

**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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Brain Injury Rehabilitation Directorate (BIRD)

**Re: Legislative Council Standing Committee on Law and Justice
3rd Review of the Lifetime Care and Support Authority and 10th
review of the Motor Accident Authority**

The Brain Injury Rehabilitation Directorate (BIRD) welcomes the opportunity to respond to the 3rd review of the Life Time Care Authority (LTCS). This is the third year that members of the BIRD and clinicians in the NSW Brain Injury Rehabilitation Program (BIRP) have made representation, in person and in writing to the standing committee. The opportunity provided by these Reviews to voice concerns discuss options and see the issues reflected in the final reports and recommendations are greatly valued.

Since the Second Review the LTCS has continued to work closely with the Brain Injury network to resolve issues arising from the interface between the scheme and public health services to improve any participant issues for rehabilitation treatment and support. The BIRD and LTCS Liaison meetings continue. Additionally, the LTCS initiated a process of inclusion for developing the new adult discharge procedures that were introduced in March 2010. Already apparent is an improvement in the continuum of care from inpatient to home for participants with some reduction in the administrative workload experienced by NSW BIRP clinicians during this phase of rehabilitation.

LTCS has acknowledged that there is a need to complete a similar process for paediatric rehabilitation services for children and young people who often have significantly reduced inpatient rehabilitation stays before returning to the family home so providing the level of detail required to complete the current forms in the timeframes provided before discharge can be problematic. This can result in a period of time where rehabilitation is provided before approval is received. It is anticipated that a review of the process and pathway will improve completion of LTCS processes and reduce the burden on clinicians while ensuring that the continuum of care is maintained for participants. Additionally, the BIRD appreciates the opportunity to provide comment and feedback on the draft guidelines for buying into the LTCS. There have been significant numbers of NSW BIRP clients who have received insufficient lump sum compensation.

The BIRD has reviewed the Second Review Recommendations and the NSW Government Response:

1. Supported accommodation remains an issue of concern for people with TBI who are unable to return to their pre injury living arrangements. The expert advisory group has not been reconvened. There is a gap in housing availability as a hospital discharge destination and a gap in service providers to manage the transition from hospital based rehabilitation and treatment to community living arrangements. Rehabilitation partnerships are a key factor during this resettlement phase to provide specialist expertise to establish care and support structures and improve social participation. Service providers are required to work closely with the rehabilitation team to maximise recovery and reduce activity limitations.

- LTCS is developing options to improve availability of accessible housing and has commenced working with community housing providers. However these developments are in response to individual circumstances and are slow to implement.
 - Community housing providers generally have limited knowledge skills and experience working with people with high care needs following TBI and the specialist knowledge to maximise recovery by incorporating rehabilitation programs into everyday living. This requires new skills for staff to work as part of the rehabilitation team to enhance rehabilitation goals and is not easily understood by staff from a disability or aged care background.
 - Individual solutions lack consistency in service planning and are not readily and equally available. Inpatient stays are extended or inappropriate housing is obtained while solutions are being developed. There is a need to establish homelike transitional solutions for LTCS participants to continue to improve and live in the community while individual long term solutions are established.
 - Transitional services for people with high care needs after TBI can reduce inpatient rehabilitation stays and provide appropriate rehabilitation care and support as further recovery occurs at the same time social and community living opportunities and networks are established. Challenging behaviour can occur when the individual is living in inappropriate housing or managed without consideration for the consequences of TBI.
 - There is a need to improve the knowledge and skills of staff working with people with high care and support needs after TBI by the provision of a range of learning materials, training opportunities and the establishment of minimum standards of workers to work with people with TBI who have personal, communication, cognitive and behaviour changes impacting on their independence and skills.
 - Service standards need to be developed that are evidence based to ensure that supported accommodation services address the complex care and support needs specific to LTCS participants with adjusting to the impact of TBI in all aspects of their lives.
2. NSW Health provided the completed report on the review of the impact of the LTCS on health service resources with input from the BIRP in each AHS. Approximately 75% of LTCS participants have a TBI and it is important to manage the infrastructure demands that resulted from the implementation of the LTCS on the NSW BIRP clinical services. There remains inconsistency across AHS's in responding to the additional resource requirements within the NSW BIRP network to manage the additional clinical and administrative burden of the LTCS.

The report included a number of recommendations and we offer additional comment:

- That LTCS provides a lump sum payment to enable specialised services to meet their particular requirements for billing, reporting and clinician involvement for data and administration system development. This recommendation is supported and we would suggest it is implemented over a 2 year period by involving a project officer with NSW Health financial systems knowledge to collaborate on resolving fees, billing and financial systems to achieve consistency across the state network to ensure billing matches services.

- The BIRD is convening an advisory group that will attempt to address issues for fees and funding strategy issues identified in the NSW Health report. The BIRD advisory group can include LTCS and the Spinal Network and operate as a steering committee for resolution of these issues and support a project officer.
 - The BIRD welcomes the opportunity to resolve case management services issues and a review of the fee structure for cost recovery. This would provide the opportunity to clarify the interface between the different types of case management that is experienced by the person as they move through the different stages of recovery and rehabilitation to service provision and life planning. It is our understanding that LTCS will convene these meetings and involve experts from brain injury and spinal sectors.
 - The BIRD supports a lump sum payment from LTCS to achieve infrastructure growth and recognises the importance of utilising recurrent revenue to manage the impact and growth of LTCS demands into the future. The BIRD is developing a brief for NSW Health to consider recurrently using revenue in a different way to ensure access and equity across the state network so that service provision can occur at levels that meet clinical need for those with severe TBI as a result of motor vehicle injuries across NSW.
3. The BIRD welcomes the request of the Minister for Finance that LTCS Authority prepare a proposal to include two participant representatives on the LTCSA Council. The BIRD is one of approximately 20 networks of the NSW Agency for Clinical Innovation (Formerly GMCT) with a commitment to clinician and consumer involvement in health planning as equal partners. The ACI includes a consumer network manager and has an established system for recruiting, involving and supporting consumers. This information and experience would willingly be shared with LTCS in the development of the proposal. The planned forums in 2010 would enhance the LTCSA understanding of the consumer issues and facilitate an informed approach for consumer participation in the LTCSA.
 4. The BIRD supports the scope of recommendation 7 in addressing recreation and leisure as a critical avenue for psychosocial rehabilitation goals in the post injury phase of recovery to provide everyday situations for therapeutic intervention. However, it is important that the guidelines do not ignore the shift from a therapy focus to utilising successful strategies in life planning as it is integral to Life Time Care. This enables the participant to remain engaged in the community as a person with disability with severe cognitive or other TBI sequelae. There are now some LTCS participants who require the psychosocial rehabilitation strategies to be maintained long term. Clinicians and consumers in the BIRD network would appreciate being involved in the review process for ensuring that the guidelines are responsive to these circumstances.

Issues for the 3rd Review of the LTCS presented by the Westmead Brain Injury Rehabilitation Service

The Westmead Brain Injury Rehabilitation Service (WBIRS) appreciates the opportunity to provide feedback to the third review of the LTCSA. WBIRS is one of 11 adult programs that has been providing services to interim and lifetime participants of the Lifetime Care Scheme (LTCS) since October 2007. The WBIRS working group wish to report the following positives and negatives of the scheme to the Standing Committee on Law and Justice from

the perspective of a specialised service provider. We have aimed to identify both positive aspects of the current scheme and areas of concern in a constructive manner and look forward to continuing to work closely with the LTCSA with the intent of enhancing outcomes for our mutual clients.

The April LTCS Newsletter indicated that 78% of participants have had a brain injury. The majority of these were adults. Given these statistics, we wish to highlight the importance of an ongoing, collaborative partnership between Lifetime Care Scheme Authority (LTCSA) and the NSW Brain Injury Rehabilitation Directorate and individual Brain Injury Rehabilitation Services, including WBIRS, with the goal of providing the reasonable and necessary rehabilitation services for and with participants and their families.

POSITIVE ASPECTS

1. Increased Access to Rehabilitation Services

Since the introduction of the LTCS the percentage of WBIRS patients and clients who are able to access therapy, care and equipment after hospitalisation has significantly increased. This has been a positive outcome for people with catastrophic brain injuries from motor vehicle accidents. The other significant group of patients admitted to WBIRS have severe head trauma due to assaults, falls and sporting injuries, continue to have difficulty accessing home and community based rehabilitation and care services after their hospitalisation.

Recommendation: Expansion of the LTCS scheme to other people with severe head trauma.

2. Services for Families

We continue to be pleased with the preparedness of the Authority to acknowledge the impact of catastrophic injury, particularly brain injury, on the family unit and approve services for family members. Such services are crucial to the rehabilitation outcomes of patients/clients.

Recommendation: Continued LTCSA support of services for the family unit as a vital component of the rehabilitation program of the person with the injury.

3. Leisure Discussion Paper

We commend the Authority on producing the discussion paper on leisure and await its finalization and further discussion. The Authority's recognition 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 is highly valued. Ability to engage in a leisure role, as one of many life roles, contributes significantly to participants' perceived quality of life following brain injury.

Recommendation: The Authority will accept responsibility to financially support goal oriented programs which facilitate participants' skills and engagement in leisure activities.

4. Evaluation and Reviews

The commitment of LTCSA to evaluation and review is commendable. LTCSA has actively sought feedback on its processes and forms and used this feedback to make changes and improve the systems in place. The Discharge Notification Form was a positive outcome of a collaborative, focused group of representatives from LTCSA, brain injury and spinal injury

services which will improve the efficient discharge of inpatients to community rehabilitation services.

LTCSA has recently established the Equipment Group which is developing a discharge equipment loan pool, as a collaboration between LTCSA, brain injury and spinal cord injury services. Additional groups including a case management and attendant care group are proposed in the future.

As another component of its collaborative evaluation and review process, LTCSA has participated in the Liaison Group established with the Brain Injury Rehabilitation Directorate of NSW.

Recommendation: LTCSA continues its commitment to evaluations and reviews, including the establishment of collaborative working parties, and its receptiveness to feedback on an ongoing basis. The LTCSA ensures that it provides timely documented feedback to BIRS on the outcomes of evaluations and reviews, and requests input and/or consultation regarding any changes proposed as a result of the evaluation and prior to their implementation.

5. Newsletter

The LTCSA is commended on its monthly newsletter which keeps all relevant stakeholders informed of the latest statistics, developments, training activities and changes within the scheme, including its forms and processes. It is the key source of our information on LTCS.

Recommendation: The Authority continues its monthly distribution of the newsletter.

6. Expansion of LTCSA

The increase in staff numbers at LTCSA and the location of an office at Parramatta has increased accessibility to participants in Sydney's west. It acknowledges the geographic spread of people with brain injuries and increases the potential for enhanced communication between WBIRS and LTCSA staff for the benefit of participants.

7. Supported Accommodation Options

LTCSA is proactively seeking a range of supported accommodations options for adult participants with brain injuries. LTCSA is also supporting the limited range of accommodation options currently available. This remains an area of high need.

AREAS OF CONCERN

1. Increased Workload

The requirements of LTCSA have continued to significantly increase the workload of service provider health professionals across the WBIRS, the Inpatient, Transitional Living Unit, Community Rehabilitation and Outreach teams. Although LTCS forms and processes have been revised, the amount of time team members spend on meeting the requirements 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 2.5 years has only marginally reduced the time spent in these activities. Accessing co-ordinators in a timely manner is frequently a difficult and time consuming task for staff members which adds to their workload and may delay the submission of requests to LTCSA for participants and consequently their discharge. The same issues arises when co-

ordinators are on leave, as WBIRS staff are not provided with an alternate co-ordinator to contact.

It is important to note that there was no additional resourcing of service providers to cope with the additional load resulting from the implementation of the scheme. To protect the clinical time therapy staff needs to give to patients/clients, it is crucial for our service to have additional resources to assist with LTCS matters.

Of note, due to the current very limited staffing and therefore capacity of the WBIRS Community Rehabilitation Team to provide home and community based therapy services for participants, a significant number of participants have been referred to private services following discharge from the Inpatient Unit and TLU.

Recommendation: 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 LTCSA without compromising therapy programs. This is a high priority given the potential for LTCS to be expanded to include all patients/clients of the WBIRS in the future.

2. LTCS certificates given to participants with severe brain injury

As identified in the second review, the detail currently provided on the participant certificates, particularly the inclusion of LTCS codes, approval numbers and costs continues to be counterproductive for many participants due to the impact of their brain injury on their cognitive, communication, psychological, psychosocial functioning. This issue has been summarized here. Please refer to the 2009 submission by Dr Joe Gurka, Director WBIRS, for details.

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 to enhance 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 liaises with the NSW BIRD Directorate Liaison Group regarding the redesign of participant certificates.

3. Dispute Resolution Processes

Although refinements have been made to the dispute resolution system which has enhanced the process, further revisions are recommended, particularly to the documentation provided by LTCSA and its processes.

Recommendation:

- i The LTCSA reviews the wording of the letter declining approval of services to ensure clarity with the participant.
- ii The LTCSA reviews its dispute resolution processes to ensure that information documented in the dispute resolution letter sent to the participant accurately reflects the LTCSA decision not to approve a request submitted by a rehabilitation service.
- iii LTCSA processes include a letter to the service provider identifying the outcome of the dispute resolution process.
- iv There is a transparent documented process to enable discussion between the LTCSA 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 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 / their person responsible being placed in the position of having to decide whether or not to initiate dispute resolution processes with the LTCSA.

4. Approval Processes

WBIRS acknowledges that benefits have ensued from the refinements to the approval processes. However WBIRS continues to have a number of concerns around approval processes

- i) Time frame a). LTCSA currently has a 10-day timeframe to assess and decide on requests/applications. On occasions, it is essential that a more timely decision is made because of eg., a need to facilitate a timely discharge and/or engage other services e.g. builder, care agency.

Recommendation: The LTCSA establishes a prioritization system to enable urgent requests to be approved in less than 10 days.

Time Frame b): An increased trend has been noted that submitted requests are taking LTCSA longer than 10 days to make a decision, requiring follow up by clinicians. A number of instances have arisen in which LTCSA Coordinators have not received requests which have been submitted in a timely manner via the required email address.

Recommendation: LTCSA to review both the approval processes and reliability of the email address for electronic submission of requests.

- ii) Informing service providers: Rehabilitation services are informed of the outcome of a request or application submitted and justified by them, via receipt of a copy of the certificate/letter from the Authority to the participant.

Recommendation: LTCSA directly communicates with rehabilitation services 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 letter on LTCSA letterhead.

- iii) Informing suppliers: There continues to be no formal system for LTCSA to inform suppliers such as equipment suppliers, private therapists or other service providers eg lawn mowing businesses, organizations providing relative accommodation, of LTCSA approval of their services. Currently rehabilitation team members inform such suppliers which increases their workload. 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 LTCSA letterhead before they will provide a service or equipment item.

Recommendation: The Authority provides formal notification of approval to suppliers either by letter on LTCSA letterhead or via the approval section at the end of LTCS

request forms. This formal notification can be returned to the rehabilitation service, (as recommended in (ii)) and the rehabilitation service can in turn forward these on to the relevant suppliers. It will be important that there is an approval letter per each supplier.

- iv) Administrative support for suppliers and external service providers: Currently there are no administration personnel for suppliers and external service providers unfamiliar with the LTCS to contact to obtain information and assistance in establishing accounts and invoicing. This information provision is currently provided by necessity by rehabilitation staff. WBIRS has received reports of missed and late payments as a result of inadequate supplier knowledge of the LTCS system, and family members receiving phone calls from suppliers requesting payment.

Recommendation: LTCSA establishes administration support for suppliers and external service providers to ensure accurate and timely information relevant to their needs. This may include a 'hot line' to explain LTCS processes including the invoicing system and, to respond to supplier queries.

5. Supported Accommodation Options

Although progress has been made by LTCSA in increasing supported accommodation options, the options remain extremely limited and there is an urgent need for expansion. This has resulted in an increased length of stay in the Inpatient Unit or TLU for some participants which also has the potential to impair their rehabilitation.

Recommendation: The Authority urgently establishes/expands partnerships with Department of Housing and other private agencies to have a range of solutions and options across geographical areas for participants in need of modified housing and supported accommodation. LTCSA to establish a clear referral system, process and criteria for participants who require this style of accommodation.

6. Attendant Care

The provision of attendant care services continues to be a vital component of LTCSA funded services for participants. WBIRS continues to experience a range of concerns regarding the provision of attendant care services to participants. Please refer to the 2009 submission by Dr Joseph Gurka, Director WBIRS for details. The key ongoing concerns are:

- Delays in carer recruitment and inadequate training, including concerns relating to LTCSA funding participant specific training;
- Confusion and lack of clarity about attendant carer roles and appropriate tasks;
- Professional behaviour;
- Inconsistency in program implementation;
- Issues with the timetables required for the Care Needs Assessment;
- Communication channels between service providers, LTCS and care agencies;
- Lack of clarity about responsibility for attendant carer expenses.

Recommendation:

LTCSA continues current action to gather information about the provision of attendant care.

LTCSA to review and improve the process and time frames of implementing care from the time a Care Needs Assessment is submitted to the ongoing implementation and re-assessments of care in the home.

LTCSA to liaise with ACiA and BIRS about establishing improved education programs in TBI which aim to improve the core knowledge and skills of carers working with participants who have a brain injury.

LTCSA facilitates a forum to explore current issues relevant to the provision of attendant care services and establishes a working group to address these issues.

7. Equipment hiring

Delays continue to be experienced in the availability of equipment that has been approved by LTCSA for purchase for a participant, eg. due to ordering, delivery time and other issues. In these scenarios, we request hire of equipment on a short term basis until the definitive equipment is available. LTCSA currently requires resubmission of the request forms for the hire which contains the same information including 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 accepts the original requests as justification for equipment hire without the need for repeat paperwork.

8. Pharmacy Accounts for Participants

WBIRS supports the approval of pharmacy accounts by LTCSA for participants, for injury related medications. The pharmacy account eases the practical and financial burden on a participant and / or their family in paying for medications initially and avoids the need to seek reimbursement via a 'Participant Expense Claim Form'. Inconsistencies in processes for establishment of accounts are noted however, particularly when the need for these accounts is identified outside of when LTCSA rehabilitation plan documents are being completed (e.g account is required prior to discharge such as when a participant is engaged in a Transitional Living Unit program, and therefore can not be included on the 'Discharge Notification Form', and alternative documentation of the request is required). These inconsistencies can result in participant and family stress and an increased workload for WBIRS staff involved in following up the request for the approval an account, which is typically required in a prompt and timely manner.

Recommendation: The Authority develops a short, user-friendly 'Pharmacy Account Request Form' to be utilised by the treating team, to request approval for set-up of a pharmacy account for a participant's injury-related medications and pharmaceuticals.

9. Newsletter

Although the monthly newsletter is largely a highly valued LTCSA product, the inclusion of participant examples which neither clearly identify the complexity of the issues experienced by participants & their families nor the rationales for approval/not by LTCSA results in confusion and potentially inaccurate information.

Recommendation: The Authority excludes participant examples from its monthly newsletter and seeks alternative methods to address issues that arise.

10. Accessibility of Coordinators

WBIRS acknowledges the overall collaborative working and communication that occurs regarding LTCS participants and their medical, rehabilitation and / or care and support needs. Challenges are however noted in being able to consistently access Coordinators via telephone and / or email in a timely manner, with variability in response times. From a rehabilitation perspective, this can impact negatively on ongoing service provision due to potential delays in being able to address participant needs. This is particularly a concern when the need to liaise with a Coordinator is regarding an urgent issue.

Recommendation:

The Authority reviews the overall availability of Coordinators to attend to phone / email enquiries, on a daily basis.

The Authority reviews processes for service providers to be able to contact Coordinators for issues of an urgent nature, including options for contacting an alternative Coordinator, when the participant's nominated Coordinator is unavailable due to other commitments or on leave.

Other issues for consideration in the 3rd review of the LTCS

- The regular meetings with BIRD and LTCS continue providing the opportunity to recognise and respond to challenges. This collaborative approach is required to continue discussing identified issues and address other issues not covered in detail at the Second Review. The LTCS has utilised special meetings of key stakeholders around issues of concern and this can be an effective and meaningful process for addressing geographical service delivery issues, education support and access to vocational and employment related services. Case management and supported accommodation are 2 issues where this process has commenced and although not completed it does provide clinician engagement for developing practice guidelines to respond to participant need.
- The Kaleidoscope Paediatric Brain Injury Rehabilitation Team is developing a submission that will focus on 2 key issues
 1. Equipment and modifications when discharging an adolescent
 2. The working arrangement with LTCS paediatric coordinators when one is located in Newcastle with geographical limits and the remainder are located in Sydney.

The PBIRT Manager, Matt Frith has been given an short extension to provide this information so it will be submitted separately.

Submission prepared by
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