

**FIRST REVIEW OF THE EXERCISE OF THE FUNCTIONS
OF THE
LIFETIME CARE AND SUPPORT AUTHORITY OF NEW
SOUTH WALES
AND THE
LIFETIME CARE AND SUPPORT ADVISORY COUNCIL OF
NEW SOUTH WALES**

Organisation: Carers NSW
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Position: Chief Executive Officer
Date received: 29/04/2008

This submission addresses both the Ninth Review of the MAA and MAC and the First Review of the LTCSA and LTCSAC. A duplicate submission has been processed as received by the MAA/MAC Review and is available for download from that inquiry web page.



29 April 2008

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

Dear Director,

Please find attached a submission from Carers NSW on the Ninth review of the exercise of the functions of the Motor Accidents Authority and Motor Accidents Council and first review of the functions of the Lifetime Care and Support Authority and Lifetime Care and Support Advisory Council.

Carers NSW is the peak organisation representing around 750,000 carers of people with a disability, mental illness, chronic condition or frail older people. Carers are unpaid and are usually family members or friends of those they support to live in the community.

The submission we have provided is a brief overview of the role of carers as part of the Lifetime Care and Support Scheme, including an overview of carers needs and recommendations to better support carers in their caring role.

Thank you for the opportunity to provide comments.

If you require further information please contact Anita Smith, Policy Officer on 9280 4744, or anitas@carersnsw.asn.au.

A handwritten signature in black ink, appearing to read 'Elena Katrakis', written in a cursive style.

Elena Katrakis
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Carers NSW submission to the Ninth Review of the exercise of the functions of the Motor Accidents Authority and Motor Accidents Council and first review of the exercise of the functions of the Lifetime Care and Support Authority and Lifetime Care and Support Advisory Council.

Prepared by Anita Smith, Policy Officer, Carers NSW

About Carers NSW

Carers NSW is an association for relatives and friends who are caring for people with a disability, mental health problem, chronic condition or who are frail aged. It is the peak organisation for carers in New South Wales and the only state wide organisation that has carers as its primary focus.

Carers NSW is part of a national Network of Carer Associations and works collaboratively to lead change and action for carers. 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

Our vision is that all carers in NSW are recognised, valued and supported by their communities and by governments.

Who Carers NSW represents

Carers NSW represents an estimated 750,000 carers across NSW (ABS, 2004).

A carer is someone who cares for a person with a disability, mental illness/disorder, chronic condition or who are frail aged. Carers can be parents, partners, brothers, sisters, sons, daughters, friends or children of any age. Carers may care for a few hours a week or every day. Carers are unpaid. They may receive incomes from a range of sources including wages or government pensions and benefits.

A primary carer is someone who takes on the main caring responsibilities of a care recipient. Australian Bureau of Statistics (ABS 2005) defines a primary carer as a person who provides the most informal assistance on an ongoing basis, to another person who is restricted by one or more core activities in the areas of communication, mobility and self care. A secondary carer provides informal care in a supporting role where either another family member or formal services provide the majority of care (Carers Association of South Australia Inc, 2001).

Each caring situation is unique. Some carers assist the person they support with all their activities of daily living while others provide intermittent support. Their caring tasks can range from administering medication and dressing wounds to personal care tasks such as showering or supervision of daily activities. Carers also provide emotional support day in and day out to some of the most vulnerable, isolated members of our community and they often act as case managers; navigating service systems and organising appointments. Caring is the invisible work which enables people requiring support and care to live in the community, maintaining a good quality of life.

Key statistics on caring in NSW:

According to statistics on carers from the Australian Bureau of Statistics (ABS 2004), in 2003:

- Approximately one-third of all carers in Australia live in NSW
- There were 748,000 carers in NSW (11 per cent of the population), 20 per cent of whom were primary carers
- 40 per cent of primary carers cared for a partner, 29 per cent for a child, 32 per cent for other (e.g. sibling, parent)
- Women aged 45-54 years were the largest single group of carers
- 45 per cent of primary carers provided 40 hours or more care per week on average
- 78 per cent of primary carers lived with the person they supported
- 75 per cent of carers were of workforce age although 45 per cent were not in the workforce
- The median gross personal income for a primary carer was \$224, other carers \$365 and non-carers \$435
- 55 per cent of primary carers relied on a government allowance or pension as their principal source of income
- A report by the National Centre for Social and Economic Modelling (NATSEM 2004) projects Australia faces a carer shortfall. It is estimated that by 2031 the number of older people likely to need assistance because of severe or profound disability is likely to increase by 160 per cent whereas the number of people likely to provide care will only increase by 57 per cent
- Investment in carer support by government has been shown to give financial returns of 7:1 (Access Economics, 2003)
- The physical, mental and emotional health and wellbeing of most carers was poor because of their caring responsibilities. As a result of caring over half of carers suffered a decline in physical health and two thirds felt their mental and emotional health had been affected by providing care (NATSEM, 2004).

The largest survey of carers' health and wellbeing was released in October 2007. The survey undertaken by Deakin University, Australian Unity and Carers Australia found the following:

- Carers have the lowest level of wellbeing of any group surveyed using the Personal Wellbeing Index measuring tool
- Sole parent carers had the lowest wellbeing of any carer
- The wellbeing of carers decreases linearly as the number of hours spent caring increases
- Carers are more likely than is normal to be experiencing chronic pain

- Carers are likely to have an injury and this is associated with reduced well being
- Carers have an average rating on the depression scale that is classified as moderate depression, and over one third are classified as having severe or extremely severe depression.

Submission format

This response addresses aspects of the functions of the Motor Accidents Authority (MAA) and the Lifetime Care and Support Authority (LCSA) in regard to how the MAA and LCSA support carers currently, and provides an overview of the relationship between health care provider, patient and carer, in order to identify how carers can be better supported in their caring role.

Introduction

The Australian health and community care systems increasingly rely upon family, friends and neighbours who provide unpaid care and support to children and/or adults who have a disability, mental illness/disorder, chronic condition or who are frail aged. 74 per cent of the assistance required by Australian's due to disability or illness is provided by informal carers. Every year carers provide over 1.2 billion hours of support (Access Economics, 2005).

According to the Productivity Commission (2005), the current care mix, between formal and informal care, is likely to remain similar over the next 10 to 15 years. The most likely scenario therefore is that carers will continue to provide substantial support to the health and community care systems over the next fifteen years given government policy and the wishes of members of the community to be cared for at home.

The annual reports and websites of MAA and LCSA acknowledge the integral role families play in the treatment, rehabilitation and support of a person severely injured in a motor vehicle accident, stating that the family's involvement is actively encouraged in order to best assist the consumer to participate in their roles within their home and community. Carers NSW support this proactive approach to the inclusion of informal carers in the support of a loved one.

Use of the term carer

There has been confusion in the community services field and general community about who exactly is a carer. Often the term 'carer' is applied to paid staff in the residential, community care and child care sectors. It is also applied to people who choose to volunteer their time to assist a person in the community. As a result, the specific group of informal, unpaid carers is often not acknowledged. The annual reports of the MAA and LCSA use appropriate wording to describe the care provided by paid service workers, for example the term 'health professionals' is used to describe service professionals that work in the health care sector.

The annual reports of MAA and LCSA, as well as the websites use the term 'family' when referring to those involved in the support of a loved one. Carers NSW congratulates the MAA and LCSA in recognising the inclusion of the family in providing support to a loved one with catastrophic injuries.

Carers NSW believes it is also important for families to be aware of the role of informal caring they are taking on to support their family member. Due to the nature of the sudden acquired disability of the person requiring support, it is highly likely that many family carers will not

have been carers before, or had time to prepare for the role of the carers, and will need to make rapid life decisions and changes.

For this reason it is important that families are assisted to identify as carers, to enable acknowledgement of their role and access to appropriate support. Carers NSW encourages the use of the terms 'carer' or 'family carer' rather than 'family member' when referring to family (or friends) that will take on a caring role of an individual. Identification with the term 'carer' is the first step in accessing appropriate support in their caring role.

Carer support information and access

The websites provide relevant information that is clear and easy to understand in regards to the LCSA scheme, application process, eligibility, and support.

One of the Key Result Areas (KRA's) in the MAA and LCSA annual report is for 'improved services available for injured people and their families'. It would be beneficial to provide information on carer specific support to assist family carers to both identify their role as a carer, and have access to information that will support them in their caring role.

Both websites need to have information to assist family carers to learn about and access appropriate services for their needs, different from those of the person for whom they care. Appropriate information could include access about services provided by Carers NSW and other carer support services.

The LCSA annual report states that respite care is included as part of the scheme. It would be beneficial for carers to be able to access more information about this service through the website.

Carer support information is also important for people who have been deemed ineligible for the LCSA. There should be information available to assist carers to access other support services both for themselves and the person they are supporting. Carers NSW would welcome involvement in providing information about appropriate carer support services, including both support provided by Carers NSW and support provided by other services.

Another suggestion could be a specific booklet about what to expect in a caring role in caring for someone severely injured as a result of road accident. A general information booklet will assist families to understand and cope with a range of unfamiliar systems and what to expect in navigating the systems and support available.

It is evident family carers are an integral part of the care plan for the person catastrophically injured. Carers NSW believes the MAA and LCSA should include carer support programs as part of the Lifetime Care and Support Scheme for the lifetime of the caring role.

From August 2004 to 30 December 2005 the MAA NSW funded Carers NSW to conduct the 'Carers Linked in Caring Project (CLIC) – A Support Program for Carers of People with Traumatic Brain or Spinal Cord Injury'. CLIC was designed to provide appropriate carer-specific information and support to carers of people with TBI or 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 TBI or SCI. An evaluation of the project was conducted and included the following recommendations:

1. 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

2. 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.

The evaluation demonstrates the CLIC pilot project was beneficial in supporting this specific group of carers. Carers NSW would welcome a partnership between the MAA, LCSA and Carers NSW to continue running the program on an ongoing basis.

Carers as partners in care

The *NSW State Health Plan*, together with the *NSW Carers Action Plan 2007-2012* have placed a strong emphasis on 'carers as partners in care', identifying the integral role that carers and families play in supporting people with health needs, both while using formal services, and at home in the community. The *NSW Carers Action Plan 2007-2012* places specific emphasis on the acknowledgement that improving the quality of life and health and wellbeing of carers directly benefits the recipients of care (NSW Health, 2007).

This section provides an overview of specific issues that carers have raised with Carers NSW in relation to the health and community care systems. The information is relevant to provide awareness and understanding of issues that carers face, and should be used as a guide in the delivery of services to severely injured people of road accidents and their carers.

There is a need for health professionals to understand the vital role of carers, what carers do and the impact caring can have. The complexity of the health and community service systems means that there can be a lack of understanding about carers and awareness of the toll that caring can take. It can also lead to misunderstanding about the availability of support to carers. Carers' involvement in care is generally based on a deep and abiding personal commitment. Carers do not have the same resources, pay or training as health service providers and therefore should not be tasked with the same responsibilities.

Feedback from carers indicates that there is a lack of understanding at all levels of the role of carers and impact of caring in a range of human service settings. In particular, carers often feel that their knowledge and experience is not sufficiently acknowledged or used in health and care planning. Education to health professionals, service providers and Lifetime care coordinators regarding carer awareness is vital to ensure there is a clear understanding of the support needs of carers, how to work with them, and provide relevant information, resources and referrals that support individual carer needs.

Specific needs such as the need for patient and carer to have access to adequate and appropriate information and communication mechanisms are vital for informed decision making. For people who do not have the capacity to understand and make an informed decision about their own health care needs, carers often take on this responsibility on an informal basis as advocates and substitute decision makers. Where the patient has capacity to make an informed decision, the carer is often an important contributor to assisting in providing information dissemination and communication between patient and health care provider.

There is a need for inclusion of the carer, as appropriate, throughout the patient journey. Carers have provided information that they often feel their knowledge and experience of the care recipient is not sufficiently acknowledged or used in health and care planning (Carers NSW, 2005). The role of the carer as a provider of information regarding a

care recipient to health care providers must be acknowledged and utilised to enable health care providers to gain the most relevant information about a patient's care needs.

Carers also state that the need for a smooth transition between acute and community care is vital. Assumptions are too frequently made about a family member's ability and willingness to care. Carers often feel that the system moves too fast, especially in the first 36 hours after discharge. There is a gap between assessment and provision of services which causes stress to carers. Referrals can be made but services may not be available. This reflects a continued focus in strategic direction and budget allocation on acute rather than community care. Patients may not be linked back into the community adequately after discharge. Continuity of care can be improved through greater coordination across community care, acute care and residential care and between health, ageing, disability and other key sectors.

Carers themselves often have needs within the health system that are different or additional to that of the patient. Research by Dow and McDonald (2007) illustrated the imbalance between expectations placed on family carers and the resources available to support them. They called this the 'invisible contract' that binds family members to carry out substantial care-work that was previously carried out by hospital staff. They found an expectation existed for the family members to accept a caring role with little consideration for their individual circumstances and listed examples where no consultation had occurred prior to arrangements for the transfer of care from the hospital to the home (Dow and McDonald, 2007).

Carers are often forced to accept considerable responsibilities in relation to the provision of care and support, yet provided with few rights or supports themselves. Family members should have choices about whether or not they begin, continue or cease their caring role. This choice must be enabled by the flexibility of support services involved in the scheme to adapt to changing carer and family situations.

The individual needs of the carer must be acknowledged and addressed to ensure adequate supports are in place when a patient leaves the hospital system to be cared for at home. This could include health worker training that addresses carer needs and contributions within the health care team; and discharge protocols that include and respect carer views and ensure follow-up supports are in place.

This is particularly significant for ageing parent carers. Given that young men under the age of 30 are most likely to be catastrophically injured in motor vehicle accidents, their parents will most likely provide their informal support. As these parents age, their support need will also change, with a need for not only ongoing respite care and other support services, but also planning for future accommodation and support needs of their adult child when they are no longer able or willing to provide care.

With regard to discharge planning from the health care sector to home, feedback from carers indicates there has not been support provided to them prior to discharge of their family member from hospital into their care. Consideration will need to be given to information provision and education for carers. Carers cannot be expected to know what to do once the person they are expected to care for returns home. For example, a carer may not know how to lift properly. Failure to know this information may result in injury to patient and /or carer and the ability to provide care.

Research undertaken by the Independent Living Centre of WA (2006) into family carers and the physical impact of caring demonstrates many carers suffer from poor physical and mental health, and this is as a direct result of providing informal care. The study showed many carers had not accessed formal training in regard to manual handling, and for those that did access some form of training, this was done in an ad hoc manner. A range of factors to poor access to training included:

- Limited follow up capacity within allied health system
- Limited access to allied health in the home setting
- Waiting times to receive services
- Pathways to access training are not known
- Carers own lack of awareness about the benefits of training

The research suggests that appropriate training programs need to be put in place for carers to increase their physical wellbeing. As exists with formal paid carers where employers have a duty of care to provide training, informal carers should also receive adequate training to support them in their caring role, in order to limit injury prevention of carers, enabling them to continue their caring role.

Timeliness of support is also a crucial factor. Once a person is assessed as eligible, supports must be put in place immediately. We often hear from carers that there is a delay in assessment and a further gap between assessment and commencement of service provision. It is important that supports are in place in the period between injury and assessment and that service provision commences immediately after assessment. Any delay between discharge from hospital and the commencement of vital supports such as home and vehicle modifications can be significantly detrimental to the health and finances of carers

More broadly, the interface between the various sectors, health, disability, ageing and between community, residential and acute care needs to be better coordinated and developed into models of integrated care (Carers NSW, 2005).

Conclusion

Carers NSW supports the functions of the MAA and LCSA in regard to supporting people with disability as a result of road trauma and their family carers.

This submission provides awareness of the role and support needs of carers, and issues carers have raised with us in undertaking their caring role. This submission provides the following recommendations to further assist carers in their caring role:

1. Use of the term 'carer' on the MAA and LCSA website to assist family members to identify their caring role
2. Availability of support services for carers on the MAA and LCSA websites
3. Continuation of the 'Carers linked in caring project (CLAC)' run in partnership with Carers NSW and the MAA NSW
4. Education to health professionals as part of the LCSA scheme regarding carers needs
5. Training for carers to support them in their caring role, particularly during the time of transition of the consumer for the health care setting to home.

Carers NSW appreciates the opportunity to comment on the inquiry and welcomes further opportunities to partner with the MAA and LCSA in delivering support to carers of people with a disability who have been severely injured as a result of a motor vehicle accident.

If you wish to discuss these comments further please contact:

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