Improving the experience of acute hospital care for people with a learning disability within Hywel Dda University Health Board

Duration: November 2015 – June 2017
Keywords: Learning disability, hospital care, collaboration, co-production

Project background
The number of people living with a learning disability continues to grow as people live longer and young people with complex disabilities survive into adulthood. It is widely acknowledged that people with a learning disability have greater healthcare needs and are almost twice as likely to attend a general hospital for acute care than the general population. Reports, including those by the charity Mencap, have consistently highlighted the poor experience and poor health outcomes – including premature and avoidable death – of people with a learning disability in general hospital services. In 2011 an inquiry by the Ombudsman for Wales looked into the death of Paul Ridd, a man who had severe learning disabilities. The inquiry found his nursing care on the general ward to be ‘abject and below reasonable standards’. Recommendations set out in the subsequent report by Public Health Wales were made into a care bundle that was launched in 2014. At the start of this Patients First project, Hywel Dda University Health Board was at the initial stages of implementing the learning disability acute care bundle.

Aim
The aim of the project was to work with people with learning disabilities to develop and co-deliver meaningful facilitated learning sessions for one ward in a district general hospital. It was hoped that providing learning sessions would improve the hospital experience and health outcomes for people with a learning disability. It was anticipated that the learning from the pilot ward would enable other areas to be included at a later date.

Implications for practice
• Identifying and collaborating with stakeholders is key at the start of a project
• Listening and hearing the views of stakeholders is important to help guide the service improvement
• Co-presenting the learning sessions with a service user is a powerful learning tool in itself

This project was supported by the FoNS Patients First Programme in partnership with The Burdett Trust for Nursing

Online
Further information about the project can be accessed from: fons.org/library/report-details?nstdid=73056

Key activities and outcomes
• Questionnaires
Before the start of the project, questionnaires were distributed to acute nursing staff; 97% of those who responded requested further information and expressed learning needs in terms of caring for people with a learning disability. A second questionnaire was completed by service users and their carers. The responses included either very positive or very negative feedback.

• Project group meetings
Monthly project group meetings were held, initially with the project lead and three learning disability nurses. However, as the project progressed, the group expanded to include a person with a learning disability and an independent health advocate.

• Stakeholder event
An afternoon tea was held in the offices of Carmarthenshire People First, an organisation that supports adults with learning disabilities. It was well attended by individuals with a learning disability, parent carers, support staff, senior learning disability managers, acute service nursing managers, acute ward staff from local hospitals, learning disability nurses and other professionals. The purpose of the event was to spread information about the project but also to start to develop relationships among the stakeholders. A second afternoon tea stakeholder event was held at the end of the project to provide feedback and outcomes of what had been achieved.

• Focus groups
The project team held focus groups with people with a learning disability, family members and carers and with the acute care staff. All the feedback received during these events was themed and used to develop a series of facilitated learning sessions entitled ‘My Health My Stay’ for the ward staff.

• Facilitated learning sessions
A series of six learning sessions was delivered by the whole project team including the service user. Each session lasted 30 minutes and was held during the handover period. Staff were asked to evaluate the project, which was filmed with their consent (see tinyurl.com/Hyweldda-LD). The ward sister felt the Patients First project had changed the culture on the ward and improved staff members’ ability to respond to the needs of individuals who have a learning disability. Professional links have also been established and ward staff feel confident in knowing who to approach for specialist input. Due to the positive feedback from the ward staff and key stakeholders, it is recommended that the learning from the methods and approaches used with the pilot ward are repeated on other wards within the health board.