Submission
No 18

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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Date received: 14/05/2010

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HUNTER CHILDREN'S HEALTH NETWORK

13 May 2010

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13 MAY 2010
LAW & JUSTICE

The Director
Standing Committee on Law & Justice
Parliament House
Macquarie Street
SYDNEY NSW 2000

RE: 3rd Review of the Lifetime Care and Support Authority

We are pleased to provide the attached response to the 3rd review of the Lifetime Care and Support Authority (LTCS) by the Standing Committee on Law and Justice of the Legislative Council.

Kaleidoscope's Paediatric Brain Injury Rehabilitation Team (PBIRT) at John Hunter Children's Hospital in Newcastle would like to comment on two specific issues.

Home Modifications for families in regional/rural areas of New South Wales

The PBIRT acknowledge the numerous complexities of approving major home modifications for a client returning to a rural home upon discharge from hospital. As a team we query whether some of the procedures associated with home modifications could be improved to minimise family disruption and improve transition from hospital to home.

When a young person is in hospital and the family are from rural areas of NSW additional stresses can occur such as family fragmentation, economic stress increased emotional trauma and increased risk of depression, as was the case with PBIRT's client and family during his hospital admission.

It is important that a child/young person and their family return home as soon as safely possible. Increased length of stay in the hospital increases unnecessary hospital costs and can have a negative impact on the young person's rehabilitation.

In the case of the young person and family admitted to John Hunter Children's Hospital length of stay was increased due to procedures associated with home modifications. These included:

- Delays in approval for home modification assessments
- Use of an approved assessor to conduct a home modification assessment after a local qualified Occupational Therapist was approved to conduct a home modification assessment and had submitted an appropriate report
- An approved assessor was used from Sydney for a home outside of Tamworth
- An approved assessor assessment was conducted without input from the local Occupational Therapist in Tamworth
- Lengthy delays occurred between each stage of development with the home modifications using the approved assessor

- Expectation that family attend meetings in Sydney to discuss home modifications
- An approved assessor working in isolation and not utilising local and inpatient Occupational Therapy services
- The need for interim accommodation (longer than four months) while home modifications were determined and conducted
- The transition from hospital to home has involved two interim homes for the family with delays continuing.

The PBIRT recommend the following changes:

- Once the cognitive and physical complexities of the client are flagged with the LTCS co-ordinator then a decision should be made regarding whether it is best to use an approved assessor or if a local Occupational Therapist would be sufficient to conduct the assessment. This would ensure one person is nominated and responsible and recommendations can be implemented sooner.
- The approved assessor be encouraged to liaise regularly with the local Occupational Therapist and hospital based Occupational Therapist during this time so the two teams are aware what is happening for the young person and family
- Home modifications made a priority and decisions for approvals or non approvals for each stage of the home modification be made as quick as possible so the discharge can occur as promptly as possible.

Communication between Brain Injury Teams, Families and Life Time Care & Support Coordinators

The change of location of LTCS coordinators to Newcastle has been a recent welcomed change that is supported by the PBIRT. Coordinators located in Newcastle has allowed for a smoother transition to eligibility to the scheme and better awareness for parents of what LTCS is and how it works for the families.

The PBIRT still identify weaknesses in the allocation of coordinators to geographical areas. John Hunter Children's Hospital receives children from rural areas outside the major areas of Newcastle, Port Stephens and Lower/Upper Hunter. For children who are from North Coast or New England coordinators are allocated from the Sydney office and because of distance to the hospital PBIRT have noticed difficulties with the current arrangement.

- Delays once notification is for eligibility is completed and the coordinator contacts the family.
- Reliance on PBIRT to provide more detailed information about the scheme
- Family's not receiving contact from a coordinator – less understanding of the current stressors placed on the family and the needs of the family.
- PBIRT staff explaining the request for services procedure, assisting parents with the expense form procedure while their child is in hospital and coordinators contacting PBIRT to provide feedback to the family instead of direct communication.

In addition, the introduction of more coordinators across Newcastle and Sydney has demonstrated some inconsistencies about knowledge of procedures within LTCS and inconsistent communication between the case manager, families and LTCS.

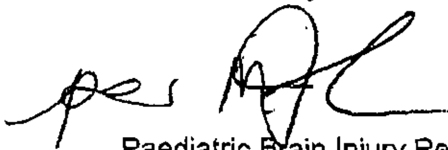
Approvals for request for services are regularly sent via email and if services are not approved, reasons are brief and not discussed with the family or case manager - sometimes clarification is only required and can be qualified quickly by a phone call but this is not usually the case. When a service is not approved and this is discussed with the family only by letter it can impact on the families wanting to ask for service as they may feel challenged and not understood. In addition, many times case managers are speaking with the coordinator who was not responsible for the deciding whether it was approved. Documentation for approval appears to be examined independently with no reference to other documentation and staff assigned to approve services can change regularly so there is appears to be no consistent understanding of the client's needs and the case manager may repeat information several times unnecessarily.

The PBIRT suggest the following changes:

- LTCS coordinators assigned to teams not geographical locations to ensure consistent transfer of information between hospital team and LTCS
- LTCS coordinators to meet with families early on to explain scheme and process – including request for procedures, approval times, process for expense reimbursement etc
- LTCS coordinator to take responsibility for assisting parents with navigating the financial expense form – especially in the acute stage when families need support to complete this paper work
- LTCS coordinators to identify early on if a service will not be approved and discuss this with the case manager directly
- Seek clarification early on with the case manager if more information is required to approve a service or piece of equipment
- Training with the LTCS coordinators to improve consistency of information between service providers
- LTCS coordinators to have more responsibility in approving services.

If you require any further information please do not hesitate to contact Kaleidoscope's Paediatric Rehabilitation Team at John Hunter Children's Hospital.

Yours sincerely



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