

Submission  
No 2

**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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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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## Outline

- |                               |         |
|-------------------------------|---------|
| 1) Introduction               | Page 3  |
| 2) Terms of reference         | Page 4  |
| 3) Submission                 | Page 5  |
| 4) Summary of recommendations | Page 11 |
| 5) References                 | Page 12 |

## 1) Introduction

Spinal Cord Injuries Australia (SCIA) 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.

SCIA's interest in the Lifetime Care Scheme (LTCS) is obvious with many of our members having acquired a SCI through a motor accident. SCIA 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 and we believe that the individual experiences of many can be utilised to produce some systemic improvements in the program.

SCIA further recognises the importance of the LTCSA in the bigger picture development of a social insurance model for all Australians with a disability. Getting the LTCS 100 per cent right now has even greater importance.

## 2) Review Terms of Reference

1. That, in accordance with section 68 of the *Motor Accidents (Lifetime Care and Support) Act 2006*, the Standing Committee on Law and Justice be designated as the Legislative Council committee to supervise 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 under the Act.

2. That the terms of reference of the Committee in relation to these functions be:

(a) to monitor and review the exercise by the Authority and Council of their functions,

(b) to report to the House, with such comments as it thinks fit, on any matter appertaining to the Authority or Council or connected with the exercise of their functions to which, in the opinion of the committee, the attention of the House should be directed, and

(c) to examine each annual or other report of the Authority and Council and report to the House on any matter appearing in, or arising out of, any such report.

3. That the committee report to the House in relation to the exercise of its functions under this resolution at least once each year.

4. That nothing in this resolution authorises the Committee to investigate a particular participant, or application for participation, in the Lifetime Care and Support Scheme provided for by the *Motor Accidents (Lifetime Care and Support) Act 2006*.

*LC Minutes No 5, 30 May 2007, Item 3*

### 3) Submission

<b>1) The development of a registry of existing accessible public and private properties should be given consideration as a priority of the LTCSA.</b>
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Member comment: *“Surely this would free up hospital beds if a stock of housing was known about. Discharge shouldn’t be that difficult.”*

The majority of people that acquire a SCI or brain injury, resulting in physical disability, will require wheelchair accessible housing. This often requires major renovations to their property (if they own it) or, if it is too difficult or costly to renovate to make accessible, they will need to sell their existing house and purchase a property that is easier to modify. Another option is that they can purchase land and build an accessible home or purchase an existing accessible property that has been purposely built as required by the local council or shire under the Seniors Living 2004 [formerly known as SEPP 5]. These are their options.

Locating wheelchair accessible housing to purchase or rent has historically been a challenge and has always impacted on a person's transition from hospital to home, regardless of whether a person is a homeowner, living with family or extended family, renting privately or in public housing etc.

To address this issue, the LTCS could implement a few initiatives that currently, as far as SCIA is aware, have not been undertaken.

- 1) Create a registry of accessible properties in New South Wales (NSW). This registry could be gathered in a number of ways including:
  - a. assess all Seniors Living 2004 Development Applications lodged with local councils and see which ones have been completed;
  - b. utilise a similar database ‘wheelestate.com’ created by Paraquad NSW and update the information;
  - c. request that the Australian census ask "whether your property will allow wheelchair access to all areas" and "if not, do you consider your property could be made wheelchair accessible with a) only minor modifications needed to make it fully accessible or b) your property would require substantial modification to make it fully accessible. "; and
  - d. place advertisements in the major newspapers to seek support from both people living with a disability in their own homes and the wider disability sector by asking people to feed basic accessibility details about their property or properties they own to an email address.

**2) The LTCSA should advocate for the NSW Government to support an increase in the percentage of accessible properties being built under the recently announced federal government funded public housing initiative. In addition the LTCSA should work alongside housing developers to ensure that there are enough private accessible dwellings available in the market place.**

Member comment: *"I was in rehab. for too long. My stay was well over my discharge date. I stayed whilst an accessible property was sourced for me. When ones did come up they were always rejected by the LTCS as unsuitable. I just wanted a home."*

Presently the federal and state governments have committed to housing figures of 10 per cent to be of universal design and 0 per cent to be wheelchair accessible. In the UK the Mayor of London in 2009/10 announced in his London Housing Strategy a commitment to 100 per cent of all public housing to have universal elements and 10 per cent to be wheelchair accessible. He recognised the growing need for accessible and easily modifiable public housing.

The LTCSA should use its power as a respected body to lobby the NSW Government to ensure that 100 per cent of all new public housing planned by the state and funded under the federal government's public housing initiative includes universal design elements and 10 per cent be wheelchair accessible.

It is of great importance that if public money is spent on public housing then the housing should be accessible and available to all members of society, particularly when considering Australia's ageing population. This could represent a great role for the LTCSA to support and actively lobby the state government to ensure that as LTCS clients make the transition from hospitals to communities of their choice, an array of accommodation options are readily available. SCIA would welcome the opportunity to work with the LTCSA to lobby for this change.

Further to lobbying for public housing change, we believe that, with many people living in private accommodation, there is a role for the LTCSA to work with developers. This work should be collaborative with the aim of increasing accessible private housing stocks.

**3) The LTCSA needs to make a minor policy change on access to sport and recreational activities from 'may fund' to 'will fund' where a clear and demonstrated interest in that activity is shown.**

*Member comment: "I used to play competitive tennis and continued playing my favourite sport through my rehab. at Moorong. My application for a Tennis wheelchair was rejected with no real feedback. I now can no longer play Tennis. This choice was made for me and I had no voice".*

The benefits of exercise, sport and recreational activities to people with a disability have been recognised through various research and studies in Australia and throughout the world. SCIA supports the LTCSA recognition of this through moving forward with a policy concerning recreational activities and sport.

SCIA believes that there should be a slight alteration in the wording of that policy. We believe that once a benefit in undertaking the activity has been demonstrated (social as well as health) that rather than 'may' support (in terms of care, equipment etc...) the LTCSA should move to a definite 'will' fund.

We believe that with the further inclusion of a 'demonstrated interest in the activity' the LTCSA can draw assurance that the activity is fair and genuine and that the client has an ongoing commitment to it. It is our aim to ensure that as many positive activities , promoting good health and mental wellbeing, are available to clients of the LTCS.

SCIA agrees with the LTCSA position concerning participation in clubs and the view that related fee costs are the responsibility of the participant. We endorse the recognition that the role of the LTCSA is to support the individual with whatever they may need.

**4) The importance of physical exercise for a person with a SCI needs to be properly appreciated as part of the rehabilitation process both in hospital and continuing in the community.**

*Member comment: "Exercise is important to me. It increases my ability to function and through participating in exercise programs I feel better. I wish there had been a greater emphasis on ongoing exercise whilst I was going through rehab. I feel that I lost time".*

There are numerous research papers (as described in Sadowsky, CL & McDonald JW, 2009) which support intensive physical therapy as a means to enhance functional recovery post SCI.



It would be valuable for the LTCSA to fund an intensive physical therapy program, upon a patient's return to the community in particular. This is of great importance, particularly in the context of the Disability Discrimination Act (1992) which places the right to the highest standards of healthcare as a basic human right.

It is recommended that people with a SCI be offered intensive physical therapy involving dynamic, full-body, weight bearing exercises for a minimum of six hours per week on an on-going basis. This would aim to promote continued neural recovery, improvements in general health and a decrease in secondary complications of SCI, such as pressure ulcers, pathological fractures and muscle atrophy, through the improvement of blood circulation, maintenance of bone density and contraction of muscle fibres respectively.

Professor Mary Galea (Foundation Professor of Clinical Physiotherapy and Director of the Rehabilitation Sciences Research Centre at the University of Melbourne and Austin Health) states a number of innovative therapy programs, including intensive physical exercise, have a capacity to restore neurological function. At this stage, the Australian health system aims to return a patient post SCI to the community with as much independence as possible within their current level of function. Exercise is currently the only known intervention which can improve function through promotion of neural recovery and decrease secondary complications.

There are 10 model centres for SCI rehabilitation in the United States of America which all offer intensive physical therapy aimed at improving function post hospital discharge. It is therefore essential that comprehensive full-body exercise programs for people with a SCI are readily available in Australia after being discharged from the rehabilitation unit. Currently there are minimal options for exercise programs and only a small number of specifically trained professionals who can provide such therapy.

There is extensive evidence available as to the benefits of physical exercise for people with disabilities yet the LTCSA has not supported the cost of participating in such programs. Funding from LTCSA can provide much needed professionals to implement these essential programs.

Best practice for exercise includes patterned motor activation (involving gait training and functional electrical stimulation (FES) ergometry), non-patterned motor activation (strength improvement and task specific training) and sensory stimulation (Sadowsky, CL & McDonald JW, 2009). Whole body vibration has been recently documented as successful by showing improvements in blood circulation, voluntary activation of muscles, improved walking speed, step length and limb coordination (Ness LL & Field-Fote EC, 2009 and Pellegrini, MJ et al 2010). These best practice protocols must be available to all people with a SCI once back in the community to allow them the potential to gain as much functional improvement as possible.

It is clear that the investment in intensive physical exercise interventions would be highly beneficial to improve the level of independence of people with

a SCI. It would most certainly provide significant economic benefits for LTCSA in the future through a decreased demand on carer and assistance costs.

**5) The majority of home modifications should be pre-approved to ensure a smooth transition between hospital, or other supportive setting, and home.**

*Member comment: "I had to stay in a serviced apartment for almost 5 months whilst modifications were argued over for my home. This serviced apartment was my transitional accommodation. This was located far away from family and friends. I felt isolated".*

Home modifications to clients' own homes cannot be undervalued. The benefits in terms of familiarity of surroundings and ease of access to social networks as well as a greater sense of belonging are all things that can bring better life outcomes to a person with a SCI and to a person with an acquired brain injury.

We have heard anecdotally of instances where large and time consuming home modifications assessments have been undertaken only to result in almost immediate rejections based upon the dollar value at the bottom of the applications rather than on the proposed modifications. We recognise that some home modifications can be costly but also recognise the great benefits that an individual receives from living in their own home in their own community.

If the clients had followed a direct compensation approach then the question of home modifications would be largely dealt with through the common law practice of suing for lifetime care costs. It is understood by us that under the LTCS the legal case for lifetime costs compensation cannot be mounted as lifetime costs are met by the LTCS. Your only avenues for recompense are to sue for loss of earnings and pain and suffering. These are not expected to fund home modifications. They may also take many years to be finalised.

SCIA supports working with the LTCSA to define a level at which modifications can simply be rubber stamped rather than rejected. As we have heard anecdotally only specific applications are rejected and so there must be recognition of a threshold. We would welcome analysing that threshold to see how better to support LTCS clients.

Our proposal is for the introduction of an LTCSA home modifications panel to review the highest 5 per cent cost applications. This panel could meet monthly or as required. The remaining 95 per cent should receive pre-approval pending standard process. Further, there should be an appeals process to ensure that applications cannot simply be rejected.

**6) The LTCSA should commit to an evaluation of appropriate care hours with the aim of ensuring that the goal of fostering independence is achieved.**

Member comment: *"I have been living in the community for 18 months now. I get 24 hours a day care I feel that I have become so dependant both socially and emotionally on my carers. I cannot remember what life was like before my accident. I have lost the confidence I'm sure I once had."*

Access to paid personal care workers and services in NSW has always been problematic in regard to the services available in a particular city, town or region. Often there are simply not enough paid carers available to support the number of clients with their prescribed hours. Care is usually provided through the NSW Government funded Home Care Service or the Attendant Care Package (ACP). It is essential that the pool of carers is managed effectively.

There appears to be an emerging issue that we have been made aware of. A number of LTCS clients are being moved from hospital to the community with 24/7 care. Whilst we are not familiar with the personal history of these individuals, speaking for hundreds of members with a SCI, this level of care seems quite out of the ordinary. Bearing in mind the previous point about the limited availability of paid carers this is certainly an issue worthy of consideration.

This issue has been confirmed through conversations with some clients who say they need far fewer hours of care and often leave their carer to watch DVDs or go out to do personal shopping simply because there are not the tasks for them to do.

Apart from the financial impact on the LTCS, there is also a concern that over providing prescribed care services can cause individual personal development to be stymied. This can prevent the person from becoming as independent as possible. The provision of 24/7 care recreates hospital levels of care in the community and continues the 'patient' experience.

SCIA would support an evaluation of the care requirements of a person living with a SCI in the community at regular intervals or encourages LTCS participants to seek a review if extra care services are not required.

In addition to this, if the LTCSA deems that a person needs 24/7 care when initially transferred from hospital to the community, SCIA proposes a sliding scale of care hours to achieve greater independence over a period of six to 12 months or whatever is deemed to be an appropriate timeframe.

We further support a more flexible approach to care hours as often a standard 35 hours worth of care may be suitable for one week but not for another. A client who is supported with attendant care should be able to, with fair notice, increase their care hours one week and decrease them the next based upon their personal situation at that time.

#### **4) Summary of recommendations**

1. The development of a registry of existing accessible public and private properties should be given consideration as a priority of the LTCSA.
2. The LTCSA should advocate for the NSW Government to support an increase in the percentage of accessible properties being built under the recently announced federal government funded public housing initiative. In addition the LTCSA should work alongside housing developers to ensure that there are enough private accessible dwellings available in the market place.
3. The LTCSA needs to make a minor policy change on access to sport and recreational activities from 'may fund' to 'will fund' where a clear and demonstrated interest in that activity is shown.
4. The importance of physical exercise for a person with a SCI needs to be properly appreciated as part of the rehabilitation process both in hospital and continuing in the community.
5. The majority of home modifications should be pre-approved to ensure a smooth transition between hospital, or other supportive setting, and the home.
6. The LTCSA should commit to an evaluation of appropriate care hours with the aim of ensuring that the goal of fostering independence is achieved.

**SCIA would like to take the opportunity to thank you for this opportunity to provide feedback on the LTCS and anticipates the content will be given favourable consideration.**

## 5) References

Galea, M (2007), 'Winston Churchill memorial trust of Australia report to investigate active rehabilitation programs for people with spinal cord injury'

Ness LL & Field-Fote EC (2009) 'Whole-body vibration improves walking function in individuals with spinal cord injury: A pilot study', *Gait & Posture*, Vol 30(4), pp 436-440

Pellegrini, MJ, Lythgo, N, Morgan, D & Galea, M (2010) 'Voluntary activation of the Ankle plantar flexors following whole-body vibration', *European Journal of Applied Physiology*, Vol 108(5), pp 927-934

Sadowsky, CL & McDonald JW (2009), 'Activity-based restorative therapies: concepts and applications in spinal cord injury-related neurorehabilitation', *Developmental Disabilities Research Reviews*, Vol 15, pp 112-116

The London Housing Strategy 2010

[http://www.london.gov.uk/sites/default/files/uploads/Housing\\_Strategy\\_Final\\_Feb10.pdf](http://www.london.gov.uk/sites/default/files/uploads/Housing_Strategy_Final_Feb10.pdf)