

SECOND REVIEW OF THE LIFETIME CARE AND SUPPORT AUTHORITY

Organisation: Department of Rehabilitation,
The Children's Hospital at Westmead

Name: Ms Martine Simons
Dr Stephen O'Flaherty
Dr Mary-Clare Waugh

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The Department of Rehabilitation, The Children's Hospital at Westmead

Submission to the:

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

Submitted by:

- Martine Simons
Senior Social Worker – Clinical Specialist
Brain Injury Service
Department of Rehabilitation
Email: martines@chw.edu.au
- Dr Stephen O'Flaherty
Head of Brain Injury Service
Head, Department of Rehabilitation
Email: stepheno@chw.edu.au
- Dr Mary-Clare Waugh
Head of Physical Disability Service and Spinal Cord Injury
Department of Rehabilitation
Email: maryw@chw.edu.au

On 11th May 2009

Executive approval by:

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

Corner Hawkesbury Road and Hainsworth Street
Locked Bag 4001 Westmead NSW 2145
Tel +61 2 9845 0000 Fax +61 2 9845 3489



Rehabilitation Department

Ph: (02) 9845 2819 - General Rehabilitation

Ph: (02) 9845 2132 - Brain Injury

Fax: (02) 9845 0685

www.chw.edu.au/rehabilitation

the
children's
hospital at Westmead

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

11 May, 2009

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

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

Dear Sir or Madam:

Please find enclosed our submission to the Submission to Second Review of the Lifetime Care and Support Authority (Inquiry). In this submission, the Rehabilitation Department will outline issues of concern as well as acknowledging any strengths and positive aspects of the Lifetime Care and Support Scheme for our client groups. The submission includes comments on clinical and administrative aspects of the Scheme.

We have prepared case examples to illustrate some the issues raised but would prefer to discuss these directly with members of the Law and Justice Standing Committee in order to provide our patients with privacy and confidentiality should this be requested.

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

Yours sincerely



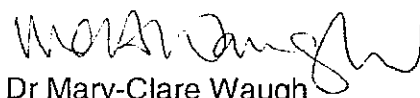
Martine Simons
Senior Social Worker – Clinical Specialist
Brain Injury Service
Department of Rehabilitation

Email: martines@chw.edu.au
Phone: 9845 2821



Dr Stephen O'Flaherty
Head of Brain Injury Service
Head, Department of Rehabilitation

Email: stepheno@chw.edu.au
Phone: 9845 2132



Dr Mary-Clare Waugh
Head of Physical Disability Service and Spinal Cord Injury
Department of Rehabilitation

Email: maryw@chw.edu.au
Phone: 9845 2132

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Introduction

The Brain Injury Service (BIS) and the Spinal Cord Injury Service, both part of the Rehabilitation Department at The Children's Hospital at Westmead (CHW), provide rehabilitation services to children with motor vehicle related traumatic injury, other traumatic injuries and non-traumatic or acquired brain and spinal cord injuries. Motor vehicle related traumatic (brain) injuries in children (167 cases 2008-2009) are 28% of our total caseload (591 in 2009). Of these, only 14 children, injured since October 2006, currently meet the criteria to enter the Lifetime Care and Support Scheme (LTCS) as interim participants. As such, this small group of severely injured children represent a small proportion of our caseload, yet are currently requiring a larger proportion of service provision to fulfil the significant administrative requirements of the Lifetime Care and Support Authority (LTCSA) in addition to their clinical rehabilitation needs.

The following submission details a range of issues and concerns that have arisen since the inception of the LTCS for children under 16 years in October 2006. Many of these issues have been raised with the LTCSA with varying levels of satisfactory outcome.

In raising these issues about the clinical and administrative aspects of the LTCS we wish to acknowledge that the LTCSA facilitates a number of consultative committees and training opportunities to assist in the implementation of the rehabilitation process. The LTCS also encourages communication between rehabilitation providers and the Authority, when needed, regarding issues that may impact both on service providers and participants.

The Scheme is relatively new and both the LTCSA and the BIS are still negotiating their way through the complex processes involved in facilitating rehabilitation through the LTCS.

1. BENEFITS OF LTCS

1.1 Equipment

Clinicians and Case Managers have found that LTCS provides equipment for children in a timely and appropriate manner. This reflects a commitment to providing and funding suitable equipment in a timely way to support children who have been catastrophically injured. Of particular note is the significant contribution made by Lifetime Care Scheme to work with PADP (now EnableNSW). This has had particular impact on the Discharge Process.

1.2 Funding

There appears to be sufficient funding for reasonable and necessary rehabilitation needs. As a result, participants are able to access services and equipment to facilitate their rehabilitation.

1.3 Support of Transport Needs

The provision of taxi vouchers to facilitate travel to appointments for some families is crucial to achieving rehabilitation. Many families do not own a car or have regular access to a reliable vehicle. At an outpatient level, for many families, the provision of taxi vouchers makes the difference between the child receiving timely and appropriate therapy or treatment in the most appropriate setting or missing out.

1.4 Recreation and Leisure

Recreation and leisure is an integral part of a child's developmental growth and regular activity. The rehabilitation programme and lifetime care goals for a child with brain or spinal cord injury should reflect this. Therefore, we view the efforts of LTCSA to undertake a formal review as to whether recreation and leisure needs should be included in and considered reasonable and necessary rehabilitation, as an extremely positive and responsive action to more fully address the needs of participants of the Scheme.

Acknowledgment of the value of recreation and leisure to rehabilitation reflects an understanding that rehabilitation for children should take into consideration the child in the context of the family and community and of developmentally appropriate life roles.

1.5 Central Email Contact

At an administrative level, having a central email address so that information can be passed on to the appropriate staff member and be acted upon during staff leave when appropriate is more efficient and enables requests and queries to be processed promptly.

2. AREAS OF CONCERN REGARDING LTCS - CLINICAL ISSUES

2.1 Therapeutic Support to Families

We have experienced many examples where the LTCSA has been responsive to families who have required practical assistance such as taxi vouchers or transport expenses to assist a family to attend therapy or medical appointments.

However, some recommendations for the provision of **therapeutic support** to family members who are struggling with ongoing issues of adapting to the impact of the child's disability have not been immediately approved. If the issue with which a family is struggling i.e. marital/relationship discord, in addition to the accident and brain injury or spinal cord injury, is viewed by LTCS to be separate, and not related to the child's rehabilitation, then they will not approve intervention.

The experience of the Rehabilitation Department is that a traumatic life event can impact significantly on relatively intact, well supported families. It follows that the impact then on families who may have pre-existing issues, can be catastrophic, affecting the family's ability to support and facilitate their child's rehabilitation. In both cases, therapeutic support to the family is warranted to support the injured child.

It has been the experience of the Rehabilitation Department that there is sometimes inconsistency in what kind of counselling and therapeutic support is approved and for whom. It would be useful to gain greater understanding of the rationale which has led to queries regarding requests for services of this nature.

2.2 Introduction of LTCS and the Lifetime Care Coordinator

Inpatient rehabilitation issues

During the inpatient stage of rehabilitation the LTCS Coordinator has requested early access to families to explain the Scheme. While this may appear to be a positive and proactive approach to facilitating an application to the Scheme we have continued to have significant concerns about the potential detrimental impact on the family to a psychologically premature introduction to the Scheme.

Our clinical experience has shown that families remain in a crisis state for some time following a motor vehicle accident and thus they require sensitive and timely provision of information. We believe that the decision regarding appropriate timing of the introduction of this (and any) new relationship to the family should be made by the treating inpatient team. This ensures that the needs of the child and family are met in well-timed, sensitive manner that reflects the psychological, social and emotional status of the family in regard to their comprehensive rehabilitation.

Families have expressed that they have felt overburdened with requirements to meet extra people and deal with issues that are not vital to their understanding of their child's immediate needs while they are still in the acute stages of rehabilitation.

The principle of being guided by the inpatient team is also practiced within our Brain Injury Service. Outpatient case managers and clinicians attend family meetings, clinical planning meetings and ward meetings at the discretion of the inpatient team who are best placed to judge appropriate timing.

In order to avoid confusion and to keep services relevant to the family and client the role of the inpatient treating team may include: introduction of services as appropriate; provision of appropriate information to those stakeholders as it becomes available; explanation of new services and introduction of new people.

The key issue is that Coordinators should continue to trust the clinical judgement of Brain Injury Service health care providers in regard to timing of involvement of Lifetime Care Coordinators.

2.3 Discharge planning and changes to the Community Discharge Plan

The LTCS Scheme Community discharge plan, Service request and Equipment requests forms are submitted by clinicians using the best clinical judgement of the child's needs at that time and in anticipation of their future needs. In these situations, while the child still requires a significant level of service, his/her recovery may be such that equipment needs have changed or may even be reduced so that the plan does not reflect the client's improved functional status at the time of discharge.

Children are often discharged home at an earlier stage of their rehabilitation because they have parents/carers who are able to provide appropriate supervision and transport to therapy. While an adult with an 'equivalent' level of disability would require a lengthier hospital stay. As a result, at discharge, children are *still* changing from week to week and month to month. Therefore, flexibility needs to be built into the community discharge plan. In those instances where the Case Manager identifies a need for change or modification to the Community discharge plan it has

created difficulties in our continued communication and liaison with LTCS Coordinators who have on occasion queried why certain therapy goals and recommendations have not been pursued or why equipment is no longer needed.

This scenario can only be remedied by either providing requests for services/equipment *later* in the child's recovery process or for LTCA to acknowledge that service and equipment needs of the child may change over time with recovery and that recommendations are made with best clinical judgement at the time of assessment. We wish to reinforce that decisions to make changes to plans are not made lightly and always in response to the current and anticipated clinical needs of the child and their family.

This issue is an ongoing concern as it has occurred on a number of occasions and creates a stressful situation in a relationship with LTCSA.

2.4 Outpatient rehabilitation issues

2.4.1 Clarification of roles

Confusion continues regarding the role of the Life Time Care Coordinator when a CHW case manager is involved. There appears to be a duplication or overlap that is not always clearly negotiated between parties and not always understood by participants. This has lead to separate recommendations about interventions being made by the Life Time Care Coordinator which did not reflect the current care plan, confusion from families and other community rehabilitation providers regarding how community rehabilitation needs are to be met and at time mixed messages regarding how rehabilitation services are to be obtained.

Negotiation concerning the direction and auspice of the rehabilitation management requires clarification for both treating teams and families. We acknowledge that the LTCSA has a responsibility to its participants to foster an independent relationship which may at times identify issues for the participant that may not be captured in an earlier or current care plan. How these differences are then merged into the current plan continues to be a challenge.

2.4.2 Educational Support

The interface between LTCS, Rehabilitation Providers/Case managers and educational services needs continued clarification to improve communication and coordination to ensure the client receives services in the school setting as needed and the roles of each party are understood.

Sometimes information, liaison and funding applications for educational support occurs directly between the school and the LTCS Coordinator, but on other occasions the Coordinator leaves this entirely to the Brain Injury Service Case Manager. The Coordinator may also hold separate meetings with school personnel and/or family members without informing the case manager of the outcome. This may impact on implementation and relevance of a current care plan.

2.5 Client Confidentiality and therapeutic psychosocial interventions:

During the course of the patient's inpatient stay and during their outpatient follow up a therapeutic alliance is often established with children and families. Families are

vulnerable and their personal and family issues are exposed in a way that most people would find very challenging. This occurs within the context of dealing with their children's injury, trauma and managing the systems. The therapeutic alliance between the treating clinician, the team and the client must be acknowledged. The level of information required by LTCS around psychological and social issues which are complex and private appears to be very detailed and potentially crosses the boundaries of professional confidentiality in clinical psychology and social work. Assessment and therapy may involve disclosure of interpersonal issues within relationships, problems with drug and alcohol use or previous trauma or past issues which are re-emerging as a result of the new trauma of the motor vehicle accident.

These issues may emerge during therapeutic intervention regarding the child's injuries and rehabilitation. Family members should be able to trust the treating clinician in regard to confidentiality.

This is an area of client duty of care that clinical staff at the Department of Rehabilitation continue to negotiate with LTCS.

2.6 The name of the Scheme

An additional concern is the name of the Scheme itself. The phrase 'Lifetime Care' has the potential to be viewed by families in a negative way. It may, at some level, be seen to indicate that the treating team is giving 'mixed messages' about the potential for recovery and is actually indicating a prognosis of severe brain injury which the family may not be ready to hear.

We understand that at some later stage families view the concept that their child may be eligible to participate in the LTCS for the rest of their lives as reassuring and beneficial, but in the early stages of rehabilitation the name itself has potential to exacerbate loss and grief.

2.7 Assessment and entry into the Scheme: Issues

2.7.1 Use of WeeFIM®

The WeeFIM® is a measure of burden of care and is heavily weighted to physical functioning eg transfers, mobility, toileting and dressing. The WeeFIM® is a very useful tool to document change during the inpatient rehabilitation period.

Additionally it permits comparison of paediatric rehabilitation across multiple centres as a benchmarking tool.

For monitoring of change over a more prolonged period of time the WeeFIM® has a number of shortcomings. There are limited items in the areas of cognitive and behavioural sequelae following brain injury. Cognitive, behavioural and social impairments are the most common long term deficits in paediatric brain injury.

This has implications for children when they reach the end of the two year period as Interim Participants of the LTCS as the WeeFIM® is readministered to ascertain the severity of injury at this stage of recovery. Some children will make an excellent physical recovery and achieve age-appropriate independence in activities of daily living. However, they may have significant difficulties in the areas of cognition, behaviour control, language and psychological recovery as a result of their accident

and the WeeFIM® is not sensitive enough to highlight the significance of these well documented brain injury sequelae.

Limitations of current paediatric assessment tools indicating life time care needs of clients is an issue impacting on paediatric rehabilitation services across many clinical specialities. Efforts continue with a new assessment tool (PCANS) which is currently being validated and tested for Australia norms for 5 – 18 years olds. This may be a useful tool for the LTCS and rehabilitation providers in the future.

2.7.2 Decision making regarding entry to the Scheme (Interim Participant)

Some children especially those younger than eight years of age whilst an inpatient, may not be entered into the Scheme until further information after discharge is obtained. At times there is pressure to enter the children, when all the information regarding potential long term significant problems is not yet available. Deferring enrolment is very reasonable option to ensure the best rehabilitation management of the child.

2.7.3 Timing of evaluation for permanent participation in the Scheme

The children whom the LTCS is designed to support may be excluded from the program even though they have significant and permanent long term needs. Timing of the evaluation to determine status and continued involvement in the Scheme would be better deferred until 8 years of age for those children injured at a young age.

It is important to acknowledge that children have not been accepted into LTCS as Interim Participants will be still eligible to make a claim under the CTP Scheme. Equally, as the first interim participants are now reaching the two year assessment phase if they are not accepted into the Scheme as Permanent Participants they will be able to revert to their CTP application using the Children's Special Benefit.

3 AREAS OF CONCERN REGARDING LTCS - ADMINISTRATIVE ISSUES

LTCS continues to demand significantly more allocation of formal and informal meeting time on a regular basis to assist clinicians to complete administrative work and fulfil the requirements of LTCA. The time required to prepare requests and plans impacts on the availability of a clinician for clinical intervention.

3.1 Paperwork

Some of the clinical issues raised above have included aspects of the complex administrative procedures of the LTCSA. We wish to stress that despite ongoing feedback to the LTCSA and efforts of the LTCS to streamline their processes that the amount of paperwork and documentation remains onerous and laborious.

The BIS is required to provide the same clinical information on different types of applications for services. But the varied service request forms actually request either completely different or subtly different information leading to unnecessary re-writing and re-formulating what could be quite straight forward requests. Conversely, some forms appear to repetitively ask for the same information in different sections or parts of the same form.

3.2 Sharing of Reports and Feedback on Approval of Services

The Department of Rehabilitation is currently waiting on clarification from the LTCA Privacy Auditor regarding their policy on releasing and sharing of plans, requests for services and equipment and then who receives notices regarding approval for the same.

Our experience has been that there has been some inconsistency in how rehabilitation information about the client has been shared and concern that not all relevant parties are made privy to what has or has not been approved. This has led to confusion between hospital and community services providers in terms of how and when service delivery is to take place.

3.3 Approval Process of LTCSA

An additional issue is that the Plans for individual participants are approved by different LTCSA personnel on each occasion. This contributes to the requirement for constant repetition of information because each request for services or equipment is required to be a free standing piece of documentation.

The CTP Scheme manages this aspect of continuity of care by providing a consistent team who can develop over time an understanding of the client's needs and rehabilitation. Our experience is that Claims Managers and Injury Management Advisors gain an understanding of the child and family over a long period negating the need for repetition without losing objectivity of what is reasonable and necessary rehabilitation.

3.4 Financial Tracking and Accounting

An issue that is currently being addressed by Brain Injury Rehabilitation Directorate (NSW) in conjunction with the LTCSA is the complex billing requirements of LTCSA and how this interfaces with variable NSW Department of Health accounting systems. The continued support of LTCSA to assist in liaising with Department of Health administrators is highly desirable to allow LTCSA to have their invoicing needs met and for rehabilitation providers to have their services appropriately recompensed.

4. Conclusion

Thank you for the opportunity to raise these issues in spirit of improving communication with the LTCSA. As a result we hope that a continually improving Scheme will emerge.