Submission No 6

# SECOND REVIEW OF THE LIFETIME CARE AND SUPPORT AUTHORITY

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The Director
Standing Committee on Law and Justice,
Legislative Council
Parliament House
Macquarie St
Sydney NSW 2000

5<sup>th</sup> May 2009

Dear Sir.

# Re: Second Review of the Lifetime Care and Support Authority

The Westmead Brain Injury Rehabilitation Service (BIRS) has been providing services to interim participants of the Lifetime Care Scheme (LTCS) since October 2007. We now have 18 months of experience working with this scheme and are in a position to report the positive and negative aspects of the scheme from the perspective of a specialised service provider.

#### POSITIVE ASPECTS

1. Greater percentage of clients having access to rehabilitation services Prior to the introduction of the LTCS, between 20-25% of patients admitted to the Westmead BIRS had access to insurance claims such as CTP or workers compensation which funded their rehabilitation, equipment and care needs. People without such claims had great difficulty accessing therapy, care and equipment after their hospitalisation because of the vast limitations in the public system to provide these services. Since the advent of the LTCS for adults, 50% of patients admitted to the Westmead BIRS have either compensation or eligibility to be participants of the LTCS. This means that the percentage of patients who are able to access therapy, care and equipment after hospitalisation has almost doubled in the past 18 months as a result of the introduction of the scheme. This has been a great outcome for people with catastrophic brain injuries as a result of motor vehicle accidents. For the other 50% of patients who have sustained severe head trauma due to assaults, falls and sporting injuries there remains inadequate compensation systems. These patients continue to have difficulty accessing rehabilitation and care services after their hospitalisation.

# 2. Access to support for Families

We have been pleased with the preparedness of the Authority to acknowledge the impact of catastrophic injury, particularly brain injury, on the family unit. The authority has been supportive of applications we have submitted requesting support for families in the way of respite, counselling, rental assistance and transport. Such support is crucial to the rehabilitation outcomes for the patient.

<u>Recommendation:</u> We encourage the LTCSA to continue its support of the family unit as a vital component of the rehabilitation program of the person with the injury. Furthermore, we encourage the LTCSA to interpret the phrase 'families and significant others' in a broad way to encompass the whole family, be it either primary secondary and tertiary caregivers or those affected by the consequences of the brain injury.

# 3. Leisure Discussion Paper

We would like to commend the authority on producing a discussion paper on leisure. It appears that the Authority is recognising that leisure is an important life role for most people and that catastrophic injury can significantly change a person's ability to pursue leisure interests and activities. We strongly believe the ability to engage in leisure activities, or any other life roles for that matter, contributes significantly to people's perceived quality of life.

<u>Recommendation:</u> The Authority will be supportive of programs facilitating leisure and it will accept responsibility to financially support some leisure activities where a participant has experienced significant changes to their ability to return to their pre injury life roles.

#### 4. Evaluation and Reviews

We have been pleased that the LTCS has embarked on a number of reviews since its inception. It has actively sought feedback on its processes and forms and used this feedback to make changes and improve the systems in place. By doing so – the Authority appears committed to evaluation and feedback and is striving to be flexible in the way it interfaces with other stakeholders such as the Department of Health. A further example of this is the way the LTCSA has willingly participated in an Implementation and Liaison Group established within the Brain Injury Rehabilitation Directorate of NSW.

<u>Recommendation:</u> The Authority will continue its commitment to review and its receptiveness to feedback on an ongoing basis.

# 5. Newsletter

Keeping all relevant stakeholders informed of the latest developments and changes within the scheme must be a challenging task for the Authority. The LTCS Newsletter, which is widely distributed each month, has been a very useful resource for service providers to keep themselves abreast of developments within LTCS. It provides information on relevant training such as FIM/CANs, etc. It helps to keep us informed of any changes to processes or forms. It is the usual way we become aware of any reviews and evaluations taking place and the process by which we can contribute to those reviews.

Recommendation: The Authority continues its monthly distribution of the newsletter in its current format

#### AREAS OF CONCERN

# 1. Increased Workload

The advent of the LTCS has significantly increased the workload of health professionals of this service provider. Although there has been a review of forms and processes by the Authority, the amount of time all staff, especially case managers, occupational therapists and social workers spend on meeting the needs of the authority remains very high to the extent that clinical time and intensity of therapy for patients has been compromised. Familiarity of forms and processes after working in the scheme for 18 months has only marginally reduced the time spent in these activities. It is important to note that there was no resourcing of service providers to cope with the additional load the scheme would bring them. To protect the clinical time therapy staff needs to give to patients, it is becoming crucial for our service to have additional resources to assist with LTCS matters.

<u>Recommendation:</u> The Authority explores with the NSW Dept of Health ways in which the specialised Brain Injury Programs can be equitably resourced to meet the demands of the LTCS without compromising therapy programs

2. LTCS certificates given to participants with severe brain injury

Adults with severe brain injury and who meet the criteria for acceptance into the LTCS typically have significant cognitive, communication, psychological, psychosocial and insight difficulties as a consequence of their injury. We have concerns that that current processes and forms within LTCS do not take these difficulties into account. Cognitive impairments impact on participant's ability to appropriately interpret the LTCS certificate in its current format, particularly adults in their post acute rehabilitation phase of recovery. Rehabilitation providers/therapists frequently need to engage in skilful strategies to encourage participant engagement in rehabilitation that will enhance their functional outcomes and participation in community living in the short and longer term. The detail currently provided on the participant certificates, particularly the inclusion of LTCS codes, approval numbers and costs creates confusion for many participants and can be counterproductive especially for those participants for whom engagement is an issue. For many participants with brain injuries, although their CDP and CLP would have been discussed with them in a manner to enhance their understanding prior to submission, participants' memory difficulties invariably result in them not recalling the detail of this information when the certificate is received in the mail. Family members are not always available to explain the certificate, nor is it always appropriate for them to explain due to the challenging behaviours demonstrated by some participants. The costings can often be interpreted by participants to be the amount paid directly to the service providers/therapists and/or the participant may become angry with service providers if they perceive the costs noted in the certificate as money belonging to them and they wish to use it for alternate purposes e.g. to pay off debts or

purchase a car. The complex identification of services approved on some certificates also impairs comprehension by participants. As a result of the executive function difficulties experienced by participants with brain injuries, the certificate in its current format has a strong potential to negatively impact on their rehabilitation, particularly in the post acute recovery and rehabilitation phase.

Recommendation: The Authority redesigns a LTCS certificate which takes into consideration the typical cognitive, communication, psychological, insight and psychosocial consequences of a brain injury. The detail in the certificate should be minimal and simple to enhance the participants understanding and facilitate their ongoing participation in their program. To this end, we suggest that the revised certificate should not include costs, codes or approval numbers. We would recommend that LTCSA liaise with the BIRD Directorate Liaison Group regarding the redesign of participant certificates.

3. Dispute Resolution Processes

We are concerned that the dispute resolution process relating to non approval of services also fails to take into account the significant cognitive, communication, psychological, psychosocial and insight difficulties resulting from severe brain injury. LTCS legislation requires LTCSA to provide participants with a certificate for each approval/non approval for services. The only person currently who can raise a dispute about the non-approval of services is the participant. The impairments described above can significantly limit a participant's ability to understand, initiate and engage in the current dispute resolution processes. There is also no process of notifying the relevant service provider of the outcome of requests before a participant receives their certificate. Therefore, there is no ability on the part of the service provider to "prepare" participants on the outcome of requests or assist in the process of reasoning and rationalising with the participants why outcomes might be the way they are.

Recommendation:

- The dispute resolution process is expanded to enable the service providers who submit the CDPs, CLPs, service requests etc to LTCS, to be involved in the dispute resolution of non approved of services.
- There is a transparent documented process of discussion between the LTCS Coordinator and rehabilitation service with the aim of negotiating a mutually agreeable outcome on the 'reasonable and necessary' services with/for the participant. Such a process would precede the dispute resolution process and may consequently negate the need for engagement in the dispute resolution process. The development of a transparent, known process may alleviate misunderstandings and misinterpretation of documentation and avoid participants with severe brain injuries being placed in the position of having to decide whether or not to initiate dispute resolution processes with the LTCSA. Such a process will also provide the participant with perception of both LTCSA and the rehabilitation provider as professional services that can negotiate a positive outcome on their behalf. The consequence will also be a certificate more understandable to the participant and less potentially counterproductive to their rehabilitation and community re-integration.

4. Approval Processes

There are a number of concerns around approval processes:

LTCSA currently has a 10-day timeframe to assess and decide on any requests/applications. This time frame exists for all types of requests be it Care Needs Assessments, Community Discharge Plans, an item of equipment, etc. There are times when it would be desirable to have a quick decision made on some requests because of need to facilitate a timely discharge and/or engage other services e.g. builder, care agency. In such situations it has been our experience that the LTCSA have been inflexible around the 10 day rule. In fact, in some situations, it has taken longer than 10 days to get a decision on some requests.

<u>Recommendation:</u> The LTCS establishes a flexible system of prioritising requests so that those which are more urgent can be attended to in a quicker than 10 day time frame.

At present, the way a service provider becomes aware of the outcome of a request or application is via receipt of a copy of the certificate/letter from the Authority to the participant informing them of the outcome of the request. Given that the original request was submitted and justified by the service provider on behalf of the participant, it would be courteous, helpful and desirable that there be a system of providing formal direct feedback to the service provider. The service provider can then appropriately liaise with the participant, family and supplier re the outcome of the request.

Recommendation: LTCS directly communicates with service providers regarding the outcome of requests submitted by them. This can be done via the approval section at the end of the LTCS forms or by way of a letter on LTCS letterhead.

currently there is no formal system for informing suppliers such as equipment suppliers or private therapists of LTCS approval of their services apart from passing on a copy of the participant's certificate. We feel that it is inappropriate for suppliers to receive a copy of a participant's certificate when this certificate contains confidential clinical information which is not all relevant to the supplier and thus could breach the privacy act. Suppliers have indicated that they require formal notification of approval of their services – preferably documented on LTCS letterhead before they will provide a service.

Recommendation: The Authority provides formal notification of approval either by letter on LTCS letterhead or via the approval section at the end of LTCS request forms. This formal notification can be returned to the service provider, (as recommended in (ii)) and the service provider can in turn forward these on to the relevant suppliers. It will be important that there is an approval letter per each supplier.

5. Supported Accommodation Options

We have had a number of participants come through our program (some who are still inpatients) who have severe disability and have supported accommodation needs. Prior to the LTCS, patients who had an accepted CTP claim had a

number of options open to them when attempting to secure accommodation e.g. buy a home with advanced settlement money or modify an existing home with there being no apparent ceiling on modification costs so long as they could be justified. Our experience since the advent of LTCS is that there is a paucity of solutions available for people with supported accommodations needs when they do not have a CTP claim. Patients are spending longer in hospital because of lack of timely options. LTCS's current policy of not purchasing homes for people and setting limits on what it will spend on modifications is contributing to long delays in solving accommodation options for participants. The Authority has informed us that it is researching supported accommodation solutions for its participants and that talks have occurred with the Department of Housing however in 18 months there appears to have been little progress on this front.

Recommendation: The Authority urgently needs to establish viable partnerships with Dept of Housing and other private agencies to have solutions and options for participants in need of modified housing and supported accommodation.

#### 6. Attendant Care

The provision of Attendant care services to participants with a brain injury is a vital aspect of the LTCSS. As such we have had extensive experience now working with a number of private attendant care agencies on the LTCSA preferred providers list. One of the most significant issues facing participants in the post acute recovery and rehabilitation phase is the time it takes for care to be implemented from the time of referral to the attendant care agency to the actual implementation of care staff in the home. We have found that care is often not available in a timely fashion and that the recruitment process can have detrimental effects on participant's length of stay in hospital.

One of the main objectives of care provision under a rehabilitation philosophy is to facilitate independence in the participant and maximise the participant's engagement in activities to the capacity of their ability. Our experience is that many carers struggle with this aspect of care as their tendency is to allow themselves to be directed by the participant in what they do for them. A cognitively and behaviourally impaired participant is often unable to make appropriate choices about their care and often needs prompting to prevent them from regressing into dependent or unsafe behaviours. We feel that carers need greater understanding of how cognitive and behavioural issues impact on a participant and what the expectations on carers are when approaching care in this diagnostic group from a rehabilitation perspective. Unfortunately, when attempting to do this and when we recommend this as part of our training of care agency staff, LTCSA has been reluctant to agree to the funding of this education by our service as it believes it to be the role of the care agency to train its staff in core brain injury skills. The problem with this is that carers are usually recruited at short notice and do not have any time for training and education in generic skills before they have to embark on specific training for the participant. Our own belief is that education of agency staff in core brain injury skills would be much more appropriately and efficiently provided by a specialised service provider such as ourselves.

Recommendation:

- That the process and time frames of implementing care from the time a Care Needs Assessment is submitted to the implementation of care in the home is reviewed and improved.
- For the LTCSA to liaise with ACIA around establishing improved education programs in TBI which aim to improve the knowledge and skills of carers across the board working with participants who have a traumatic brain injury.
- iii For LTCSA to be agreeable to specialised service providers giving education to agency staff on relevant core skills appropriate to the care of the participant for which they are being educated/trained.

#### 7. Evaluation Processes

Although we have been pleased that the Authority has engaged in evaluation and review processes of its procedures and forms, we have none-the-less been disappointed in some aspects of these reviews. Firstly, the reviews have generally been delayed from when they were originally proposed and promised to take place. This has caused some frustration in service providers who had been looking forward to the reviews as a way of improving a difficult workload situation for them. Secondly, when the reviews finally take place, they are generally nonstructured, non-specific and leave a lot to those providing the feedback in being proactive with thoughts, ideas and suggestions. When the forms were being reviewed, we expected a more structured and collaborative review process in the form of a detailed questionnaire or focus groups - especially since LTCS were fully aware of the general discontent that existed with the paperwork and forms it was imposing. Finally, once the review was completed, there has been no formal feedback of the results back to the service providers (apart from the Care Needs Assessment Form) and there has been no collaboration around the changes which have been introduced. Given the general discontent that existed with the original forms - we would have welcomed more consultation around the look of the new forms before their introduction. This appears not to be happening

Recommendation: The Authority takes a more collaborative approach when reviewing its processes and procedures. We request formal feedback be provided on the results of any evaluations we have participated in and we request input and/or consultation regarding any changes proposed as a result of the evaluation and prior to their implementation

# 8. Interface with Vocational Rehabilitation

A procedural conflict exists for those participants on a centrelink payment who have been assessed as ready and appropriate for vocational rehabilitation. Although LTCS has approved vocational rehab programs for these participants and will fund them, Centrelink still demands a Job Capacity Assessment as per its protocols. This seems highly unnecessary

<u>Recommendation:</u> The Authority engages in discussions and liaison with Centrelink to establish a collaborative and mutually agreed way of dealing with participants on the scheme to avoid unnecessary assessments and processes.

# 9. Equipment hiring

It is our experience that although items of equipment have been approved by LTCS for purchase for a participant, that there is often a lag period before the equipment is available due to ordering, delivery times, etc. In these scenarios, we request hire of equipment on a short term basis until the definitive equipment is available. LTCS currently expects us to resubmit requests forms for the hire which contains exactly the same justification as the original request for the definitive equipment. The authority will not accept a request for purchase and hire on the same request form. This results in unnecessary duplication of work.

Recommendation: The Authority adopts a more flexible, common sense approach to requests such as this where the justification has already been acknowledged and accepts the original requests as justification without need for repeat paperwork

The Westmead BIRS is grateful for having been given the opportunity to make a submission to the second review of the LTCSA. In this submission we have attempted to be balanced in our feedback — highlighting both positive aspects of the scheme as well as areas of ongoing concern. We hope that the information provided is clear and understood and that the recommendations made are received constructively and found to be useful. We look forward to continuing to work closely with the LTCSA for the ongoing benefit and outcomes of our mutual clients.

Yours Sincerely,

Dr Joseph Gurka

Head, Brain Injury Rehabilitation Service

Westmead Hospital