Submission
No 18

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

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Date received:	1/09/2011

Kids Rehab

Brain Injury Service

The Children's Hospital Westmead

The Sydney Children's Hospital Network (Westmead)

Submission to the

NSW Parliament Legislative Council

Standing Committee on Law and Justice

Fourth Review of the Lifetime Care and Support Authority (Inquiry)

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On 11th August 2011

Executive approval by:
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The Sydney Children's Hospitals Network

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Introduction

The Brain Injury Service (BIS) is a service of Kids Rehab at The Children's Hospital at Westmead (Sydney Children's Hospital Network, Westmead) providing care and services to approximately 600 children and young people in 2011 with traumatic and non-traumatic brain injury.

The Brain Injury Service has been providing care to 42 children and young people who have been eligible to be participants of the Lifetime Care Scheme (LTCS) since its commencement in 2006. The Brain Injury Service currently provides inpatient and outpatient services to 32 children and young people registered with the Life time Care Scheme.

The children and young people who meet criteria to be eligible for entry to the Lifetime Care Scheme require a significant amount of case coordination and administrative attention from the Brain Injury Service as a part of attending to their complex clinical rehabilitation needs.

The coordination and administrative burden continues to be significantly higher than for client with similar needs who are not in the scheme. Kids Rehab fully supports the efforts being made to redirect revenue billable services back into Kids Rehab to allow for an increase in staffing to address what is now an almost untenable administrative burden impacting on clinical delivery.

The Brain Injury Service continues to be actively engaged in working parties and collaborative research with the Lifetime Care Authority.

The following submission details a select number of issues that have been of particular concern in the last 12 months which we feel would benefit from closer attention and greater clarification. These are:

- Participant Choice
- Education
- Remuneration for documentation

Issues Raised

A. Participant Choice

There are a number of issues around the role of the participant and family in terms of choice and decision making in selection of services which we feel would benefit from clarification and further improvement.

The Brain Injury Service provides services based on a model of care that supports specialised, seamless and coordinated multidisciplinary services to the client with an acquired brain injury and their family. By virtue of the acute inpatient stay at The Children's Hospital Westmead, continuing outpatient services are coordinated and /or offered by the Brain Injury Service of Kids Rehab. This model of care is particularly important at the transition period of moving from inpatient stay to outpatient services.

The Brain Injury Service will assist the family to access suitable services to best meet the needs of the child and their family. For example, the family may choose to access services that are more geographically appropriate.

When children and young people are catastrophically injured, it is fundamental that the care needs of the injured party are acknowledged as primarily the responsibility and concern of the family unit to which the child belongs. For this reason, Brain Injury Service maintains that the parents and carers of children and young people remain significant stakeholders in the decision making process in the selection and management of ongoing medical and rehabilitation services for the injured person.

This role is by no means diminished when the young person approaches school leaving age though where appropriate and possible, the young person's involvement in identifying personal goals and choosing suitable services increases significantly.

For the most we work together with Lifetime Care to ensure that the participant and their family can actively participate in the process of planning appropriate rehabilitation. For this reason it is concerning that our experience of the Brain Injury Service has been that the choices of the families and the participants with the Lifetime Care & Support Scheme have apparently been, significantly limited.

The following issues have been identified both by the families of The Life Time Care and Support Scheme participants and clinicians within the Brain Injury Service:

Lack of consultation with the participant and family
Situations have occurred where the Lifetime Care Case Coordinator has directed the participant's community living plan without appropriate and respectful consultation with the participant, their family and the existing rehabilitation provider. In one particular case the Life Time Care Coordinator has never actually met the participant in person despite the client having been a participant for three years.

Lack of choice
The Brain Injury Service is aware that there have been instances where the Lifetime Care Authority has directed the participant's family to disengage from the services offered by The Brain Injury Service and to commence with another community provider. On each occasion, The Lifetime Care Authority was highly directive regarding their preferred service provider and a choice of potential providers was not offered to the participant and their family. In at least one instance this process neglected to involve the participant, their family or The Brain Injury Service who were currently providing direct clinical care according to an approved rehabilitation plan.

It appeared that the participant had no personal agency to make a choice to either remain with their current service or to make a selection from a range of community providers.

Decision making about ongoing care that does not include the participant, their family and existing clinical services does not reflect an approach of patient-centred care. It disempowers families and removes the ability of the treating team to be collaborative in planning with the family, The Lifetime Care Scheme and future client services.

Lack of consultation with the Brain Injury Service regarding rehabilitation planning.
The Brain Injury Service believes that establishing and maintaining a therapeutic relationship with its clients is a key component in the provision of effective, high quality multidisciplinary rehabilitation. We provide both a clinical and advocacy role as an integral part of our rehabilitation interventions. Therefore major changes should be managed in a timely, consultative manner so that the participants and the treating team have the opportunity to carefully consider the implications of change for the client and their family.

For the most part The Life Time Care and Support Scheme and the Brain Injury Service work effectively with the participant and family to plan for service delivery. However, the occasions when The Life Time Care and Support Scheme has recommended the transfer of participant care to alternative private community providers without any consultation, constitutes a breakdown in a significant process around patient centred care and frustrates the clinical decision making process of long term rehabilitation providers such as The Brain Injury Service.

The tailoring of treatment and organising services is an integral part of our core business based on framework which informs our processes of referral to private practitioners. Poor collaboration undermines the clinical management devised by the treating team for which plans have been submitted and approved by The Life Time Care and Support Scheme

The lack of effective collaboration may lead to the following issues:

- Expressions of concern from the family regarding the impact of changing services on their child's progress and the potential detrimental effect on their child.
- It has a negative impact on therapeutic relationship of the patient, their family and the current treating team
- It undermines the collaborative relationship between the Brain Injury Service and The Life Time Care and Support Scheme.

B. Education

Supporting the learning of children and young people following an acquired brain injury is one of the major roles executed by The Brain Injury Service, The Children's Hospital Westmead and paediatric brain injury services across New South Wales. The Brain Injury Service has skills and expertise in the area of cognitive rehabilitation which is reflects the contribution of neuropsychological, speech and occupational therapy assessments especially in relation to changes in cognitive functioning following an acquired brain injury.

The Brain Injury Service has always worked in collaboration with schools, the participant and the participant's families to provide appropriate educational services to support the student's learning and participation in the school environment.

This collaboration is particularly important as each type of school (public, Catholic and independent) requires to some degree, assistance from the role of a case manager, to act as the interface between medical and rehabilitation providers and funding bodies such as Life Time Care and Support Scheme and insurers of the Motor Accident Scheme. In this role, The Brain Injury Service works with relevant parties making clinical recommendations based on assessment, clinical experience and the needs of the family to facilitate the process of obtaining appropriate learning support and monies to fund that support.

This role has been particularly important with the introduction of the Lifetime Care and Support Scheme however, while the Scheme is some four years into existence, there remain issues around policies and procedures specific to the interface of the scheme with schools and rehabilitation providers such as The Brain Injury Service.

Feedback from several schools and from case managers of The Brain Injury Service, is that the processes for informing schools about the requirements of the Life Time Care and Support Scheme and assistance to complete the paperwork required to apply for learning support services continues to be variable from school to school. The new administrative load now on schools reflects the excessive documentation which has been reported in previous reviews by The Brain Injury Service.

The Brain Injury Service welcome continued efforts of the Life Time Care and Support Scheme to clarify their relationship with school organisations. However there is a need for greater clarity about how The Brain Injury Service, the schools they with whom they interact and the Life Time Care and Support Scheme will work towards more timely, appropriate learning support for participants.

Recommendation
In light of these comments, it would be extremely helpful if the Lifetime Care and Support Scheme could formally clarify their policies and position regarding:

- The provision of teacher aide support in class and additional learning support strategies such as home tutors.
- The role of the Lifetime care coordinator in explaining the Lifetime Care scheme and how the schools will be informed, trained and resourced to provide the documentation required.
- The collaboration of the Lifetime Care and Support Scheme, school and rehabilitation specialist in making recommendations for school based services. Currently The Lifetime Care and Support Scheme require all educational goals to be supported in the school planning documentation eg Individual Learning Plans. However, some aspects of learning support which greatly benefit student participants in the home such as tutoring generally do not fall within the governance of the school education system.
- The level of support and additional resources that The Life Time Care and Support Scheme is giving to schools to assist them to complete paperwork (Requests for Educational Services) required to apply for additional funding for service.
- Identifying within the Lifetime Care and Support Scheme who undertakes the tasks of:
- Educating the schools about the Scheme and its support role for the student
- Assisting education staff when they have issues with providing documentation or are needing clarification about how funding for services can be sought.
- It would be helpful to have clarified if all participants of the Lifetime Care and Support Scheme are required to apply for Department of Education and Community based funding BEFORE they can apply for additional support from The Scheme. Any formal agreements should be made explicit to paediatric service providers to facilitate their role in the process of supporting the student with the ongoing learning needs.

C. Remuneration for Report Writing
It is the opinion of Kids Rehab that report writing costs under Life time Care should not be uniformly capped as is the current practice as it does not always reflect the true time taken by clinical staff to provide required information. There are many instances where a far greater amount of time and detail is required to put together an application, notable the Community Living Plans. Equally, when less time is taken to produce a report it is billed as such.

Recommendations
It is the belief of the Brain Injury Service, Kids Rehab that service providers should be recompensed directly for the actual hours it takes to provide a report.

Conclusion

The Brain Injury Service continues to collaborate with the Lifetime Care and Support Scheme on a regular basis in formal and informal settings.

It is hoped that continued dialogue and communication between the Lifetime Care and Support Scheme and service providers such as the Brain Injury Service will continue to bridge the gap in our service delivery models and move to mutually satisfactory working relationship for the benefit of our common clients.