ACI NSW Agency for Clinical Innovation

14 July 2010

Our Ref:

Rachel Callinan
Director
Standing Committee on Law and Justice
Parliament House
Macquarie Street
SYDNEY NSW 2000

Dear Ms Callinan

Re: Inquiry into the exercise of the functions of the Lifetime Care and Support Authority – Third Review

Thank you for the opportunity to provide a response to the questions on notice as listed in your letter dated 25 June 2010. We have provided a response to those questions addressed to the State Spinal Cord Injury Service (SSCIS), a network of the Agency for Clinical Innovation (ACI), questions 2, 3 &4. Question 1 is directed to the Brain Injury Rehabilitation Service, however, we also advocate for greater acknowledgement of situations seen to be clinically urgent by clinicians and greater flexibility in the approval process at these times when an urgent response is required to prevent further deterioration of the clinical status of the client.

2. **In response to concerns raised by the State Spinal Cord Injury Service about the role of the LTCS Co-ordinators and Case Managers, the LTCSA has noted that there is an advantage in having some overlap between the two roles in that it creates flexibility and allows both roles to adapt to the individual circumstances and needs of the participant.**
    a) **Can you briefly outline the role of the Case Manager, LTCS co-ordinator, and clinicians in meeting the needs of the participant?**
    b) **What is your response to the view that some overlap between the roles of case managers and Coordinators is advantageous?**

Response
Firstly, it is important to clarify that the roles of Case Manager and LTCSS Co-ordinator referred to here are both LTCSS roles whose responsibilities are determined by LTCSA. The clinician is one of a number of health care disciplines working in a State Spinal Cord Injury Service (SSCIS) member adult spinal cord injury services in NSW (inpatient and Spinal Outreach Service (SOS). With the exception of the Royal Rehabilitation Centre Sydney (RRCS), these services do not have specific Case Managers. Instead, they do generally nominate one member of the clinical team to be the 'contact person (or similar title)' for each client. The role of the 'contact person' is to be the central point of communication in relation to the clinical management and discharge planning for that person. However, it is not to provide 'case management' as defined by LTCSA. In light of this clarification, our responses to questions are as follow:

Level 3, 51 Wicks Road
North Ryde NSW 2113

PO Box 6314
North Ryde NSW 2113

T +61 2 9887 5728
F +61 2 9887 5646

www.health.nsw.gov.au/gmct/
ABN: 89 809 648 636

Response to 2a)
The focus of case managers, coordinators and clinicians alike is to work with the person/client with a spinal cord injury and their families/significant others to achieve the best outcome for that client through identifying their goals and needs and then working with the client, clinicians, and service providers to achieve these goals.

The **LTCSS Coordinator**, as defined in the LTCSA 'Frequently Asked Questions' information leaflet is to '*work with the participant (client), their family, clinical staff and other service providers in order to assist participants to achieve their life goals. This is achieved by developing, implementing and evaluating life plans*'. The LTCS Coordinator '*will have a life long relationship with a participant and will assist the participant to develop life roles and participation throughout stages of life'* and, as defined in the LTCSA Guidelines, '*is the participant's primary point of contact with the Authority'.*

Current discharge approval processes for people with a SCI includes pre-approval for the appointment of a private Case Manager towards the end of their inpatient stay. They may be appointed for a limited or extended period depending on the specific client needs.

The role of the clinician is to be at the forefront of care and service delivery and identifying the participant's needs. The SSCIS clinicians work with the client during their inpatient stay to achieve the goals required to prepare the client for a safe discharge back to community living. A person with a newly acquired SCI who is a resident in Sydney, is referred to the Spinal Outreach Service (SOS), a multidisciplinary team that provide follow up for a period of 18 months following discharge to ensure a smooth transition to community living. Both inpatient and outreach clinicians provide the specialist expertise to achieve optimal inpatient rehabilitation outcomes and prepare the client with the knowledge and skills to manage or direct their care and reintegrate to community living following discharge. Like public patients, LTCSS participants are routinely referred to the SOS and therefore have the opportunity for this specialist support during this period of reintegration. With the introduction of the new LTCSA pre-approval process, an initial assessment by SOS is now routinely conducted. The findings of this assessment are reported to the private Case Manager who is then responsible for directing appropriate follow up and interventions. <u>With the introduction of multiple private non-SCI specialist case managers the importance of understanding the spinal specific health concerns is often overlooked.</u>

Clinicians acknowledge and recognise the important role of LTCSS Coordinator and private Case Managers in continuing to support the participant on a lifelong basis from the time of discharge. It is the view of clinicians that while the participant /client is an inpatient, the LTCSS Co-ordinator and the LTCSA funded private Case Manager do not have a role in directing the client's care and service delivery. However, they do have the role of providing guidance to clinicians on the expectations, parameters and limitations of the Scheme and should consult with the clinician teams about how their role can be useful in advocating for participant needs as identified by the treating team.

There needs to be mutual recognition of the unique skills and training of those undertaking each of these roles. However, there also needs to be clear role definition and delineation. Any overlap between these roles should only occur following negotiation and consultation between the LTCSS Coordinator, Case Manager and the treating clinical team. Currently, this role delineation is blurred with LTCSS Coordinators at times seen to be making decisions related to the clinical aspects of the client's management. Such examples of role overlap leads to confusion not only for the treating clinical team, but also for the client.

Response to 2b)
The interactions in the inpatient setting generally occur between the clinicians and the LTCSS Coordinator, and in the community setting it is between the outreach clinicians and the private Case Managers.

From the inpatient and outreach clinicians' perspective, overlap between the roles of the LTCSS Coordinator and LTCSA funded Case Manager creates confusion for the scheme participant /client. It is their view that the participant benefits from having clear role boundaries between these two positions, which causes less confusion and anxiety for the participant in terms of smooth systems of communicating their needs. The participant may already have other services and support systems to deal with and understand hence less complication is more beneficial to the participant's adjustment, within an already stressful time.

Less overlap is also beneficial for the clinicians working with the client, in terms of knowing the right lines of communication to advocate for the participant's needs along the continuum of rehabilitation and integration into the community. As mentioned above, any overlap between these roles should only occur following negotiation and consultation between the LTCSS Coordinator, Case Manager and the treating clinical team.

It is our opinion that conflict may arise due to the following:

- Lack of clarity in relation to the role and responsibilities of the Coordinator and the private Case Manager, and the boundaries and overlap between these roles and responsibilities, in particular with the roles and responsibilities of the clinicians in the inpatient setting.
- This lack of clarity leads to tensions when the Coordinator or the Case Manager is seen to be interfering.
- Inconsistencies in the responses and actions across the many LTCSS Coordinators and private Case Managers across a spectrum of issues eg LTCSS requirements, processes, understanding of spinal cord injury (SCI) client issues, understanding of roles and responsibilities of clinicians.
- Lack of clarity with regard to the expectations of LTCSA of the services expected from the specialist services for the LTCSS participants in their service.

We believe that more work should be done to clearly outline the:

- Role and responsibilities of the LTCSS Coordinator and the private Case Managers while the participant is an inpatient, and continue to promote consistent communication pathways and processes between them and the treating clinicians.
- Expectations of the treating teams in relation to the provision of service to LTCSS participants.

3. **The State Spinal Cord Injury Service has indicated that it would be happy to provide training for LTCS Coordinators and case managers on the complexity of managing patients with spinal cord injuries.**
   a) **Can you outline the areas such training would cover and how it would improve service delivery to participants?**

   b) **Have you made this offer to the LTCSA?** Yes, this offer was made and minuted at a meeting between the SSCIS Director, Co-Chair and Manager and Susanne Lulham and Neil Mackinnon, LTCSA, held on the 18th December 2009, where the proposal for the establishment of a SSCIS & LTCSS Liaison Meeting was discussed.

Response

SSCIS acknowledges that LTCSS Coordinators, private Case Managers and private therapists may have considerable experience in their profession, but perhaps do not have an understanding of spinal specific issues, in particular that 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. This results in a difficulty in appreciating the health implications of the underlying condition which can occur in an unpredictable way, which 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 members, and in particular the Spinal Outreach and the Rural Spinal Cord Injury Services have considerable experience in providing education to non spinal specialist clinicians, consumers and carers on health monitoring, health maintenance and illness prevention related to spinal cord injury. It is not the expectation of spinal specialist services that non specialist services be expert in the field, however, it is their expectation that those involved in the longer term care and support of people with SCI are aware of the health risks and subsequent rapid deterioration in health should the warning signs not be picked up early and as part of routine prevention and monitoring strategies.

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.

Education programs for LTCSS Coordinators, private Case Managers and therapists would include information to improve their 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, as they are an essential component of the lifelong management of a person with SCI. The inclusion in LTCSS participants' lifetime plans of risk assessment and profiling with flags that identify the risks which result in increased costs, with suggested action to be followed, would help non SCI specialist staff in identifying when further action is required.

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. The early and timely flagging of the risks would ensure the individual is referred to appropriate services in a timely manner to prevent the risk deteriorating further becoming an actual problem.

It is acknowledged that the depth of understanding of these issues required by each of these groups will differ and therefore the education would be tailored to each group. A Coordinator is not expected to understand the day to day management of the person with a SCI, however, a general understanding of the issues and risks, and when urgent response is required, would be appropriate.

4. **The LTCSA has noted that the draft guidelines for case managers have been amended following feedback and now include 'increased reference to the specific health management needs of people with spinal cord injury.'**

    a) **Have you seen the amended guidelines?**
    SSCIS notes that the draft guidelines for comment were added to the LTCSA website on the afternoon of Thursday 17 June 2010. Our comments are in relation to this version of the guidelines.

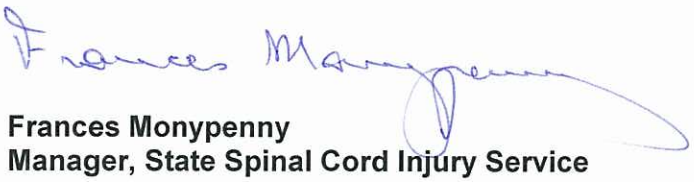
b) If so, do they address the concerns in the State Spinal Cord Injury Service submission about the draft guidelines not providing for the integration of care and services to achieve health outcomes?

On review of the current version of the draft guidelines it is evident that previous feedback has been considered and changes made to the guidelines reflecting this feedback, in particular:

- Recognition of the lifelong impact of SCI on health and well being, including psychosocial factors.
- Consideration of a more directive approach to case management for people with SCI when mitigating factors are present such as cognitive impairment or mental health issues.
- Greater use of terminology relating to health.
- Greater focus on health promotion and in developing client skills and knowledge in monitoring and maintaining their health status and illness prevention.

Should you require further information please do not hesitate to contact me on mobile 0404 010 918.

Yours sincerely



Frances Monypenny
Manager, State Spinal Cord Injury Service