

**FIFTH REVIEW OF THE EXERCISE OF THE FUNCTIONS
OF THE LIFETIME CARE AND SUPPORT AUTHORITY**

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LEGISLATIVE COUNCIL STANDING
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FIFTH REVIEW OF THE LIFETIME CARE AND
SUPPORT AUTHORITY SUBMISSION

NSW HEALTH

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Fifth Review of Lifetime Care and Support Authority

The Lifetime Care and Support Authority (LTCSA) is a statutory body that administers the Lifetime Care and Support Scheme.

The LTCSA was set up to ensure that people who are catastrophically injured in motor accidents receive necessary care and support for the rest of their lives, regardless of who was at fault in the accident.

The LTCSA has been operating for almost seven years and the Legislative Council Standing Committee on Law and Justice will be examining how well the Authority is fulfilling its role and assisting its clients

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1. Introduction

The response from NSW Health response is based on issues raised by the Agency for Clinical Innovation (ACI) following consultation with NSW State Spinal Cord Injury Service and Brain Injury Directorate (BIRD), two of the clinical networks of the ACI who have been working closely with the Lifetime Care and Support Authority (LTCSA) through the Lifetime Care and Support Scheme (LTCSS).

The NSW State Spinal Cord Injury Service (SSCIS) 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.

The NSW Brain Injury Rehabilitation Program provides acute and sub-acute rehabilitation services in metropolitan and rural locations for the people of NSW and is a provider for many of the LTCSS scheme participants.

2. Comments on Lifetime Care and Support Authority Annual Report 2011/2012

The Lifetime Care and Support Authority (LTCSA) has continued to work on strategies to improve and enhance the quality of life of LTCSS participants. These include:

- **In-Voc program** – The success of the project was recognised by LTCSA which has funded the continuation of the program.
- **Competency standards for attendant care workers** – NSW Health acknowledges LTCSA's collaboration with Ageing, Disability and Home Care in the joint project to develop specialist competency standards for attendant care workers supporting people with either a spinal cord injury or acquired traumatic brain injury. This gives recognition to the specialist needs of this cohort and aims to ensure attendant carers have the knowledge, understanding and skill in the care and support needs of these individuals using a prevention and early intervention approach to activities of daily living and basic care needs. Planning for implementation of the competencies is currently in progress.
- **Return to Community Project for people with high care and support needs in the community** – This project recognises the special needs of this small cohort of people and the demands on those caring for them. NSW Health looks forward to the findings and outcome of this project.
- **Five year follow-up** – This is a project looking at the predictors of early intervention on the outcomes of LTCSS participants. Knowledge of these predictors will help in planning and streamlining timely early intervention and management to prevent deterioration and achieve better outcomes.
- **Review of the case files of all 2012 LTCSS participants** with the aim of reviewing their 'journey', identifying information gaps and requirements and developing timelines / pathways highlighting recommended time frames for submission of requests for equipment and care supply and reviews. These pathways will provide recommended timeframes for completion of required submissions and equipment supply. and will also form the basis of an audit tool to review case files to identify areas for improvement.
- **Funding of external projects:** NSW Health acknowledges that LTCSA has provided grant funding for projects relevant to improving the outcomes, care and support of people with catastrophic injury as a result of a motor vehicle accident. Current projects relevant to spinal cord injury funded through the grant program include the following:

- ParaQuad NSW 'Personal Care @ Home' project
- Agency for Clinical Innovation Chronic Pain in spinal cord injury project
- Review of Sargood Centre
- Psychosocial strategies in people with a SCI.

Additional challenges and issues being considered by LTCSA

- It is appropriate that the LTCSA consider the impact of the National Disability Insurance Scheme. In particular consideration of a self-directed funding trial where the individual LTCSS participant receives and manages their LTCSS funding package would be beneficial noting that selection and purchase of their own attendant care services is included.

3. Progress in relation to the Recommendations of the FOURTH Review of LTCSA

The recommendations from the Fourth Review most relevant to NSW Health were recommendations 6, 7, 9, 10, 11 and 14 relating to SSCIS, BIRD and The Sydney Children's Hospital Network.

- **Recommendation 6** highlighted the need to simplify and standardise forms and reduce duplication of information and limiting the administrative burden on service providers.
 - A survey of SSCIS network members in 2012 was conducted to determine whether the forms and administrative burden continued to be a problem. While the results showed that duplication was no longer a problem, administrative burden appears to remain an issue. LTCSA has continued to refine and simplify the on line submission process to reduce the time clinicians spend in completing the forms.
 - LTCSA meet regularly with staff of the Children's Hospital at Westmead regarding information collection, with the aim of simplifying and standardising forms. While an administrative burden persists, cooperative work to develop and improve these processes is ongoing.
- **Recommendation 7** noted the need for LTCSA to work with the SSCIS Directorate to improve communication between clinicians and the Authority and to act on concerns and provide meaningful responses to these concerns.
 - A number of strategies have been undertaken since the last review. These include:
 - The LTCSA newsletter regularly updates service providers on changes, requirements and improvements.
 - Feedback provided to service providers on the information required by LTCSA to help in its determination of whether a request fulfils the 'reasonable and necessary' criteria has helped clinicians better understand the information they are required to provide in their submissions.
 - LTCSA staff to attend regular meetings with staff in NSW spinal cord injury units. The purpose of the meetings is to: address any areas of concern in relation to processes or procedures; ensure communication between LTCSA and the service provider in a timely manner; to review difficult case scenarios and to identify and work on areas for improvement.

- The Terms of Reference for the SSCIS and LTCSA Liaison Committee have been reviewed and updated to ensure it has representation from all spinal cord injury service providers and provides a forum where issues unable to be resolved at a spinal cord injury unit level are addressed. The Committee meets three times per year.
- **Recommendation 9** states that LTCSS Coordinators receive as part of their induction training information on respect for expert clinician decision making and treatment recommendations.
 - Ensuring LTCSS Coordinators are able to understand the specialist health care, treatment and mobility equipment needs of a person with a SCI is critical. This education should be standard practice, particularly as the numbers of LTCSS Coordinators increases and some variability and inconsistency continues.
 - LTCSA has established an internal newsletter in an effort to keep Coordinators informed and updated. The State Spinal Cord Injury Service will be taking up the recent invitation to provide short articles on spinal cord injury specific issues for inclusion in the newsletter. NSW Health is also supportive of the use of a range of education and information strategies by the Authority to support increased understanding of the specialist needs of the person with a spinal cord injury by LTCSS Coordinators and Case Managers.
- **Recommendation 10** asks the LTCSA to consult with The Children's Hospital at Westmead to develop an agreed protocol to enable discussion of a participant's appropriate treatment options with clinicians prior to discussion with the family.
 - Advice from The Children's Hospital is that regular meetings have been held to work towards an agreed protocol which remains incomplete. A process to resolve disputes has been clarified and is utilised when required.
- **Recommendation 11** asks LTCSA to investigate options for permitting participants to be discharged from hospital to interim accommodation, prior to long - term accommodation having been secured.
 - It is acknowledged that accommodation is not within the remit of LTCSA. The efforts to date of the Authority in identifying and supporting individual LTCSS participants to access available interim transition accommodation options such as the ParaQuadNSW Ferguson Lodge are appreciated.
- **Recommendation 14** asks the LTCSA to liaise with the Department of Education and Training and review the issues raised by the Children's Hospital, Westmead, to improve and clarify the process of obtaining educational support for child participants in the Scheme.
 - The Sydney Children's Hospital Network advises that liaison has occurred between LTCSA and the Department of Education and Communities. Possibly due to the very limited experience individual schools may have with LTCSS processes, it practical improvements in this area appear limited.

4. Additional Comment

- **Health monitoring and promotion, and illness prevention**

The involvement of specialist health care services in providing regular review; monitoring; advice and support of health maintenance, as well as promotion and illness prevention are key goals for people with spinal cord and brain injury who are LTCSS participants. Ensuring this goal is included in the individual's life plan is seen as a key responsibility of LTCSS Case Managers and should be encouraged.