

**INQUIRY INTO THE EXERCISE OF THE FUNCTIONS OF  
THE LIFETIME CARE AND SUPPORT AUTHORITY AND  
LIFETIME CARE AND SUPPORT ADVISORY COUNCIL -  
THIRD REVIEW**

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# NSW Agency for Clinical Innovation

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

To the Director

## **Third Review of the Lifetime Care and Support Authority**

Thank you for the opportunity to provide comment to the Standing Committee on Law and Justice of the Legislative Council in relation to the third review of the Lifetime Care Support Authority (LTCSA) under section 68 of the Motor Accidents (Lifetime Care and Support) Act 2006. Our response reflects the issues raised by members of the NSW State Spinal Cord Injury Service (SSCIS), in particular in relation to the Lifetime Care Support Scheme (LTCSS).

The NSW State Spinal Cord Injury Service (SSCIS, a Network of the NSW Agency for Clinical Innovation (ACI), previously the Greater Metropolitan Clinical Taskforce (GMCT) is responsible for providing multidisciplinary health services for adults and children with acquired spinal cord injuries (SCI) where the cord lesion is non-progressive, and there is persistent neurological deficit arising from either traumatic or non-traumatic causes.

We provide the following comments:

### **Establishment of the LTCSS**

We reiterate some of the comments we provided to the Second Review in 2009. Introduction of the LTCSS by the NSW Government funded by levies on the CTP insurance premiums has been a very important development and most welcome change in the provision of no-fault funding for supporting treatment, rehabilitation and lifetime care costs for people who have been severely and permanently injured in motor accidents. The benefits of insurance funding being available immediately through the LTCSA support scheme rather than the victim having to await the outcome of an often lengthy court case, are far reaching in terms of facilitating discharge from hospital with appropriate support and community participation. The benefits to society of a greater number of people being eligible on a no-fault basis and the possible impact on hospital length of stay and timely access to social support services in the community are important.

The Authority has developed suitable policies and guidelines regarding eligibility criteria, treatment, rehabilitation and care needs assessment, services that will be funded, dispute resolution, and so on. LTCSS has developed a number of important guidelines collaboratively with involvement of other agencies, such as NSW Health, DADHC and Enable NSW, including essential equipment items, professional criteria for equipment providers and competencies for attendant care providers.

### **Annual Review of LTCSA**

We acknowledge the requirements under the Motor Accidents (Lifetime Care and Support) Act 2006 that an annual review be conducted of the LTCSA, however, it is

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our view that not enough time has elapsed since the publication of the Report on the Second Review for the implementation of its recommendations and the evaluation of the impact of the strategies and changes made as a result of these recommendations, to take effect.

## **COMMENT ON PROGRESS OF ISSUES RAISED BY SSCIS AT THE SECOND REVIEW**

We provide the following comments and progress on issues reported by SSCIS during the Second Review which continue to raise concern by SSCIS members. We also provide comment in relation to recommendations of the Second Review relevant to Scheme participants with spinal cord injury.

### **1. Increase in administration and paperwork requirements**

We would like to applaud the introduction of the Discharge Services Notification form as it has streamlined some of the paper processes and acknowledged that people with catastrophic injury will require a range of interventions on return to home. We also applaud work by both LTSS and EnableNSW towards aligning their application and paperwork requirements, considerably reducing clinician confusion and frustration.

However, clinicians continue to report the significant burden imposed by the bureaucratic requirements of LTCSS involving paperwork forms distracting them from direct clinical responsibilities of providing rehabilitation to patients. Excessive bureaucracy continues to delay responsiveness impacting upon the health system's ability to meet the needs of patients in a timely manner. Crisis situations faced by community-based clients require urgent treatment and subsequent changes to the agreed plan of care in order to reduce the risk for health deterioration. Time delays of more than 2 days can impede this.

### **2. Accidents not covered by the Scheme and the creation of a tiered system in the provision of treatment and care for people with catastrophic injuries.**

The tiered system in the provision of treatment where clients with similar levels of impairment may receive very different levels of equipment and support continues to be of concern to clinicians who are faced with managing tensions between patients with similar needs receiving these different levels of support. As previously stated, we would support continuing dialogue between the various major insurance schemes (such as LTCSS, Workers Compensation Scheme) to harmonise their processes, procedures and service guidelines.

### **3. Confusion of the role of the LTCSS Coordinator and Case Managers**

#### **3.1. Variability and inconsistencies**

We previously reported concerns expressed by clinicians regarding inconsistency and variation in the processes followed by LTCSS Coordinators in their response to the information provided by clinicians and in the approval processes. They also expressed the view that some coordinators are micromanaging at the clinical level and directing care delivery through the approval or non-approval of recommendations made by clinicians.

These concerns are ongoing with issues arising in variation in training, background and philosophy of the Coordinators resulting in ongoing complexities in advice, approval and relationships.

We therefore reiterate our previous suggestion that providing greater clarity, transparency and consistency in requirements and processes would be very valuable for clinicians and case managers alike. We also suggested, and now reiterate that clarification of the expectations and delineation between the role of clinicians as managers of patient care, and the role of the coordinators as the administrators of the scheme, are required. Further clarity is required in relation to who is responsible for selecting/recruiting the Case Manager, and

the level of expected involvement by LTCSA funded Case Managers during the inpatient period of their allocated client.

SSCIS acknowledges that the LTCSA continues to develop new procedures and guidelines, seeking input into their development, and feedback on the draft documents from clinicians and service providers (eg discharge planning guidelines, attendant care providers, case management guidelines). The role out and implementation of these and future guidelines will help improve communication and understanding and, hopefully, achieve greater clarity and consistency in the requirements, processes, and expectations of LTCSA.

Additional communication forums with LTCSA have been established by SSCIS in an effort to improve communication and identify and address difficulties and inconsistencies experienced by all SSCIS services in relation to the management and discharge of LTSS participants. The first meeting of the SSCIS & LTCSA Liaison Committee was held in February 2010 and will meet quarterly hereon. SSCIS units also hold regular meetings with LTCSS staff to discuss and find resolution to day to day LTCSS management and processing issues, and individual patient/client needs and issues at the clinical level.

SSCIS suggests that further work is required by LTCSA to ensure their Coordinators have the correct education, supervision and communication channels to achieve greater consistency in their interactions and communication with, and information delivery to, specialist service providers.

SSCIS members, in particular staff of the Spinal Outreach Service, have expressed interest and willingness to LTCSS management in providing input to the education and training programs for their coordinators and case managers in relation to spinal specific issues to attempt to assist with this problem and await an invitation to participate in further discussions.

### **3.2. Education of Coordinators and Case Managers in key issues related to spinal cord injury (SCI) and their impact on the individual's life, health and community living**

Lack of skills and experience in SCI is evident in some of the case managers and private therapists who may have considerable experience in their profession, but perhaps not an understanding of spinal specific issues. Health problems arising in spinal cord injury are often not body system specific, but inter-related systems which require a range of approaches and professional disciplines working together. There is a difficulty for Case Managers and LTCSS Coordinators to appreciate the health implications of the underlying condition which can occur in an unpredictable way. Consequently, this results in poor and limited responsiveness to risk management. If the Case Manager and or independent therapist is screening and interpreting information they are unfamiliar with, then the client's issues and clinical risks and complications go unrecognised, or are not managed in the appropriate timely manner with multidisciplinary input, resulting in poor outcomes for the client.

SSCIS is happy to provide education and training for these groups and be involved in lifetime health planning for people with spinal cord injury

### **3.3. Case Manager's Guidelines**

We acknowledge that draft guidelines for Case Managers have been developed by the LTCSA. However, these do not highlight the complexity of the health issues faced by people with SCI and the importance of timely multidisciplinary review to prevent further deterioration and the subsequent, and often lengthy, hospital admission. The current case management model offers a holistic approach, pulling professionals from various sources to meet the

needs of the client, but requires further refinement as the model does not provide for integration of care and services to achieve health outcomes.

It is the view of SSCIS members that there should be a greater emphasis on health monitoring and promotion, and illness prevention included in the support and monitoring processes provided by Case Managers. The impact of SCI on the individual does not only result in physical disability related to mobility. SCI also affects many of the body's normal physiological processes, in particular those associated with the normal functioning of the skin, the respiratory, bowel and bladder systems, blood pressure control, and muscle tone, and in a reduction in the body's natural resilience to respond and protect against noxious stimuli to these normal bodily functions and systems. Understanding of these changes, how they should be monitored for signs of deterioration, and the strategies that need to be implemented without delay to prevent further deterioration and return to optimal status, are an essential component of the lifelong management of a person with SCI. Neglect of this aspect of the person with a SCI invariably leads to unnecessary and often, extended hospital admissions. These admissions are one of the most disruptive and expensive events in the life of a person with SCI and their families, as it often results in loss of employment, disbanding of their attendant care team, loss in confidence with community living skills, and reduction in physical fitness. It is therefore essential that the person with SCI, their family, attendant carers and case managers are aware of these issues and the importance of including them in a daily routine and long term goals.

SSCIS suggests that the involvement of health care services in providing regular review, monitoring, advice, and support of health maintenance and promotion and illness prevention are a key goal for people with SCI who are LTCSS participants and that ensuring this goal is included in the individual's life plan is a key responsibility of Case Managers. Addition of this responsibility to the current draft LTCSS Case Management Guidelines is strongly recommended by SSCIS.

#### **4. Return of revenue to the clinical unit / department providing the service**

In response to the 'question on notice' during the Second Review on how the revenue gained via Scheme reimbursement is administered by the area health services, SSCIS provided the following response:

*SSCIS does not administer the funds required to run the spinal cord injury services across the State and has been unable to gain detailed information from the Area Health Services in relation to the use and distribution of the LTCS reimbursements. ... and that ...in some cases ... The payments received by the organisation from LTCSA **appear** to be returned to the cost centre of the spinal services on a cost recovery basis. These reimbursements to the services are therefore not additional to their yearly budget instead they are to reimburse the cost of the service provided. Service managers receive limited information on their running budget, financial status and cost of the services they provide. It is their view that their services have not seen a financial gain nor an increase in resources at the service level since the implementation of the Scheme... It is the impression of the SSCIS that, whilst LTCSS pay and expect a certain quantity and quality of service provision, this is difficult to deliver at the ward level, particularly in light of recent cuts to services across hospitals.*

SSCIS is aware that there has been some improvement in the invoicing of LTCSA by Area Health Services. However, there has been little change, and no increase, to the funding and resources of the services providing the specialist care to LTCSS participants.

Of particular concern to SSCIS is the recent advice from NSW Health in their review of the impact of LTCSS (copy received by ACI (previously GMCT) from Ms Cathrine Lynch, Director, Primary Health and Community Partnerships, NSW Health) that during the establishment of the LTCSA '*there was no express intention (in legislation, explanatory memoranda or regulation) that revenue generated by NSW Health under the Scheme should*

*be protected for services for Scheme participants only' and that the LTCS Scheme Fees Policy (PD2008\_058) 'does not require revenue to be directed to LTCS services'.*

In light of our findings and above response, we were in agreement with the recommendation from the Second Review that a Memorandum of Understanding between NSW Health and LTCSS be developed to ensure that the expectations of LTCSS were able to be met. To our knowledge, this has not been achieved and therefore we believe requires further review and discussion.

## **ADDITIONAL COMMENTS AND ISSUES OF CONCERN RAISED**

### **a) Need for spinal cord injury specific education for LTCSS Coordinators, Case Managers and private therapists**

The monitoring and prevention of deterioration in health issues are seen as essential if the person with SCI is to live a fulfilling and productive community based life. SSCIS services play an important role in providing education to the person with SCI, their family and carers in the health related issues that require regular monitoring and prevention. However, SSCIS resources are not able to provide the extensive and ongoing education, advice and consultancy services to the broad range of community based health care service providers and therapists used by people with SCI, particularly those under the LTCSS or other compensation schemes.

LTCSS Case Managers regularly source private community based therapists. As noted under 4.2 above, SSCIS members have expressed concern regarding the use of these private therapists who may have considerable experience in their profession, but lack comprehensive understanding of spinal specific issues. Similarly, the need for inclusion of the promotion of life long health maintenance strategies as an aspect of the Case Manager's role (as noted in 4.3 above), requires some understanding by the Case Manager of the health issues that require monitoring.

In line with this, SSCIS suggests that LTCSA considers providing funding to SCI specialist services for the establishment of a Health Education Officer or similar position. It is recommended that these positions sit within the specialist services in order to maintain their clinical expertise and currency in knowledge and understanding of clinical management, but have a broader geographical area of responsibility providing SCI specific education to LTCSS Coordinators, Case Managers and private therapists of LTCSS participants.

### **b) Attendant Carers during client readmission to hospital**

The experience of SSCIS members and an area of great concern and frustration is the situation where Attendant Care providers disband the client's attendant care team when the person is admitted to hospital. The recruitment and training of a new care team places significant additional and unnecessary workload on clinicians, and stress on the client and their families, significantly increases their length of stay in hospital, and reduces bed availability for new patients with SCI. SSCIS request that the LTCSS consults with Area Health Services and negotiates agreement from them that the client's attendant care team continue to provide support to the activities of daily living of their client during their hospital stay. Where this is not possible due to the acuity and severity of the patient's illness, agreement is reached with the Attendant Care provider that the team will not be disbanded.

### **c) Vocation**

The SSCIS strongly supports the interest and commitment of the LTCSS towards the pursuit of early vocational involvement. We look forward to an opportunity to work together more closely on this aspect of rehabilitation in partnership with other vocational organisations.

Once again, thank you for the opportunity to provide comment. Please do not hesitate to contact Frances Monypenny on (mobile) 0404 010 918 if further information or clarification is required.

Yours sincerely

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