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

Eleventh Review of the MAA and the MAC and 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 a submission to the Eleventh Review of the Motor Accidents Authority (MAA) and the Motor Accidents Council (MAC) and Fourth Review of the Lifetime Care and Support Authority (LTCSA) and Lifetime Care and Support Advisory Council (LTCSAC).

1. Introduction

1.1 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.

1.2 Who Carers NSW represents

Carers NSW defines a carer as any individual who provides unpaid care and support to a family member or friend who has a disability, mental illness, drug and alcohol dependencies, chronic condition, terminal illness or who is frail.

Carers come from all walks of life, cultural backgrounds and age groups. For many caring is a 24 hour job that is often emotionally, physically and financially stressful.

Across NSW there is an estimated 850,000 carers, comprising individuals as young as eight years of age through to the very elderly.ⁱ

1.3 About this submission

This response addresses the concerns of Carers NSW regarding support and recognition of carers by the MAA and LTCSA in the context of the passing of the NSW *Carers (Recognition) Act 2010* and the shift towards person-centredness in the disability service system.

2. Summary of Recommendations

1. Carers NSW again recommends that the MAA and LTCSA use the term carer on their website and in publications in line with the *Carers (Recognition) Act 2010* and make a clear distinction between informal, unpaid carers and paid care workers.
2. Carers NSW again recommends that the MAA and LTCSA websites provide information about services to support carers.
3. Carers NSW again recommends that an information booklet for people new to the caring role be developed and distributed.
4. Carers NSW again recommends that staff employed by the MAA and LTCSA and service providers receive training in carer awareness and carer support.
5. Carers NSW recommends that carer responses to the participant survey be used to assess and improve the experience of carers in the Scheme.
6. Carers NSW recommends that the LTCSA ensures the needs of carers are considered and that appropriate support is provided to carers who take up self-management options.
7. 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.
8. Carers NSW recommends that consumer and carer representatives engaged by the MAA and LTCSA receive appropriate training, support, remuneration and reimbursement.

3. Carer recognition and inclusion

In 2010 the *Carers (Recognition) Act 2010* was enacted in NSW. The Act entails specific obligations for public sector and human services agencies such as the MAA and the LTCSA, including taking all reasonable steps to ensure that the agency, and the members of staff and agents of the agency, take action to reflect the principles of the *NSW Carers Charter*.

The *NSW Carers Charter* recognises the role and contribution of carers to the community and to the people they care for, while also outlining the rights of carers and the obligations of public sector and human services agencies such as the MAA and LTCSA. These include making carers aware of appropriate services to assist them in their caring role and consulting with bodies representing carers when developing policies that impact on carers.

3.1 Information and terminology relating to carers

Carers NSW made several recommendations to the previous review in 2010, including the recommendations that the MAA and LTCSA use the term 'carer' and provide information on their websites about services for carers, so as to better support carers and assist family members to identify their caring role. Identification as a carer is an important step in accessing support for carers in their caring role.

Currently both the MAA and LTCSA websites have few references to carers and there is confusion between paid care workers and carers. It is inappropriate to refer to paid care workers or volunteers who assist members of the community as carers. Greater consistency is also needed so that carers are uniformly referred to as carers, throughout the website and other publications.

Recommendation 1: Carers NSW again recommends that the MAA and LTCSA use the term carer on their websites and in publications in line with the *Carers (Recognition) Act 2010* and make a clear distinction between informal, unpaid carers and paid care workers.

Carers NSW is disappointed to note that there is still limited information for carers provided on the MAA and LTCSA websites, and that the information that does exist is difficult to find. Carers NSW again recommends that a page with information about services for carers, including young carers, be developed. This section could also include a definition of a carer to avoid the confusion with paid care workers which currently exists.

Previously, Carers NSW also suggested that a booklet explaining what to expect as a carer for a person with a severe injury due to a motor vehicle accident should be developed and distributed. This could include the types of services and professionals they may find themselves dealing with as well as support available to assist carers in their caring role.

Recommendation 2: Carers NSW again recommends that the MAA and LTCSA websites provide information about services to support carers.

Recommendation 3: Carers NSW again recommends that an information booklet for people new to the caring role be developed and distributed.

3.2 Education for staff and service providers

Carers NSW's submission to the previous review also recommended education for health professionals and service providers regarding the needs of carers, as well as training for carers to support them in their caring role.

Carers NSW provides tailored training for service providers including the workshop 'Understanding and supporting carers'. Carers NSW recommends that staff employed by the MAA and LTCSA and approved service providers attend workshops such as those provided by Carers NSW, or alternative training, in order to better understand the needs of carers and how to support them effectively.

Recommendation 4: Carers NSW again recommends that staff employed by the MAA and LTCSA and service providers receive training in carer awareness and carer support.

3.3 Inclusion of carers in participant survey

Carers NSW acknowledges the participant survey conducted in 2009 and the positive feedback received. Carers NSW is pleased that this survey will be conducted on an annual basis to monitor the performance of the Scheme over time and to capture differences between participant groups.

Carers NSW recommends that the responses from carers be analysed as a separate group to enable an assessment of the experience and wellbeing of carers under the scheme. This would enable the identification and rectification of any particular problems or issues experienced by carers, and assist the Scheme to ensure compliance with the *Carers (Recognition) Act 2010*.

Recommendation 5: Carers NSW recommends that carer responses to the participant survey be used to assess and improve the experience of carers in the Scheme.

4. Person centred approaches

The NSW Government is currently working towards a person-centred disability service system in NSW. Carers NSW is supportive of this transition and optimistic that this change will mean that the choices and preferences of people with a disability, their carers and family will be respected.

Carers NSW recognises that the Lifetime Care and Support Scheme (the Scheme) aims to provide participants with 'the best opportunities and choices in achieving quality of life' and that the LTCSA 'seeks to be an international leader in the delivery and development of disability services'.ⁱⁱ The largely positive feedback from the participant survey indicates that the Scheme is performing well in regards to meeting the needs of most respondents. However, previous reviews of the Scheme suggest that there are still some issues faced by participants and their families.

In the hearing for the 2010 review, the LTCSA advised that it was moving towards developing an option for participants in the Scheme to manage their own care.ⁱⁱⁱ This self-management option has the potential to allow people with a disability, their family and carers to direct their own care and to exercise greater choice and control in their lives.

Carers NSW is unaware of the extent to which the self-management option has been implemented to date, or how this has been implemented. It is important that if a self-managed option is to be available, that it should be optional. Participants in the Scheme should be able to choose what degree of choice and control they exercise over their care and support services. Participants must be able to opt in and to opt out of managing their own care if their circumstances change, or they no longer wish to be self-managing.

Carers NSW is aware that self-management can be time and energy consuming, and is often a responsibility that falls to the carer of the person receiving services.^{iv} It is therefore important that any carer who takes up the self-management option is provided with the training, resources and support that they need to effectively manage the care, and to avoid an unnecessary increase in their workload and stress.

Due consideration must also be given to the needs and choices of carers and family members, and how to resolve potential disagreements or conflict between the choices and aspirations of the person with a disability and those of carers and family members.

The extensive consultation process currently being conducted by the NSW Government in relation to person centred approaches may inform the LTCSA's implementation of self-management. Opportunities may exist for mutual learning and collaboration between the LTCSA and Ageing, Disability and Home Care, Department of Family and Community Services, as both entities grapple with some of the complications and challenges arising from the introduction and implementation of individualised funding and person centred approaches.

Recommendation 6: Carers NSW recommends that the LTCSA ensures the needs of carers are considered and that appropriate support is provided to carers who take up self-management options.

5. Carer participation and representation

Carers NSW recommends increased carer participation and representation in the governance and direction of the Scheme. Carers NSW recognises the changes made to facilitate consumer participation in the Advisory Council through the creation of two positions for consumer representatives and commends the LTCSA for increasing consumer participation. Similar steps must be taken to increase carer participation, as carers are directly impacted upon by the quality and effectiveness of the Scheme and should be recognised as key stakeholders. One or more positions should be created for carer representatives on the Lifetime Care and Support Advisory Council.

Opportunities for carer participation would allow carers of participants in the scheme to share their unique knowledge and experience and for this to be recognised. Carer participation can also assist policy makers and service providers to provide services in a manner that is relevant, sensitive and responsive to carers. Encouraging membership of the Advisory Council by carers would be in line with the *NSW Carers Charter* and the obligations established by the *Carers (Recognition) Act 2010*.

Recommendation 7: 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.

It is important that the Advisory Council provide training and support for consumer and carer representatives so that they can engage and contribute effectively as members of the Council. Carers NSW supports an earlier recommendation that the Authority 'create and facilitate a participant and family carers working group that can support the participant representative on the Lifetime Care and Support Advisory Council'^v and would be happy to work with the Authority to further develop this initiative.

The Carers NSW Carer Representation Program provides training and support for carers in their role as Carers NSW Carer Representatives. Carers NSW Carer Representatives receive training which covers topics such as communication, effective representation, ethics and self-care. Similar training should be provided to consumer and carer representatives on the Advisory Council to ensure that they have the support and skills required to be effective representatives. Carers NSW could assist with the provision of such training to carer representatives on the Advisory Council.

It is important that consumer and carer representatives receive appropriate support and remuneration in their capacity as Advisory Council members. Carers NSW position is that carers engaged as carer representatives should receive remuneration and reimbursement of their expenses, which may include travel costs, accommodation and respite care.^{vi} Remuneration is important as it recognises the valuable contribution of carer representatives and the knowledge and experience which they bring. Remuneration places carer

representatives on an equal footing with their professional counterparts. Remuneration also ensures that the carer's participation does not disadvantage them financially, which is especially important given that carers are often under significant financial stress, and may be sacrificing paid work opportunities in order to participate.

Recommendation 8: Carers NSW recommends that consumer and carer representatives engaged by the MAA and LTCSA receive appropriate training, support, remuneration and reimbursement.

6. Conclusion

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

For further information about Carers NSW's submission to this inquiry please contact Alison Parkinson on 02 9280 4744 or email alisonp@carersnsw.asn.au.

Yours sincerely



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End notes

ⁱ Australian Bureau of Statistics, *Survey of Disability, Ageing and Carers (SDAC)*, Canberra, 2009

ⁱⁱ Lifetime Care and Support Authority of NSW, *Lifetime Care and Support Authority Annual Report 09/10*, Sydney, October 2010

ⁱⁱⁱ Standing Committee on Law and Justice, *Review of the exercise of the functions of the Lifetime Care and Support Authority and the Lifetime Care and Support Advisory Council: Third Report*, Sydney, 2010

^{iv} The Winston Churchill Memorial Trust of Australia, *The Vincent Fairfax Churchill Fellowship to investigate "consumer-directed" aged care policy and practice*, Report by Ian Hardy 2008 Churchill Fellow, accessed at: http://www.churchilltrust.com.au/site_media/fellows/HARDY_Ian_2008.pdf, 2008.

^v Standing Committee on Law and Justice, *Second review of the Lifetime Care and Support Authority and the Lifetime Care and Support Advisory Council*, Sydney, 2009.

^{vi} Carers NSW, *Carer Participation and Representation Policy*, Sydney, 2010