

SECOND REVIEW OF THE LIFETIME CARE AND SUPPORT AUTHORITY

Organisation: Social Workers in Brain Injury Professional Interest Group,
Australian Association of Social Workers (NSW)

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Date received: 6/05/2009

Legislative Council Standing Committee on Law & Justice Enquiry into the Lifetime Care & Support Scheme

Submission into issues pertaining to psychosocial care, specifically relating to item LTCS 403 'provision of supportive and specialist counselling services to participants and their families and significant others where related to the injury'.

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1.0 Introduction

We welcome the opportunity to comment on the LTCS after their first year of operation for adults and second year for children.

Overall, the parameters of the scheme and associated payment scheme provide important recognition for the assessment and treatment of the psychosocial dimension of the individual sustaining the traumatic injury. This enables participants registered under the scheme to be treated in a 'holistic' manner, addressing all aspects of life that are affected by the injury and the consequences of the injury.

Our particular interest is in working with the family where the family play a central role in supporting the person with the traumatic injury.

LTCS 403 refers to 'provision of supportive and specialist counselling services to participants and their families and significant others where related to the injury'.

Our two concerns are with the wording, interpretation and application of LTCS 403:

1. Although we believe that the wording 'families and significant others' is adequate, it may be interpreted and applied too narrowly.
2. We believe that the wording 'supportive and specialist counselling services' may be too narrow to encompass the range of interventions that are needed to treat the 'family and significant others'.

2.0 Interpretation of 'family and significant others'

We are concerned that the phrase 'families and significant others' is being interpreted too narrowly at times by the LTCS.

By narrowly we mean that families are being defined in dyadic terms (e.g. spouse - injured partner; parents – injured adult child).

By means of background, one of the critiques of the family research literature in the field of TBI is that it has been too narrowly focused on a dyadic relationships between a single family carer and the person with TBI.¹ One of the few studies to examine the pattern of care provided by the whole family, found that siblings and adult children also contributed to providing care, either as the primary caregivers, or as secondary and tertiary caregivers supplementing the support provided by parents or spouses.² In addition, the possibility of being involved in future care was the second biggest concern among a sample of 280 adult siblings who participated in a research project examining their experiences of having a sister or brother sustain a TBI.³ Moreover, the small number of studies that have researched the issue of distress among broader family members, have documented elevated levels of emotional distress among siblings and relations.^{2,4,5}

This type of 'dyadic' mindset in the **interpretation** LTCS 403 then has consequences for **application**, in how the guidelines are applied.

Specifically, it raises difficulties in seeking services for members of the extended family network who have needs directly related to the injury as the following case scenario and case study highlight.

Different families are given varying information as to their eligibility and entitlement to claim out of pocket expenses such as accommodation, transport etc. This variance has caused financial hardship as workers have endeavoured to use other means to assist families depending upon the deemed eligibility for assistance to claim costs through the LTC&S scheme.

Case scenario:

The accommodation costs of a sister who is providing essential psychological support since a 19 year old young woman's admission with paraplegia are deemed ineligible for coverage unless letters of advocacy are provided by the treating team verifying the role her sister is fulfilling.

Furthermore, the definition of family to be included in LTCS 104 Psychosocial Assessment appears to be appropriately expansive, and yet when social workers seek to treat some of these family members under LTCS 403, the criteria seem to be far more restrictive.

Case study:

A young man in his early 20s living with his de facto sustained a severe TBI. His parents were very involved in his rehabilitation and support for the partner. The younger sibling was also involved with providing support for his brother. The younger sibling started to engage in some very disturbed behaviour which brought him to the attention of the police. The behaviour on discussion with the sibling was linked to his anxiety and grief over the significant injuries his brother had experienced and the uncertainty of the outcome of rehabilitation.

LTCS explained that while education and support for immediate family is appropriate they did not cover counselling for family members, especially extended family. I saw the young man under education about brain injury for a couple of sessions and saw some improvement to his adjustment to the changes in his family structure and understanding over the social isolation he was experiencing as related to the grief and stress he'd been living through. He'd started reconnecting with school mates and age appropriate activities that were normal before his brother's accident.

To get approval for the above required what I considered a significant period of time on the phone.

Recommendations:

(a) NH&MRC definitions of "family" may need to be considered as the template to ensure inclusive non discriminatory practice particularly for CALD and indigenous families.

(b) LTCS Case Co-ordinators receive training on (i) impact of a person's TBI on the family as a system (ii) interventions required to address such impacts, including counselling for significant others as designated in LTCS 104 Psychosocial Assessment (which includes parents, siblings, grandparents, children, and others as appropriate) (iii) what constitutes sufficient evidence from health professionals/clinicians/Social Workers to demonstrate 'Reasonable and necessary' interventions for family and significant others under LTCS 403 code

3.0 The wording 'supportive and specialist counselling'

There is a concern that other interventions that target 'families and significant others' do not fit easily under the terminology of 'supportive and specialist counselling'. This includes group work such as sibling support groups, spouse support groups, and carer support groups as well as interventions that aim to maintain and support friendship networks^{6,7}

Recommendation:

That the phrase 'or other approved interventions including peer support, carer, spouse and sibling support, as well as those which support maintenance of friendship networks' be inserted after 'supportive and specialist counselling'.

4.0 Eligibility for the LTCS scheme

Finally, we wish to raise one issue about the basic eligibility criteria for entry into the scheme.

Cyclists who have accidents on the road that do not involve motor vehicles are currently not covered by the scheme leading to inequities between cyclists with catastrophic injuries in the longer-term support that they can access.

Recommendation:

That the eligibility criteria for the LTCS be expanded to include cyclists who have accidents on the road that do not involve motor vehicles.

5.0 Final

If you require any further information please do not hesitate to contact Dr Grahame Simpson on 9828 5495 or by e-mail: grahame.simpson@sswahs.nsw.gov.au

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