

To:	Trust Board
From:	Rachel Overfield, Chief Nurse
Date:	26 <sup>th</sup> June 2014
CQC regulation:	Outcomes: 1, 4, 16

Title: Carer Experience Feedback - Transition for Patients with Learning Disabilities from Children to Adult Services

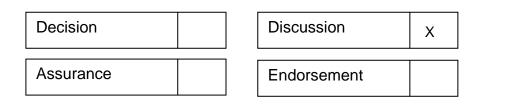
#### Author/Responsible Director:

Katrina Dickens, Learning Disability Acute Liaison Lead Nurse Practitioner

#### Purpose of the Report:

To describe for the Trust Board, the impact of transition from paediatric to adult care for a patient with a learning disability

### The Report is provided to the Board for:



## Summary / Key Points:

The Learning Disability Nurses distribute patient feedback diaries in an easy read format to patients with learning disabilities who access hospital. A general overview of the feedback received from the diaries is included in the team's annual report.

During the team's time working within the hospital they have encountered patients who have transferred from children to adult services who have experienced concerns.

It was decided to have a face to face conversation with one of the patient's carers to identify the issues that they have encountered within the transition process. The patient had been admitted to hospital with chest infections and vomiting and required management of the infection and maintenance of their oxygen saturation levels.

Carer's Feedback of the Transition Process

- The carer experiences were a feeling of isolation and being alone. Within paediatrics • there is one doctor that co-ordinates all the care, but this changes when you go into adult services dependent on the reason the patient is admitted to hospital.
- The carer found on one occasion the handover between paediatric and adult • services was an ineffective exchange of information. The handover was undertaken via a letter.
- Staff not trained in the use of the Portacath when emergency admissions occur. A Portacath is placed under the skin, with the catheter inserted into a vein. It can be used by clinicians for the delivery of fluids and medications as well as for obtaining blood samples.
- Lack of bathroom facilities for the patient's to have a shower or bath due to their body posture. The individual is not able to sit on a standard shower chair.
- Limited support for family members who stay with their child/family member.
- Limited involvement of family members in discussions to ensure the care is given in accordance with the patient's needs.

#### Actions in response to Feedback

- A DVD called Freddie's story is on the hospital e-learning site for the staff to see. It gives insight into a patient's journey through hospital. The patient has learning disabilities.
- Transitions Team in City Children's Community Service CQUIN initiative. The team will visit all year 9 pupils. If they feel a person coming up to 16 years of age has a learning disability they will inform the Learning Disability Acute Liaison Nurse Team (LDALN). To date the LDALN team have had three referrals with home visits planned this month.
- The team is currently promoting within the hospital the use of the Emergency Grabsheet, the Traffic Light Hospital Booklet and the DisDAT Tool for patients with learning disability. The forms can also be found on the Betterlives website at <a href="http://www.betterlives.org.uk/learning-disability-acute-liaison-nursing-team/">http://www.betterlives.org.uk/learning-disability-acute-liaison-nursing-team/</a>

# The Future

To look at ways of increasing awareness of the needs of patients with a learning disability.

What carers and the LDALN team would like to happen:

- Joint handover appointments required between Consultants within child and adult services prior to discharge from child services as a priority.
- To involve the learning disability acute liaison nurse team in the transition process.
- To promote the use of the dependency scale for patients with learning disabilities to assess the level of risk/support needed.
- To develop a rolling plan of learning disability awareness sessions for Trust personnel/ clinical teams and to develop an e-learning package.
- All hospital clinical personnel to undertake the above learning disability awareness sessions and e-learning package when devised.
- All clinical areas to refer to the learning disability acute liaison nurse team when someone with a learning disability is admitted.
- To continue to disseminate the patient feedback diary.

## **Recommendations:**

The Trust Board is asked to :

- Receive and listen to this carer's story
- Support the improvements/recommendations identified in response to the feedback.

Previously considered at another corporate UHL Committee? No

## Strategic Risk Register: N/A Performance KPIs year to date: N/A

Resource Implications (eg Financial, HR): N/A

## Assurance Implications:

This paper provides assurance that the Learning Disabilities Team are listening and acting upon patient / carer feedback to improve patient's experience of care

Patient and Public Involvement (PPI) Implications: Carer has been encouraged to share story at the Trust Board

Stakeholder Engagement Implications: N/A

**Equality Impact:** Feedback taken from a carer who cares for a person with learning disabilities

Information exempt from Disclosure: N/A

Requirement for further review? None