Submission
No 10

SECOND REVIEW OF THE LIFETIME CARE AND SUPPORT AUTHORITY

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GENERAL SUBMISSION TO THE LEGISLATIVE COUNCIL STANDING COMMITTEE ON LAW AND JUSTICE INQUIRY: THE SECOND REVIEW OF THE LIFETIME CARE AND SUPPORT AUTHORITY.

RESPONSE FROM THE GREATER METROPOLITAN CLINICAL TASKFORCE MAY 2009

The Greater Metropolitan Clinical Taskforce (GMCT) has been established to promote clinician and consumer involvement in planning and health service delivery. Our ongoing commitment to improving health care in NSW is based upon the principles of clinical governance with a focus on developing services based on clinical need, quality of care and safety for patient equity of access and equity of outcome within the hospital system and clinician / consumer driven planning

Through the twenty clinical networks chaired by clinicians and involving doctors, nurses, allied health professionals, scientists, managers, and consumers we identify how and where improvements can be made in the particular specialty and implement these changes in association with NSW Health and the Area Health Services. The two clinical networks that are closely involved with LTCSA are Brain Injury Rehabilitation Directorate (BIRD) and the associated network of Brain Injury Rehabilitation Program (BIRP) services and the State-wide Spinal Cord Injury Service (SSCIS).

1. Some positive outcomes for LTCS participants from GMCT perspective

The introduction of the LTCS by the NSW Government funded by levies on the CTP insurance premiums has been a very important and most welcome change in the provision of no-fault funding for supporting treatment, rehabilitation and lifetime care costs for people who have been severely and permanently injured in motor accidents.

The benefits of insurance funding being available immediately through the LTCA support scheme rather than the victim having to await the outcome of an often lengthy court case, are far reaching in terms of facilitating discharge from hospital with appropriate support and community participation. The benefits to society of a greater number of people being eligible on a no-fault basis and the possible impact on hospital length of stay and timely access to social support services in the community are important.

There are well developed guidelines regarding service delivery procedures, eligibility criteria and so on. Existence of the LTCSA has also had indirect system benefits supporting collaborative development of various key guidelines with other agencies, such as NSW Health, DADHC and Enable NSW.

The introduction of the LTCS has enabled people with severe brain injury to access and receive non health services as part of their recovery and rehabilitation. This has supported continuity of care across different health settings and in the community resettlement phase post hospital discharge.

Access to equipment, home modifications and importantly to support services (e.g. attendant care) for people returning to live with families had been a primary barrier for people without insurance and where insurance liability was not accepted.

2. Some general difficulties experienced by GMCT with the LTCS Scheme

Workload

From a health provider perspective, there appears to be excessive bureaucracy burdening clinicians with increased paperwork, and lengthy and repetitive forms, distracting them from direct clinical time with patients. Bureaucracy also delays responsiveness impacting upon the system's ability to meet the health needs of patients in a timely manner, in particular in crisis situations faced by community based clients requiring emergency treatment and subsequent changes to the agreed plan of care. Bureaucratic inflexibility and delays have increased the gap between LTCS and non LTCS eligible clients, with greater delays experienced in approvals for clients under the LTCS scheme.

Concerns have also been expressed by clinicians that there is inconsistency in the processes followed by LTCS coordinators resulting in variability between coordinators and their response to the information provided by clinicians, and inequality in the approval processes. They have also expressed the view that coordinators are micromanaging at the clinical level and directing care delivery through the approval or non approval of recommendations made by clinicians. Specific

Difficulties experienced by NSW BIRP include:

- The LTCS has been introduced as a change to the existing CTP infrastructure and NSW Health services that is externally driven. This appears to have resulted in differences in the collaborative approach than occurred in previous insurance driven health service changes. There has been enormous goodwill on both sides regarding the introduction of structural changes to ensure that the LTCS is successfully integrated into NSW Health services.

- The NSW BIRP's definitely struggle to meet LTCS timelines and deadlines. NSW BIRP allied health staff needs to be identified as critical to the recovery and rehabilitation pathways of people with TBI to maintain capacity and be able to meet LTCS service expectations. Reduced allied health staff workload capacity reduces revenue. Different Area Health Services deal differently with revenue and responses to changing workload needs with very few programs receiving additional resources to manage additional workload. This approach does not support increasing capacity for increased earnings. There needs to be a way in which BIRP teams are able to access revenue to increase workload capacity by increased staff resources to meet service requirements as the LTCS load increases.

- The NSW BIRP's experience difficulties with LTCS participants when planning discharge from hospital and community resettlement. Key factors are the increased workload arising from the introduction of LTCS combined with reduced workload capacity and in circumstances where there is a lack of service support infrastructure.

- The community discharge plan (CDP) provides the paperwork to request services to facilitate a participant's discharge from hospital home and to their community. BIRP staff is required to have the CDP approved by the discharge date for LTCS participants or there is the risk of an interruption in the recovery, rehabilitation and resettlement process. LTCS have 7-10 days to provide a response further limiting the time available to BIRP staff to complete assessments and develop a team approach to community discharge planning.

Formal relationship

- There is no Memorandum of Understanding to provide the ethical framework that encapsulates confidentiality and privacy, sharing outcomes and data, identifying service expectations goals and responsibilities within identified timeframes.

Revenue

- The prior DOH/MAA memorandum of understanding acknowledged the implementation costs to NSW Health and provided funds to support structural changes. LTCS are providing NSW Health revenue on a fee for service basis and there is no link to access revenue for service enhancements. The statewide reduction in NSW Health staff numbers to manage budgets has compromised the NSW BIRP's ability to respond to the workload changes for the LTCS within current resources.

Recommendations and Suggestions
That the LTCS and NSW Health consider a memorandum of understanding that addresses these 3 areas. The previous MOU with MAA and NSW Health successfully established the Brain Injury Rehabilitation Program by clarifying systems and processes within the partnership.

3. Some specific difficulties experienced by BIRP's with Community Resettlement

Accommodation services gap

- The provision of supported accommodation for people with TBI for whom family care arrangements are not possible is a discharge planning issue. These individuals can remain in the acute rehabilitation ward for some time after rehabilitation goals are achieved or are discharged to local hospitals to manage the issues without specialist support.

  The supported accommodation expert advisory group established by the LTCS has not been convened for some time. Developments in this area are ad hoc and individual rather than within an identified framework with a process for bridging the gaps. Individual solutions are time consuming for staff and delay hospital discharge while appropriate alternatives are explored, negotiated, approved and implemented

Recreation and leisure

The definition of recreation and leisure in the LTCS Consultation Paper 19 March 2009 is restrictive. In this paper the definition of leisure is "...free of commitment, duties or responsibilities ....(and) Recreation is defined as 'an activity done for pleasure or relaxation" or refreshment of mind....through activity that amuses'...." The focus of the guidelines discussion is the funding of recreation and leisure activities and participation on the basis of ".....artistic, creative, cultural, physical, sporting, play, social and skill based activities."

- There is a need to recognise the importance of recreation and leisure services for LTCS participants who are not able to return to vocational employment or education as a result of the injury severity.

- There are limited opportunities for the LTCS participant with significant and permanent loss of skills to independently maintain and enhance their living circumstances, develop and sustain social and community relationships and participate in community life when employment and further education is no longer an option.

- There is a need for some LTCS participants to access and maintain participation in existing and new programs matched to their skills and interests.

- Participation in recreation and leisure activities can provide a structured therapeutic environment for LTCS participants to manage everyday life situations while continuing to recover and develop the skills for a return to education and vocational employment.

Community Participation

- People who as a result of their injury severity are unable to achieve a return to work or education but require different opportunities to achieve meaning in their lives and maximum social participation over years/their lifetime.

- There is a need to include descriptions supporting long term social outcomes into the guidelines and procedures for requesting treatment, rehabilitation and attendant care support for LTCS participants. The transition from community resettlement and goal focused rehabilitation services to living in the community with longer term care and support needs is not clearly identified. Many individuals after TBI will need support over many years and not just at the point of integration into the community.

Recommendations and Suggestions
That the community resettlement workload issues for NSW BIRP's be addressed in the MOU as suggested above. The gaps in accommodation, recreation and lifestyle support continue to be addressed through the existing GMCT: BIRD and LTCS liaison meetings and the Interagency Agreement that involves LTCS DADHC Dept of Housing and NSW Health.

4. The Definitions and Payment Codes for treatment and rehabilitation services provided under LTCS

Counselling

The general definitions and payment codes do not address the specific need to provide the individual, couple and family relationship counselling to address the changes to the person. These changes affect relationships with others, the need to receive specialist support to maintain pre-injury relationships and develop new relationships. Services will be provided primarily by social workers and relationship counsellors with individual and group work.

Sexuality

The general definition includes physical and psychological assessment and intervention. This area is relevant to all LTCS participants regardless of the injury type. It is also a specific issue for people with TBI who may need specialist intervention to address specific physical, cognitive, communication and social behaviour that result in changes in sexuality and the ability to form and maintain relationships. Service types include medical tests for function, and therapy involvement for adjustment counselling, education and support.

Lifestyle support

The payment codes and general definitions do not address the long term lifestyle needs of people with significant changes in physical, cognitive, behavioural, communication, and social participation skills and who cannot interact with others in a variety of settings without support.

Services can reflect pre injury interests or new interests and opportunities matched to skills. The goal is for achieving and maintaining long term social engagement. Service support is facilitated (e.g. within a lawn bowls club or art class without one to one support) or service support is provided (e.g. with one to one as part of attendant care or family care arrangements).

Recommendations and Suggestions
The addition of at least 3 codes is added to (F) Care and Support Services as being relevant across the lifespan of the LTCS participant is supported. ▪ Current payment codes are task focused and do not address the accumulated effects of brain impairment that can result in poor social outcomes. The result is a lack of scope for codes to reflect the lifelong nature of brain impairment and the care and support services required with changing circumstances to achieve and maintain social participation.

5. **Difficulties identified with Community Awareness and education about LTCS**
Prior to the introduction of LTCS in 2006 (for children) and 2007 (for adults) there were a number of consultations for information and education across NSW. Since the introduction of LTCS the E Bulletin has provided ongoing information across a broad section of the community. However, there continue to be situations where non specialised providers are not aware of the LTCS Scheme, the request and approval procedures and processes.

This issue was raised last year at the first review and while further education has occurred there are continuing issues of lack of awareness. Some of these issues will resolve as more providers are involved with LTCS participants and obtain experience with system processes.

- Delays in notification are occurring when management occurs at a regional hospital or across the border e.g. Injury in Greater Southern AHS but retrieval is to ACT with return to NSW when medically stable and notification has not occurred.

- Service providers are using incorrect approval numbers when plan periods have expired but the approved treatment is not complete.
  - There may be the opportunity to manage the interface between administrative requirements that do not disadvantage the participant or interrupt continuity of care.

- Some LTCS participants do not have readily available information about their participation in LTCS when visiting service providers and treatment /services are not pre approved.
  - An ID card for accepted LTCS participants so they learn to present it to service providers may be useful

- Some service providers do not have clear processes in place for managing the service request approval and billing processes to ensure services start and continue in a timely manner following referral.

Recommendations and Suggestions
Further education and public awareness forums be conducted by LTCS across NSW and in particular in rural areas and cross border locations. Print material about LTCS is made available at strategic locations e.g. Patient information stands.

6. Data collection

There is a greater requirement within NSW BIRD for statewide clinical and service related data with the introduction of the LTCS scheme.

There is a need for data system infrastructure in NSW Health and in the NSW BIRP network to be further developed to meet the current and future needs of NSW Health, other insurers and LTCS. Comprehensive and efficient information management systems will be able to provide information to LTCS and allow for improved evaluation and service developments for NSW Health and GMCT: BIRD.

Recommendations and Suggestions
That NSW Health and LTCS explore options to further develop statewide data collection systems within an agreed framework that supports data sharing between GMCT: BIRD and Brain Injury Rehabilitation Programs for LTCS participants..