

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

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Submission to the  
New South Wales Parliament  
Legislative Council's review of the exercise and the functions of the Lifetime  
Care and Support Authority and the Lifetime Care and Support Advisory  
Council.

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## Introduction

Spinal Cord Injuries Australia (SCI Australia) is Australia's leading community organisation supporting people catastrophically injured with a spinal cord injury (SCI) and similar conditions. Our organisation was established in Sydney in 1967 by a group of young men who had survived SCI resulting in quadriplegia to advocate for appropriate support services as none existed at the time. We have a long history of developing and providing services to people with SCI, their family, friends and carers and being a voice for their concerns both socially and to government.

SCI Australia's interest in the Lifetime Care and Support Scheme (LTCSS) is obvious with many of our members having acquired a SCI through a motor vehicle accident. SCI Australia is keen to ensure that a well thought out scheme, which supports a newly injured individual to reach their full potential throughout their life, is in place.

We understand the need, recognised by the Lifetime Care and Support Authority (LTCSA), to invest in support from the moment of injury, through the rehabilitation process and into the period of returning home to the community. Support provided throughout these phases, leading to the maximisation of physical and psychosocial independence will bear dividends throughout the life of a traumatically injured person. We are therefore enthusiastic to ensure that all opportunities to explore systemic support and focus on individual needs are enhanced through the development of LTCSA practices.

We have developed a ground level understanding of the program with the involvement of our Peer Support Program within the spinal units. We believe that the individual experiences of many can be utilised to produce some systemic improvements in the program. Our close links with hospital supportive staff, at all levels, places us in a strong position to present a comprehensive set of comments as to the true operations of the LTCS.

Given the federal governments' recent commitment to start developing a National Disability Insurance Scheme and a National Injury Insurance Scheme (NIIS) there has never been a more important time than now to highlight issues with the LTCS. Under the NIIS there is the potential for the LTCS model to go national and support all traumatic injuries placing a significantly larger group of people through an expanded LTCS.

## **Submission**

### **Accommodation**

There are a number of pressing concerns in the area of accommodation for people in the Lifetime Care and Support Scheme. Foremost, is the lengthy process in getting people discharged from hospitals and into suitable affordable and accessible accommodation, be it their current home or finding a new dwelling. At times, people are stuck in hospitals for months after they are ready for discharge. This is financially costly for the Scheme paying thousands of dollars for specialty care beds and placing further strain on an already over-burdened health system. It can also be financially, psychologically and emotionally draining for people who are delayed from discharge to return home with their family, children, friends and relatives. It may also hinder their ability to return to work.

Getting approval from the LTCSS Authority itself is time-consuming with lengthy guidelines to adhere to. There needs to be a way of speeding this up, especially when a person can no longer return to their previous accommodation. A common scenario is this: a professional service such as Complete Home Hunters is used to find suitable private rental accommodation to meet the needs of someone in a wheelchair. A possible dwelling is found. An occupational therapist then has to inspect the place and write up any modifications needed. This then goes back to the authority for approval. In the meantime other applicants for the dwelling have come forward, offered their deposit and the place is no longer available.

It has been put to SCI Australia that the Scheme is not funding transitional accommodation for a newly injured if the person no longer has a 'fixed address.' Many people who end up in the Scheme after injury, do not own a home. So you have a situation where someone is catastrophically injured, they have a lengthy stay in hospital. This means they have to give-up their rented accommodation, and therefore they have been assessed as having no fixed address and being rejected for transitional accommodation when it is then time to leave hospital. This then further increases the time spent in hospital. SCI Australia believes there needs to be greater priority in speeding up the process of funding accommodation to enable discharge from hospital and rehabilitation, be it transitional or long-term accommodation.

It is important to acknowledge that the primary health care centres are often a long way from a person's home, family and work, especially for those who come from rural and regional areas. There is a need to fund transitional accommodation to support the individual to move back into their respective communities. Through the support and confidence that a person can acquire through being a short term resident in transitional accommodation they are being set up to succeed in the community.

### **Aids, Equipment and Attendant Care Service Delivery**

Again, the issue is the length of time people are waiting for essential aids and equipment. SCI Australia note from the 2010 review of the Scheme that participants are complaining of the delays for access to aids and services. If someone has acquired a serious spinal cord injury, then a timely turn-around in the approval of aids and equipment is vitally important. People are waiting up to 12 months for things like adaptive computer aids such as a QuadJoy mouse. For someone with high level quadriplegia this can mean the difference in gaining some form of independence.

Gaining speedy approval for services to assist people in their home to live independently such as Attendant Care is important, so the acknowledgement by the Authority of problems in this area will, we hope, improve provision. Attendant Care Packages give participants the flexibility to control how they coordinate the personal care they receive to match the individual's lifestyle and as needs change over time.

SCI Australia would like to make mention of the role of recreation and leisure in a participant's rehabilitation and day-to-day life. The Scheme's second review in 2009 had the role in this area as one of its recommendations for further review. SCI Australia feels that this area does not receive enough acknowledgement in the provision of care delivery for people with high needs. Too often people with severe disabilities find themselves isolated in their homes. Old friends drift away and family members are often living far apart. Having the ability to receive care outside the home to follow leisure pursuits assist to reduce isolation and increase community participation.

### **Participant Representation on the LTCS Advisory Council**

It has been recommended that there be included two participant representatives on the Advisory Council. SCI Australia is keen to see this happen as soon as possible as it feels it would expedite the resolution of any problems raised by participants in the overall running of the scheme. This would further empower the rights of participants of any grievances they have and gives other members on the Advisory Council a chance to hear first hand the views of participants. There has been a philosophical shift in how services are delivered to people with disability. This shift aims to place the participant at the centre of service provision. It's the same shift that is being seen with the 'Putting People First' policy by the NSW Government. So having participant representation would assist the Scheme in its approval of services and equipment.

### **The Role of LTCSS Coordinators**

The 2010 Scheme review made mention of the need to improve communication and contact with participants. SCI Australia is keen to see Case Managers and Coordinators consult with participants in working to achieve life goals. It is important to acknowledge the importance of the views and desires of participants and that they are regularly informed of changes and decisions made by the LTCSS in the approval and/or rejection of services, aids and equipment and the overall provision of care received.

SCI Australia would also like to highlight the unique nature of spinal cord injury and insuring that Coordinators have an adequate understanding of the health risks associated with this condition. Adequate care, aids and equipment is important in the prevention of these risks. We simply would like to make note of the recommendations by the State Spinal Cord Injury Service to provide training for LTCS Coordinators and Case Managers on the complexity of managing people with spinal cord injuries.

### **Over-supply of Care Hours**

There is enough anecdotal evidence that, at times, people are being over-prescribed care hours for their level of needs. There is a need to insure that people are receiving the adequate level of care; however, providing too much care can be stifling for the person involved and has a detrimental effect on them gaining maximum independence. It also affects a person's confidence in doing something for oneself. After a life-changing accident it is necessary to be given an opportunity to develop skills independent of care workers.

### **Bureaucratic Nature of the Funding Authority**

Scheme participants report it can be very frustrating having to deal with the lengthy process of the funding authority. The guidelines they need to follow to secure services and equipment and having to ask for every detail through an authority means people feel like they have no independence. There is a lot of anecdotal evidence that people don't like having to ask for everything, because of the rigid prescriptive nature of the guidelines. There needs to be a better way of achieving this like depositing funds, say, on a monthly basis to cover someone's day-to-day needs.

### **Summary of Scheme recommendations**

- There needs to be greater priority placed on speeding up the process of funding accommodation to enable discharge from hospital and rehabilitation.
- Aids and equipment provision is taking too long. The LTCS needs to ensure that a participants transition into the community is correctly supported through the timely provision of aids and equipment.

- The LTCS needs to recognise the benefit that leisure and recreational activities have to an individual with a disability and provide appropriate supports.
- The LTCSA Advisory Council needs to have two participant representatives on it.
- The LTCS needs to support the recommendations by the State Spinal Cord Injury Service to provide training for LTCS Coordinators and Case Managers on the complexities of managing patients with spinal cord injuries.
- The LTCS needs to take count of previous submissions that have highlighted the inherent risk to the individual with a disability of the over prescription of care hours.
- The LTCS needs to be more holistic in its approach to working with people with a Spinal cord Injury and recognise that guidelines, whilst providing a clear framework for supports, may equally work to stymie a person's development.

SCI Australia appreciates and support the role of the committee in analysing the inner workings of the LTCS. Thank you for the opportunity to provide feedback on the LTCS.

Kind regards

Spinal Cord Injuries Australia  
Policy Department.