

**INQUIRY INTO THE EXERCISE OF THE FUNCTIONS OF
THE LIFETIME CARE AND SUPPORT AUTHORITY AND
LIFETIME CARE AND SUPPORT ADVISORY COUNCIL -
THIRD REVIEW**

Organisation: Kids Rehab, The Children's Hospital at Westmead
Name: Ms Helen Chew (Coordinator Brain Injury Service), Dr Angie
Morrow (Head of Brain Injury Services) and Dr Stephen
O'Flaherty (Head of Kids Rehab)
Telephone: 9845 0000
Date received: 30/04/2010

RECEIVED

30 APR 2010

LAW & JUSTICE

the
children's
hospital at Westmead

Rehabilitation Department

Corner Hawkesbury Road
and Hainsworth Street
Locked Bag 4001
Westmead NSW 2145
Sydney Australia
DX 8213 Parramatta
Tel +61 2 9845 0000
Fax +61 2 9845 3489
www.chw.edu.au
ABN 53 188 579 090

14 April 2010

The Chairperson
NSW Parliament Legislative Council
Standing Committee on Law and Justice

Re: Submission to Third Review of the Lifetime Care and Support Authority (Inquiry)

Dear Sir or Madam

Please find enclosed our submission to the Third Review of the Lifetime Care and Support Authority (Inquiry).

The Brain Injury Service, Kids Rehab, The Children's Hospital at Westmead wishes to take this opportunity to highlight both strengths and issues of concern which impact on the delivery of timely and appropriate rehabilitation and support services to Paediatric participants of the Lifetime Care and Support Scheme.

Where appropriate we have provided case examples to illustrate some of the issues that continue to frustrate the provision of care to those severely injury children that are eligible to be participants of the Lifetime Care and Support Scheme.

We would be happy to provide further information to the Inquiry where required.

Yours sincerely



Helene Chew
(for the Brain Injury Service)
Coordinator Brain Injury Service
Kids Rehab



Angie Morrow
Head of Brain Injury Services
Kids Rehab



Stephen O'Flaherty
Head of Kids Rehab

Kids Rehab The Children's Hospital at Westmead

Submission to the: NSW Parliament Legislative Council Standing Committee on Law and Justice Third Review of the Lifetime Care and Support Authority (Inquiry)

Submitted by:

- Helene Chew
Coordinator
Brain Injury Service
Kids Rehab
Email: helenet@chw.edu.au
- Dr Angie Morrow
Head of Brain Injury Service
Kids Rehab
Email: angiem@chw.edu.au
- Dr Stephen O'Flaherty
Head of Kids Rehab
Email: stepheno@chw.edu.au

On 29 April 2010

Executive approval by:

- Ms Cheryl McCulloch
Director of Clinical Operations
The Children's Hospital at Westmead



Contents	Page
Introduction	3
1 Positive Outcomes	3
	3
1.1 Timeliness of responses to requests	3
1.2 Timing of Plans	3
1.3 Introduction of LTC Coordinators	4
1.4 Recreation and Leisure	4
1.5 Discharge Process	
2 Issues of Concern regarding LTCSS	4
2.1 Decision making process of LTCS	4
2.2 Educational Support	7
2.3 Relationship between the LTCSA and CTP Scheme	8
2.4 Privacy and Confidentiality of Personal Participant and Family Information	9
2.5 Health Service Resources	9
3 Support of Department of Education and Training	10
Conclusion	10

Introduction

The Brain Injury Service (BIS) is a part of Kids Rehab (formally the Rehabilitation Department) at The Children's Hospital at Westmead providing care to over 600 children and young people in 2010 with traumatic and non-traumatic brain injury.

The Brain Injury Service has provided care to 24 children and young people who have been eligible to be participants of the Lifetime Care Scheme (LTCS) since its commencement in 2006.

The children and young people who meet criteria to be eligible for entry to the Lifetime Care Scheme require a significantly greater proportion of administration time and case coordination from the Brain Injury Service in addition to their clinical rehabilitation needs than other children seen for Rehabilitation. This has created what is now an almost untenable administrative burden on clinical staff.

The Brain Injury Service continues to be in active communication with staff of the Lifetime Care Scheme participating in working parties targeting processes, information sharing and service delivery, in addition to several research initiatives.

The following submission details a select number of issues that take greater priority and concern for The Brain Injury Service as we provide care and rehabilitation to the severely injury children and young people who are eligible to participants of the Lifetime Care Scheme.

1. Positive Outcomes Working with the Lifetime Care and Support Authority

1.1 Timeliness of responses to requests

Case managers note that overall the timeliness of responses to requests for services are being consistently met by the Life Time Care for the benefit of the client.

1.2 Timing of Plans

The ability of Case manager to negotiate the timing of community care plans is important as it reflects the changing need of the client and assists in coordination of services for the client. Being able to negotiate to lengthen the plan period that is in place provides flexibility to allow revision of services and planning for future services in a more time efficient manner.

1.3 Introduction of LTC Coordinators to New Inpatients (recommendation 4 from Summary of recommendations, 2nd Review of the LTCS)

The consultative process between the treating rehabilitation team and the Lifetime Care and Support Authority has improved overall with greater understanding of roles and understanding of the duty of care which guides the practice of these organisations. Given the enormous emotional strain to the family and the sensitive nature of the time surrounding a newly injury child or young person, the direction of the treating team as to the timing for introduction to the LTCS and hence, the LTCS coordinator continues to be highly supported.

1.4 Recreation and Leisure

The Brain Injury Service looks forward to the outcome of the LTCSA review of recreation and leisure as it represents a significant role in the life of the developing child and young person and their families in terms of physical, emotional and social well being.

1.5 Discharge Process

The Brain Injury Service is pleased to be invited to the working party looking at streamlining the process of discharge planning for participants from the inpatient stay to the community.

2 Issues of Concern regarding LTCSA

2.1 Decision making process of LTCSA

There are a number of factors regarding the process of making requests to the Life Time Care Scheme for ongoing services and care that continue to cause concern for the service providers interfacing with the Life Time Care Authority (LTCSA). These concerns fall into 3 inter-linked issues

- a. Information and documentation requirements & loss of continuity in the decision-making process
- b. Clarification of what services are deemed 'reasonable and necessary' and who has financial responsibility for these costs
- c. Client choice in decision making about services accessed

a. Information and Documentation Process and Loss of Continuity between requests

The stated requirement of LTCSA is that every submission made must house free standing information regarding the client's medical history, current status and requested needs. This necessitates a significant administrative burden for service providers who for the Brain Injury Service, are clinicians who carry a much wider workload than just participants of the LTCSA. Clinicians and case managers are expected to repeat the clinical history from scratch for all subsequent and even related applications to try and gain support for the most simple to the most complex service and care requests.

There is a loss of continuity and client medical and social history that is not easily communicated from one submission to another without necessitating significant reproduction of the most basic medical and social facts related to the client. There is apparently no provision for LTCSA to draw on the long and detailed cumulative history of the client from previous submissions and requests, and subsequently is reflected in repetitive written communication between LTCSA and service providers.

It is the impression of the Brain Injury Service that the intention of the LTCSA is to administer and manage the monies related to the rehabilitation costs, care and service needs of clients over their lifetime, and that LTCSA coordinators have been given the mandate to liaise with service providers and guide the provision of appropriate form usage, information giving and rationale to assist the decision making process. The Brain Injury Service notes however that there is no provision for Life Time Care Coordinators to directly intervene with decision makers and advocate for the

submission by providing some form of a history regarding the request. This is a significant weakness in the present LTCS setup.

While the Brain Injury Service understands this statutory requirement of the LTCSA and appreciate the rationale of providing impartial decision making, there is a perceived loss to the total process which then isolates LTCS decision makers to events in time, rather than decision making based on understanding the life long burden and implication of an acquired brain injury to the **actual person** and their family.

While service providers can and do provide detail as requested, it is suggested that by not accessing past provided detail, the LTCSA is perpetuating a financial and administrative burden on service providers. In addition the effort and cost to LTCSA required to provide the vast quantity of additional detail does not rationally equal the cost of the actual service being requested.

Eg. Client A Mobilising by wheelchair following severe traumatic brain injury.

Care Needs assessment Number 3 was submitted for a 3 month period. to include the school holiday period. The total care requested was for 66 hours per week in the school holiday period. In addition to care hours there was a request for Kilometre allowance of **10 km return** to a local leisure centre, and kilometres for the participants to attend weekly therapy to attend swimming lessons.. During the school holiday period it was requested that 10km per day for 6 days be approved to allow the client to attend community activities.

Lengthy phone discussion with the LTCS coordinator seeking clarification on what activities the 10km allowance would be required for was backed up in writing in an email to LTCA coordinator.

Holidays hours were not approved and additional information was requested to support the submission. This information was provided which outlined :

- Information that had been reported previously in the Community discharge plan explaining that the family had no car and were involved in community activities prior to the injury
- The school holiday activities that the client would be likely to participate in if the allowance was approved.

The additional hours to access community activities request was rejected as they were deemed by LTCSA to be usual school holiday activities and that the cost would have been incurred regardless of the client's injuries.

A phone call to LTCS coordinator (previous coordinator on leave) where it was explained that the client was not able to use public transport as he had done previously with his family prior to the injury as he now used a wheelchair when participating in community activities.

The LTCS pointed out that in the response for additional information the need for a wheelchair was not highlighted by the treating team. The wheelchair had been reported in all previous documents to LTCS and that the LTCSA had recently approved a request for the purchase of a wheelchair.

When this was pointed out approval was granted within 24hrs.

In previous documentation to LTCS it had been reported that Ernest used a wheelchair and the family prior to the injury regularly participated in community activities by the use of public

transport. There was no cross referencing to this already provided information. The coordinator was well aware of the current status of the client through phone calls with the case manager.

There was a 5 week period from the date of submission to the end approval – during this time there were numerous phone call and emails to LTCS and to the care agency.

When the additional information was requested the approval was then 24 hours

The cost of the km allowance that was requested was minimal compared to the time and effort in phone calls and written correspondence by the case manager.

b. 'Reasonable and Necessary'

Clarification is sought regarding the decision making process surrounding request for care and services. While all staff involved with clients eligible for the LTCS receive training as provided by the LTCSA and have liaison with Life Time Care Coordinators regarding requests, there is at time insufficient rationale provided by LTCSA regarding why services are or are not accepted and inconsistency across cases in the decisions that are made.

These concerns largely surround the issue of what is deemed 'reasonable and necessary' in regard to ongoing medical, rehabilitation and care services. While the LTCSA have guidelines as to what services may or may not be approved, The Brain Injury Service feels there is a need to review these guidelines in respect to services that are somewhat 'grey' in that they fall into the category of care needed when there are lifelong, permanent changes to life skills .In these instances the client cannot be rehabilitated to their pre-accident functioning .and deficits may fall across all categories of function: physical, cognitive, social, behavioural, emotional.

Eg. Client A with a severe brain injury and initially significant reduction in upper limb ability related to the injury, is granted permission to receive professional waxing services. This service is continued to be supported by LTCSA until the client's upper limb function resolves sufficiently for her to complete the task independently.

Client B with a severe brain injury with resultant and unresolvable upper limb tremor is refused the professional waxing service (legs and eyebrows) Despite provision of extensive evidence of treatments and the current status of the client, the Life Time Care Coordinator suggests initially that there be more evidence of treatment to resolve the tremor. Following lengthy phone discussion and written communication to the same effect which resolves that the tremor is not able to be treated, the LTCC suggests that the participant considers other options such as having her attendant carer wax or shave her. The application is denied as the request does not meet guidelines.

The decision making process does not allow understanding of what medical or rehabilitation basis a well documented and evidenced submission for a service is accepted or rejected.

Further clarification is sought to understand whether the LTCSA considers that independently accessing appropriate services to compensate for loss of function as an appropriate, reasonable and necessary cost under their banner of provision of medical, rehabilitation and care costs.

Access to such services is in itself a rehabilitation goal that is giving the participant a sense of independence, empowerment over their choices and contributes to their sense of self worth and participation.

It is not clear how services, such as described above, are to be funded if the LTCSA scheme does not deem those services within its mandate. If the injuries related to the accident cannot be fixed or rehabilitated and represent to the participant a life long change to function there needs to be support to assist the participant access appropriate monies to compensate for this loss of function.

c. Understanding the role of Participant Choice in Decision Making Process

The Brain Injury Service seeks clarification in understanding to what role and significance participant life choices influences the decision making process regarding submissions for specific service requests made of the LTCSA.

This request would extend to how the Life Time Care participant wishes to actively participate in the community and what type of services they want to access because of loss of function related to their injuries.

Clinicians of the Brain Injury Service have had experiences in communication with Life Time Care Coordinators where the coordinators have used their own life experience as the benchmark for what they would consider to be 'reasonable' in terms of a request for services.

Eg. It was considered that a participants request for holiday program access would be unlikely to be approved as they care coordinator did not provide daily out of home activities for her own child.

In another case, while the participant expressly requested waxing from a professional service, the care coordinator felt the participant should consider alternate options such as being shaved or waxed by a family member or paid carer.

In advocating for the child and their family, the case managers for the Brain Injury Service do liaise and discuss options with the family and consider what is 'reasonable and necessary', but do so in balance with the wishes of the participant and the family where possible.

2.2 Educational Support

A specific example of long term service that is required by the participant as a direct result of injuries sustained from the MVA is provision of a teacher aide or tutor to support educational participation

It is a continued source of frustration of Brain Injury Service that despite well documented cognitive sequelae of acquired brain injury and its long term impact on the developing child, that submissions for these teacher aide services need to be so heavily justified on such a regular basis. For the sake of decreasing administrative burden to school staff and Rehabilitation Services, and to support the participant in school and home in a timely and appropriate manner, LTCSA approval for teacher's aide funding on a yearly basis with regular reviews is strongly supported . Further dialogue between LTCSA and The

Department of Education and Training may be beneficial to further negotiate how support for students should be funded and monitored long term within educational facilities..

Discussion

Teachers Aides services are a resource often sought by Rehabilitation Service Providers to support children and young people in the school setting with behaviour, social participation and cognition. These services may not be aimed for therapeutic intervention/rehabilitation, but rather long term habilitation.

Teacher's aide services are valuable in facilitating the school student's participation, minimising the gaps in performance between peers, assisting in maintaining safe attendance, facilitating in class participation, self esteem and academic progress and social participation. While teacher aide services can be for short term goal attainment, it is largely the experience of the Brain Injury Service that teacher aide services tend to be for longer periods as the impact of the brain injury is long term cognitive dysfunction that requires support and the student benefits from maintenance in the challenging school setting over the primary and secondary school years.

As students with cognitive dysfunction mature and face specific learning challenges in approaching the latter years of school life (eg exam technique, essay writing, diary skills), they may be able to benefit from direct therapy input to assist them to identify and acquire such compensatory skills and strategies. This is not possible for all students with severe brain injuries and for some young people where this skill acquisition is not possible attendant care support may be a life long requirement.

2.3 Relationship between the LTCSA and CTP Scheme

The Relationship between the LTCSA and CTP Scheme (MAA) and how clear this relationship is to the participant and their family, and to rehabilitation providers:

The relationship between LTCS and Motor Accident Authority is not clearly stated. In theory it would appear that service providers and participants of LTCSA are required to be engaged in a working relationship with both the LTCS and MAA yet the relationship between the two organisations is not so clear in reality.

For service providers such as the Paediatric Brain Injury Service, there is no clear path as to how participants actively advocate for themselves to breach the apparent gap in services between the older scheme, Motor Accident Authority and the new LTCSA, nor guidelines to assist service providers to advocate for their clients in this regard.

Under the MAA Scheme, case managers could argue the needs of a range of services for severely injury clients ranging from transport purchases or transport options, personal care services, home modifications, access to holiday programmes etc that individual insurers would then negotiate in terms of 'what pot of money' these services would be funded i.e. under rehabilitation costs or advances from head of damages.

In addition, under the CTP scheme, families were required to actively engage legal representation. During times of dispute regarding service payment, this legal representative could advocate for the family:

The experience of the Brain Injury Service in working with children and young people is that there are incidences of recommendations from LTCSA for services providers to try

and access 'CTP funds' for services that fall outside their legislative guidelines, but there is resistance from the respective insurers under the CTP systems to cover these costs.

Under the CTP scheme, the Rehabilitation Advisors know the cumulative history of their clients with a severe brain injury and are able to advocate directly to the Claims Managers for services. The process of accessing the CTP system for costs not accepted by the LTCSA has not been greatly tested by the Brain Injury Service.

It is the impression of the Brain Injury Service that for some participants of the LTCSS they will be required to access dual compensation systems (CTP and LTCSA) to have all of their reasonable and necessary rehabilitation costs met which would necessitate access to legal representation for those costs and the need to establish a relationship with another personal injury management scheme (CTP)- a burden of time, emotional energy, administration and finances.

2.4 Privacy and Confidentiality of Personal Participant and Family Information

Clarification is sought regarding the interface between health care facilities such as the Brain Injury Service and the LTCSA in regard to the sharing of personal information about the participant and their family. The decision as to what sensitive client and family information should be included in documentation to the LTCSA has been a challenge as is determining to what degree personal information is required by LTCSA to make an informed decision relevant to a request.

This issue may be address by provision of further clarification regarding 'ownership' of client information and the role of the LTCSA in the lives of the participants.

2.5 Health Service Resources

Lifetime Care and Support requirements continue to place an enormous burden on Public Health Services

- a. Ongoing issues related to provision and repeated provision of justification for care, services and rehabilitation for clients with extremely well documented needs. Documentation continues to be an extremely time consuming practice for simple to the most complex of care needs.
- b. Time of staff in written and verbal correspondence with the Lifetime care coordinators in regard to requests for services and submission writing. The Lifetime Care participants are a very small portion of our total clients numbers, yet continue to take up significant amounts of case management time without provision of staff to compensate for this increase demand for coordination and paperwork.
- c. Financial Support – It is not currently within the resources of Kids Rehab, The Children's Hospital Westmead to meet the requirements of the LTCSA in regards to invoicing requirements and code changes for billing purposes for services. The commencement of the LTCSA did not come with additional financial management support which has not been addressed sufficiently to allow satisfaction for either organisation.

3 Issues of Concern regarding LTCSS – Support of Department of Education and Training

While this submission relates to the interface of the Brain Injury Service with the Life Time Care Authority, staff of the Brain Injury Service are privy to concerns expressed by staff of The Department of Education and Training. The Brain Injury Service wishes to raise this issue as The Department of Education and Training is a key service provider to young people with an acquired brain injury and has a significant role with the client over their school life. In our desire to continue to support the vital work of schools we wish to raise an area of care that may benefit from future review.

Feedback from school relates to the burden of administration around submitting requests for providing additional in-class support to the participant (teacher or attendant care time), the process of filling in forms (timing and quantity) and reporting back on outcome of service delivery. These requirements of LTCSA are not classically within the expected role or experience of teaching staff and constitutes a huge change in their work practice with children with acquired brain injury.

While a great deal of support and training has been provided to NSW health facilities in understanding the LTCSS and implementing its processes, it is the observation of the Brain Injury Service staff that teaching staff may benefit from a revision of the way LTCSA obtain information from educational facilities. This might mean in house training of school staff (executive staff, teachers, counsellors etc), changes to the processes currently in place to get information from schools (eg. LTCSA aligning their process with current practice of school via Dept of Education and Training rather than an alternate unfamiliar one) or more hand-on support from LTCSA staff to assist school staff provide the required information.

Conclusion

As the Lifetime Care and Support Scheme progresses it is pleasing to see the benefit to the client in terms of timely and appropriate care and service provision.

It is hoped that continued dialogue and communication with serviced providers such as the Brain Injury Service will continue to bridging the gap in our service delivery models and move to mutually satisfactory working relationship for the benefit of our common clients.