## the children's hospital at Westmead

# Kids Rehab The Sydney Children's Hospital Network 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)

## **Questions on Notice**

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#### 1. Patient Confidentiality and the Therapeutic Process

#### **Preamble**

Client confidentiality is the foundation for establishing a trusting therapeutic relationship.

Health clinicians working with children and families are required to gain a broad understanding of the status of a family and individuals with in that family – obtaining information about past and current social and medical circumstances, family culture and additional stressors (eg financial hardship). This information guides clinical actions and priorities in rehabilitation planning for the participant. This information assists clinical teams in identifying support needs of the family unit and community to which the child will ultimately return.

Clinicians are in a very privileged position when families are referred to the Brain Injury Service. Families are generally very anxious, exhausted and overwhelmed by the recent traumatic events.

Clinicians work with families in this vulnerable state to assess their wellbeing in the first instance and to gain understanding of the unique and complex nature of the family unit and the community from which they come.

Information gleaned by health clinicians ranges from very specific personal responses to the child's injury but extends quite significantly to the impact of the injury in relation to other social issues such as breakdown of relationships in the family, other family crises, mental health factors, child protection issues and financial strain.

Many of these factors are pre-existing, and are not related specifically to the participant's injury, but may impact significantly on the capacity of the family to care for their child.

Health clinicians in seeing a child in the context of their family are required to:

- · analyse the relevant histories
- detail key factors that need to be immediately prioritised
- address and maintain an awareness of how additional information may impact on the clinical profile of the family as the child progresses through their rehabilitation.

Health clinicians working with participants understand the requirement of the Lifetime Care and Support Scheme (LTCSS) to have clear justification for recommendations for current and future services. Clinicians of the Brain Injury Service provide to LTCSS only the detail required to support service applications without compromising the therapeutic relationship with the client or breaching confidentiality and privacy of the client and their family.

#### Issues Identified

- It has been the experience of The Brain Injury Service that the LTCSS has requested
  explicit detail of family social issues which the health clinician has determined not to
  be relevant to the service request.
- There are recent incidences where LTCSS funded case managers have sought to influence the content of psychological interventions or requested inappropriately the minutiae of confidential therapeutic sessions.

#### Discussion

It is not the current practice of The Brain Injury Service to divulge the personal information of clients where it does not have relevance to direct service delivery of rehabilitation to that client or directly supports a submission for services.

Medical, nursing and allied health rehabilitation practitioners are bound by the ethical and privacy requirements of both the Ministry of Health and their relevant professional boards and associations. <sup>(1) (2)</sup> Clinicians should be not required to breach these ethical requirements in order to satisfy requests by LTCSS.

All clinical staff abide by a code of conduct that prohibits a breach of the patient-clinician relationship unless it is in the best interest of the child or family member (eg. Risk of harm to the child, mental health issues) or in the safety interest of the treating team and other stakeholders (eg. Domestic violence).

It is the belief of The Brain Injury Service that the therapeutic relationship and the inherent confidentiality required between clinicians and participants and/or their family in psychological roles (e.g. Clinical Psychologists, Social Work) should be upheld. Discussion of the detail of individual psychological sessions is inappropriate. Treating clinicians should be trusted to provide information that satisfies LTCSS requirements without compromising the clinician-patient therapeutic relationship.

Additionally, it is inappropriate for either Lifetime Care coordinators or their funded Case Managers to specifically request that particular issues be addressed in therapeutic counselling sessions which aim to justify or encourage the participant's acceptance of a decision made by LTCSS to reduce or remove services. The content of therapeutic intervention is managed and agreed upon by the clinician and client.

This issue may be addressed by provision of further clarification regarding 'ownership' of client information and the role of the LTCSS in the lives of the participants. Clarification of the expectations around the working relationship that independent clinical services have with LTCSS would be helpful.

We suggest that LTCSS encompasses a number of roles within the lives of participants which could be considered to inherently conflict with their decision making role. With some similarities to CTP insurers, the Lifetime Care and Support Authority (LTCSA) is a manager of financial resources and have the very important role of ensuring reasonable and necessary medical and rehabilitation services are obtained for participants. The actually clinical rehabilitation services are provided by professional staff with specific training in the area of paediatric brain injury.

We acknowledge that the LTCSA must, at all times, be able to demonstrate that approvals for funding are made in line with strict legislative guidelines and meet rehabilitation planning process. We also acknowledge that part of that role will be to at times to question the submissions made by the professional rehabilitation services they have engage on the participant's behalf. However, in order to preserve the privacy of the participant, and the integrity of the therapeutic relationship, greater trust and clinical respect is required of those clinicians providing direct clinical services and involved in direct clinical planning.

It has been the practice of LTCSS to at time be directive in wanting to change service providers from the established rehabilitation teams such as the Brain Injury Service, the

Children's Hospital Westmead, without prior consultation or planning with the current treating clinician. In the case of psychological service provision, this can be extremely distressing to the participant and their family, and interfere significantly with psychological treatment.

When there is conflict or disagreement regarding service delivery type, how or where it is provided, direction of therapy or how much disclosure there is of confidential information to justify requests, the best outcome for participants comes when all parties can meet collaboratively to discuss the specifics of the issue.

- 1. To determine if more information is required by LTCSS to assist their decision making for requests for further or future services
- 2. To ensure that the best rehabilitation planning can take place without compromising the dignity and privacy of the participant and family
- 3. To ensure that the therapeutic relationship with clinical staff with the participant is not compromised
- 4. To understand the rationale of LTCSS for wanting to change service provider when a therapeutic relationship already exists between participant and clinician

There needs to be continued work between LTCSS and rehabilitation providers, public and private, regarding professional boundaries.

#### References

- 1. Australian Association of Social Workers, Code of Ethics, AASW, Canberra, 2010.
- 2. The Australian Psychological Society Limited, Code of Ethics, Victoria, 2007.

#### 2. Workload Management

Management of Lifetime Care and Support Scheme (LTCSS) patients generate an additional and substantial workload for case managers as they often have complex rehabilitation needs. Mandatory LTCSS administrative processes requires close tracking of the rehabilitation process, reflected in a large amount of paperwork which is extremely time consuming to produce.

The number of lifetime care participants seen by our service will increase by approximately 7 per year, this number varies greatly from year to year. Children who were 1 year old when they entered the Scheme in the year it commenced (2006) will remain with our Brain Injury Service until 2024. At which point they would be transitioned to adult services. From that year onwards, 2024, our number of LTCSS participants would become static at around 125 patients.

LTCSS participants generate an additional and substantial amount of work for case managers relative to the majority of our patients who are not compensable. The total number of patients in Brain Injury Service is 533. Over the past 6 years we have had 42 LTCSS patients in our Service. We currently have 32 LTCSS participants in our service, of these, 13 (40%) are case managed in our department with a ratio of 4 LTCSS participants per full time equivalent (FTE) case manager. We consider a ratio of 5 LTCSS participants per full time equivalent case manager to be a manageable load, taking into account the fact that the majority of our patients are not LTCSS participants.

Considering the above numbers we would estimate that by 2024 our projected number of LTCSS participants seen in our Service would be 64 with 26 (40%) of those case managed within our department. With a ratio of 5 LTCS participants per FTE case managers our required staffing for case managers in 2024 would be 5.2 FTE case managers (current staffing is 3.3 FTE case managers).

Our budget for staffing is determined by the Sydney Children's Hospitals Network (Randwick and Westmead) within the NSW Ministry of Health. This budget is unlikely to increase over the coming years and thus our staffing numbers will remain static.

Ideally if revenue raised by Brain Injury Services could be redirected back to the primary treating team, more resourcing in the form of clinical and administrative staff could be engaged to address the long term issue of managing children who have acquired a catastrophic brain injury.