better recognise and support both employees who are carers, and the carers of participants. The LTCSA should embrace this opportunity to be a leader in the implementation of the Act.

Support for family carers

- 2. In its response to questions on notice, the LTCSA advised that in relation to the establishment of an ongoing support group for carers of people with traumatic brain or spinal cord injury as previously suggested by Carers NSW. What is your response to the LTCSA's view?*

In its response to Questions on Notice, the LTCSA stated that it "has not funded or contributed to the establishment of a support group for carers."

The question refers to a Carers NSW submission to the 2010 review of the LTCSA, in which Carers NSW referred to the 'Carers Linked in Caring Project (CLIC) – A Support Program for Carers of People with Traumatic Brain or Spinal Cord Injury'. Carers NSW was funded by the Motor Accidents Authority (MAA) to conduct this project, which was designed to provide appropriate carer-specific information and support to carers of people with Traumatic Brain Injury (TBI) or Spinal Cord Injury (SCI) who had been discharged from rehabilitation for at least one year. In this case, 'appropriate' support included information relevant to all carers, as well as specific types of information and support targeting the issues most commonly faced by carers of people with TBI or SCI.

An evaluation of the project was conducted and included the following recommendations:

- that the types of support offered to the carers of people with TBI or SCI in the CLIC project continue to be offered, and new models explored which go beyond emotional support to include psychotherapeutic programs
- that services which primarily support people with TBI or SCI be funded to provide support to their carers as well, working in partnership with Carers NSW.ⁱⁱ

Carers NSW stated that it would welcome a partnership between the MAA, LTCSA and Carers NSW to continue running this program on an ongoing basis. Carers NSW stands by this statement, and would welcome the opportunity to work with the LTCSA and MAA on this or other similar projects to ensure that carers receive the information and supports that they need.

- 3. In its submission, the Australian Medical Association of NSW (AMANSW) noted that, in certain circumstances, a family member or friend who acts as a carer for a participant is reimbursed by the Scheme for doing so. The AMANSW expressed concern that there is a proposal to remove this payment. In response to this concern, the LTCSA advised that, except in the most exceptional circumstances, family members should not be paid as attendant care workers because:*

...it is inappropriate to create a financial nexus between family members and the participant which has the long term potential to disrupt normal family relationships by creating a circumstance where family income is derived from a participant's degree of injury related dependence.

What is your response to this?

Carers NSW shares the concerns of AMANSW regarding the proposed removal of the possibility of paying family members or friends. Carers NSW acknowledges the issues raised by the LTCSA, but agrees with the AMANSW that in some circumstances the payment of family members is appropriate and necessary. It is important that this remains a possibility, and that the appropriate checks and supports are in place when it does occur.

The AMANSW cites cultural and geographical issues as examples of the kinds of circumstances in which payment of family members may be appropriate. In rural areas there may be no alternative to the employment of a family member, particularly in small communities. In some cases, Aboriginal people or people from culturally and linguistically diverse backgrounds may only be able to access culturally appropriate care by employing a family member or friend to provide care, particularly in rural areas, or when the CALD community in question is a small one.

There may be other situations in which the payment of family members is appropriate. For example, a member of the extended family may provide respite when a carer needs to be away from home. In order to provide this respite, the family member may incur direct and indirect costs, including travel expenses, and time spent away from paid employment. It is appropriate that in these circumstances the family member is paid for the care they provide, particularly if this enables the carer to attend to other responsibilities, their own health needs, or to take a much needed break. For some carers, the only circumstances in which they would take a break from the caring role is if another family member is able to take over.

The payment of family members is an issue which has recently been given consideration by the Productivity Commission in its Inquiry into Disability Care and Support. In the final report of this Inquiry, the Productivity Commission recommends a trial of the employment of family members under self-directed funding, and recommends that there should be capacity for family members to be paid as support workers when:

- care is intermittent and provided by a non-resident family member
- exceptional circumstances are present and after approval by the NDIA
- the person is in the family employment trial spelt out in recommendation 8.5.ⁱⁱⁱ

The current context in NSW supports the retention of the possibility of paying family members, particularly the introduction of person centred approaches to the NSW disability sector. According to the NSW Government, "in a person centred system the rights of people with a disability, and their families and carers, to direct their lives are respected."^{iv} Ruling out the payment of family members would contradict the aims of person centred approaches.

Although the payment of family members may remain an uncommon occurrence at present, Carers NSW believes that it should not be ruled out altogether, given the circumstances of some individuals for whom paying family members is appropriate and necessary, and the person centred context the LTCSA will be operating in.

4. *In its answers to pre-hearing questions on notice, the LTCSA advised they had not funded or contributed to the establishment of a support group for carers but did not elaborate on whether they would be prepared to do so.*

What is your response to the LTCSA's statement?

Do you think that the LTCSA is the most appropriate body to establish such a group?

Carers NSW hopes that although the LTCSA has not funded or contributed to the establishment of carer support groups, it will give consideration to actively supporting carer support groups in the future.

The benefits of attending a carer support group include:

- increase in social support and networks
- greater knowledge of community resources
- enhanced coping ability
- reduced depression and anxiety
- higher self-esteem
- help to deal effectively with challenging emotions.^v

Results from the *Carers NSW 2010 Carer Survey* provide further evidence of the value of carer support groups. Carer support groups were the highest nominated source for where respondents would seek information about their caring role (37 per cent), and 30 per cent of respondents said that carer support groups would make their caring role easier for them.^{vi}

The importance of carer support groups was acknowledged in the Commonwealth Government report on the Inquiry into Better Support for Carers in 2009. The report stated:

There is no doubt of the value of peer support groups for providing carers with information, support, social contact and, at times, advocacy. The Committee believes that there is further potential for government to encourage the development and geographical coverage of such groups. ...Carers and organisations consistently reported that peer support groups and networks are an extremely valuable source of information and empowerment for carers.^{vii}

Given the evidence of the value of carer support groups, the LTCSA should give consideration to what role it can play in improving the access of carers to support groups.

Carers NSW already provides a range of support to carer support groups. Carers NSW maintains a database of carer support groups, promotes new groups in *Carers News* and provides resources to assist with the establishment and facilitation of support groups. These resources include *Setting up a Carer Support Group* (an information resource), the Carer Support Group Facilitator workshop and the accompanying information resource *Carer Support Groups: An information and support resource for facilitators*.

The LTCSA should take an active approach to ensuring that carers of LTCSA participants are aware of the benefits of carer support groups, and are referred to carer support groups in their local area. The LTCSA may not be the most appropriate body to establish carer support groups, however, carers approaching the LTCSA with the intention of establishing a support group should be supported by the LTCSA with the provision of information and other support

as appropriate, as well as being referred to Carers NSW. Other support the LTCSA could provide may include promotion of carer support groups in LTCSA publications.

Carers NSW would welcome the opportunity to work with the LTCSA to ensure that carers of LTCSA participants have access to carer support groups as well as other services and supports to assist them in their caring role.

Biennial review of the LTCSA

5. The Committee is considering whether the review of the LTCSA should be conducted biennially. What are your views about this idea?

Carers NSW would support a change from annual to biennial reviews of the LTCSA. It is important that the LTCSA continues to be subjected to review and public scrutiny at regular intervals. However, given the time and resources involved in conducting and participating in the review, a biennial review may be more appropriate than an annual review.

Conclusion

Carers NSW appreciates the opportunity to provide further information to this review, and looks forward to the report and recommendations of the Committee. Carers NSW continues to support the functions of the LTCSA in regard to supporting people with a disability and their carers, and welcomes any opportunity to work with the LTCSA in order to improve outcomes for participants and carers.

For further information about Carers NSW's response to these Questions on Notice please contact Alison Parkinson, Senior Policy and Development Officer on 02 9280 4744 or email alisonp@carersnsw.asn.au.

Yours sincerely

Elena Katrakis
CEO
Carers NSW

Endnotes

- ⁱ *Carers (Recognition) Act 2010* (NSW).
- ⁱⁱ Carers NSW, Carers NSW Submission to the Tenth Review of the exercise of the Motor Accidents Authority and Motor Accidents Council and third review of the Lifetime Care and Support Authority and Lifetime Care and Support Advisory Council, Sydney, 2010.
- ⁱⁱⁱ Productivity Commission, *Disability Care and Support*, Final Report, Canberra, 2011.
- ^{iv} NSW Government, *Living life my way*, Summit Report, Sydney, 2011.
- ^v R Toseland et al, 'Comparative Effectiveness of Individual and Group Interventions to Support Family Caregivers', *Social Work* 35(3): 209-17, United Kingdom, May 1990.
- ^{vi} Carers NSW, *Carers NSW 2010 Carer Survey*, Sydney, 2010.
- ^{vii} House of Representatives Standing Committee on Family, Community, Housing and Youth *Who Cares...? Report on the inquiry into better support for carers*, Canberra, 2008.