Improving the Experience of Acute Hospital Care for People with a Learning Disability within Hywel Dda University Health Board

Project team
Linda Phillips – Community Learning Disability Nurse
Lynsey Davies - Community Learning Disability Nurse
Aimee Crockford - Community Learning Disability Nurse
Laura Andrews – Professional Lead Learning Disability Nursing
Angie Edwards – Member of Carmarthenshire People First
Ffion Davies – Independent Health Advocate

Duration of project
November 2015 – June 2017
Date report submitted: October 2017

Key words
Learning disability, hospital care, collaboration, co-production

Contact details
Linda Phillips, Project lead: linda.phillips@wales.nhs.uk

Supported by the Patients First Programme

Improving Hospital Experience for People With Learning Disabilities

The Journey
<table>
<thead>
<tr>
<th>Easy Read Summary</th>
<th>Patients First: Making hospital Stays Better for People with a Learning Disability</th>
</tr>
</thead>
<tbody>
<tr>
<td>[Image 124x678 to 176x735]</td>
<td><strong>We are Aimee and Laura</strong></td>
</tr>
<tr>
<td><img src="image1.png" alt="Image" /></td>
<td><strong>We are Lynsey and Linda</strong></td>
</tr>
<tr>
<td><img src="image2.png" alt="Image" /></td>
<td><strong>We are learning disability nurses</strong></td>
</tr>
<tr>
<td><img src="image3.png" alt="Image" /></td>
<td><strong>We worked with Angie and Ffion from Carmarthenshire People First</strong></td>
</tr>
<tr>
<td><img src="image4.png" alt="Image" /></td>
<td><strong>There are lots of reports saying hospitals don't always get things right for people with a learning disability</strong></td>
</tr>
<tr>
<td><img src="image5.png" alt="Image" /></td>
<td><strong>We wanted to make things better in our hospitals</strong></td>
</tr>
<tr>
<td>Image</td>
<td>Text</td>
</tr>
<tr>
<td>----------------------------------------------------------------------</td>
<td>----------------------------------------------------------------------</td>
</tr>
<tr>
<td><img src="image" alt="Image of green box" /></td>
<td>We gave every ward a green box with things they would need to help people with a learning disability have a better stay</td>
</tr>
<tr>
<td><img src="image" alt="Image of cross symbol" /></td>
<td>We asked people with a learning disability what it is like being in hospital</td>
</tr>
<tr>
<td><img src="image" alt="Image of people filling out forms" /></td>
<td>We did this by filling in forms and talking in a group</td>
</tr>
<tr>
<td><img src="image" alt="Image of people at a table" /></td>
<td>We also asked carers and nurses</td>
</tr>
<tr>
<td><img src="image" alt="Image of person pointing to flip chart" /></td>
<td>We listened to what people had to say and made a teaching plan</td>
</tr>
<tr>
<td>How to talk to you and listen to you</td>
<td>How nurses can help if you become upset or angry in hospital</td>
</tr>
<tr>
<td>Things that can help you on the ward</td>
<td>How we can help you get the right support on the ward and how the learning disability service can help</td>
</tr>
<tr>
<td>We worked with the nurses on the ward. The nurses said this helped</td>
<td>We want people with a learning disability to tell us if this has helped. There are forms in the green box for people to fill in</td>
</tr>
<tr>
<td>We have told other people about our project and are going to write about it so other nurses can learn</td>
<td>We want to teach nurses on other wards how to make things better for people with a learning disability</td>
</tr>
</tbody>
</table>

**Background**

The population 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 well proven 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 (National Patient Safety Agency, 2004).
Reports 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 (Mencap 2007, 2012; Michael, 2008; Heslop et al., 2013).

In 2011 an inquiry by the Ombudsman for Wales looked into the death of Paul Ridd, a gentleman who had severe learning disabilities. It found his nursing care on the general ward to be “abject and below reasonable standards”. The inquiry made recommendations to improve hospital care for patients who have a learning disability by introducing learning disability awareness training for staff, reminders for staff about appropriate care, and relevant audits and inspections. These recommendations were made into a care bundle that was launched in 2014 (Public Health Wales, 2014). At the start of this Patients First project, Hywel Dda University Health Board (HDUHB) was at the initial stages of implementing the Learning Disability Acute Care Bundle.

A review of the literature revealed that general hospital staff had negative attitudes towards, and were less confident, in working with patients who had learning disabilities than those with a physical disability (Lewis and Stenfert-Kroese, 2010). Also people with a learning disability and their carers perceived that staff tended to lack experience and knowledge of caring for people with a learning disability (Webber, 2010). The same literature also made recommendations for improving practice. One recommendation was education and training for all hospital staff, preferably delivered by people who had a learning disability themselves. By involving people with a learning disability in the training sessions, better outcomes and a greater understanding and empathy are reported (McMurray and Beebee, 2007; Thacker et al., 2007).

**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 (initially the aim had been two) in a district general hospital. By providing the learning sessions, it was hoped to improve the hospital experience and health outcomes for people with a learning disability.

**Objectives**
In order to achieve the aim, the following objectives were set:

- Gain agreement and support from the acute care bundle implementation group for the education plan and the rationale behind it
- Carry out a baseline audit of ward staff knowledge and confidence in dealing with patients who have learning disabilities
- Gather the views of people who have a learning disability (and their carers) about their experiences of using general hospital services
- Identify, with the help of the acute services nurse manager, two wards to use as pilot areas.
- Conduct a focus group to establish what information is required by ward staff
- Conduct a focus group with people with a learning disability and with their carers to establish what information they feel is important for the ward staff to know
- Establish a group of key stakeholders. This will involve ‘nurse champions’ from the ward who have an interest in learning disabilities and in taking the project forward;
learning disability nurses; people who have learning disabilities and have experienced general hospital care, along with carers or family members of people who have a learning disability and have experience of supporting the individual in hospital

- Work with the stakeholder group to develop an appropriate education package, based on the knowledge gained from questionnaires and focus groups
- Pilot the learning sessions in two acute areas using tools to evaluate it. The baseline audit will be repeated at the end of training to capture any change in staff's knowledge and confidence in working with patients who have a learning disability
- Use the learning from the pilot ward to enable other hospitals in the health board to be included in the project

Methods and Approaches
A variety of different methods and approaches were used and developed as the project progressed. These are summarised in table 1 below.

Table 1: Outline of key activities and the methods and approaches used

<table>
<thead>
<tr>
<th>Date</th>
<th>Activity</th>
<th>Method/Approach</th>
</tr>
</thead>
<tbody>
<tr>
<td>1-4.6.15</td>
<td>Questionnaire to general hospital staff across 4 hospital sites</td>
<td>Baseline audit of staff knowledge</td>
</tr>
<tr>
<td>11.11.15</td>
<td>1st project group meeting</td>
<td>Clarifying values to create a shared vision to inform the development of an action plan</td>
</tr>
<tr>
<td>19.11.15</td>
<td>1st project group meeting with FoNS practice development facilitator</td>
<td>Evoke cards, shared vision</td>
</tr>
<tr>
<td>2-3.12.15</td>
<td>FoNS workshop</td>
<td>Focus: reflection, facilitation skills, action planning</td>
</tr>
<tr>
<td>6.1.16</td>
<td>2nd project group meeting</td>
<td>Reflection</td>
</tr>
<tr>
<td></td>
<td>Questionnaires to people with a learning disability who have been in hospital</td>
<td></td>
</tr>
<tr>
<td>3.2.16</td>
<td>3rd project group meeting</td>
<td>Update on questionnaires</td>
</tr>
<tr>
<td>4.2.16</td>
<td>Meeting with acute service nursing manger</td>
<td>Ward to pilot project identified</td>
</tr>
<tr>
<td>15.2.16</td>
<td>2nd project group meeting with FoNS practice development facilitator</td>
<td>Claims, concerns and issues exercise in relation to project. Project scaled down to be more achievable within time frame</td>
</tr>
<tr>
<td>3.3.16</td>
<td>FoNS workshop</td>
<td>Focus: Participation - different levels, enhancing participation</td>
</tr>
<tr>
<td>6.4.16</td>
<td>4th project group meeting</td>
<td>Evaluation of patient questionnaires</td>
</tr>
<tr>
<td>19.4.16</td>
<td>1st ward meeting</td>
<td>Questionnaires to establish ward staff knowledge prior to any intervention, values and belief exercise</td>
</tr>
<tr>
<td>29.4.16</td>
<td>Focus group meeting with Carmarthenshire People First whose members all have a learning disability</td>
<td>Claims, concerns and issues exercise re: experience of hospital care</td>
</tr>
<tr>
<td>4.5.16</td>
<td>5th project group meeting</td>
<td>Evaluation of ward questionnaires. Preparation for stakeholder event</td>
</tr>
<tr>
<td>Date</td>
<td>Event</td>
<td>Description</td>
</tr>
<tr>
<td>-----------</td>
<td>----------------------------------------------------------------------</td>
<td>-----------------------------------------------------------------------------</td>
</tr>
<tr>
<td>10.5.16</td>
<td>2nd ward meeting</td>
<td>Claims concerns and issues exercise re nursing patients who have a learning disability on ward</td>
</tr>
<tr>
<td>17.5.16</td>
<td>Stakeholder event</td>
<td>Afternoon Tea to share project and promote it within the Health Board</td>
</tr>
<tr>
<td>19.5.16</td>
<td>FoNS workshop</td>
<td>Focus: Person-centredness</td>
</tr>
<tr>
<td>25.5.16</td>
<td>Focus group meeting with parents/carers of People with a learning disability</td>
<td>Claims, concerns and issues exercise re: experience of hospital care</td>
</tr>
<tr>
<td>13-17.6.16</td>
<td>Learning Disability Awareness week</td>
<td>Learning disability resource boxes distributed to all wards and departments in each hospital within HDUHB</td>
</tr>
<tr>
<td>27.6.16</td>
<td>Focus group meeting with parents/carers of people with a learning disability</td>
<td>Claims, concerns and issues exercise re: experience of hospital care</td>
</tr>
<tr>
<td>5.7.16</td>
<td>3rd project group meeting with FoNS practice development facilitator</td>
<td>Reflection, action plan</td>
</tr>
<tr>
<td>6.7.16</td>
<td>6th Project group meeting</td>
<td>Themed claims, concerns and issues exercises</td>
</tr>
<tr>
<td>6.9.16</td>
<td>Project group meeting with ward</td>
<td>Identified area of learning to be addressed. Development programme devised</td>
</tr>
<tr>
<td>20.9.16</td>
<td>Learning session 1</td>
<td>Focus on communication</td>
</tr>
<tr>
<td>28.10.16</td>
<td>Learning session 2</td>
<td>Focus on reasonable adjustments</td>
</tr>
<tr>
<td>9.11.16</td>
<td>Learning session 3</td>
<td>Focus on risk dependency assessment</td>
</tr>
<tr>
<td>21-22.11.16</td>
<td>Strengthening the Commitment Conference - Cardiff</td>
<td>Presentation of project and best in conference poster</td>
</tr>
<tr>
<td>14.2.17</td>
<td>Recap of Learning session 1</td>
<td></td>
</tr>
<tr>
<td>28.2.17</td>
<td>Recap of Learning sessions 2 &amp; 3</td>
<td></td>
</tr>
<tr>
<td>14.3.17</td>
<td>Learning session 4</td>
<td>Focus on challenging behaviour</td>
</tr>
<tr>
<td>28.3.17</td>
<td>Learning session 5</td>
<td>Focus on specialist roles</td>
</tr>
<tr>
<td>5-6.4.17</td>
<td>Positive Choice Conference - Hull</td>
<td>Whirlwind Café to share the project</td>
</tr>
<tr>
<td>10.4.17</td>
<td>Learning session 6</td>
<td>Recap of sessions, contact details and evaluation</td>
</tr>
<tr>
<td>19.4.17</td>
<td>Video production</td>
<td>Project evaluation</td>
</tr>
<tr>
<td>9.5.17</td>
<td>Stakeholder event</td>
<td>Disseminate project findings to stakeholders</td>
</tr>
<tr>
<td>May 17</td>
<td>Report writing including production of accessible information</td>
<td>Project evaluation</td>
</tr>
<tr>
<td>9.6.17</td>
<td>Innovation in practice conference - Swansea</td>
<td>Disseminate project via poster presentation</td>
</tr>
</tbody>
</table>

**Questionnaires**

**Acute hospital staff**

Prior to the commencement of the project, questionnaires were randomly distributed to 8 departments in each hospital site within HDUHB. These were validated audit tools taken from the National Audit of Learning Disability Feasibility Study (Royal College of Psychiatrists, 2014). This was to obtain a baseline audit of the knowledge and confidence of hospital staff in working with a patient who has learning disabilities. The staff questionnaires produced very similar results across the health board; 97% of staff requested further information and expressed learning needs about caring for people with a learning disability.
There were also some concerning comments where a number of staff did not feel it was their job to provide care to patients with a learning disability.

The same questionnaires were provided to staff on the pilot ward before and following the learning sessions to assist in the evaluation of the intervention (see section on Facilitated learning sessions below).

Service user and carer
A sample of 40 individuals with a learning disability were selected across four Community Teams - Learning Disability (CTLD) in Hywel Dda. Community Nurses in each CTLD were asked to identify 10 individuals from their locality who had recently received general hospital care. In addition to this, participants were recruited by the Independent Health Advocate, and via the Mencap carer service. Each person was sent a service user questionnaire and carer questionnaire. Again, these were validated audit tools taken from the National Audit of Learning Disability Feasibility Study (Royal College of Psychiatrists, 2014). The questionnaires were sent out to participants in February 2016, each had a prepaid envelope and participants were asked to return them by the 18th March 2016. The Individual and carer questionnaires were examined by the project team and basic information obtained. However, due to the project team’s lack of skills in data analysis and work constraints of the Health Board’s Clinical Audit and Effectiveness Department, a full analysis of the data was not achieved until May 2017 (see Appendix 1 for report containing the data).

The data provided by the questionnaires appeared to give mixed responses from individuals and carers about their experiences of hospital care. The majority of individuals said it was not easy to ask their doctor questions, with just under half of participants confirming that they did not understand why they were in hospital. This lack of understanding may have contributed to the high number of individuals who felt unable to ask their doctor questions about their health during their stay. Unfortunately, when asked “Would it be okay to stay in this hospital again”, only five individuals said “yes”. The carers of people with a learning disability were usually family members, unpaid carers or paid carers. Out of the data collected, the majority of respondents were from paid carers. When analysing the data collected, the results appear to be polarised with either very positive or very negative feedback. It is uncertain if this is an accurate reflection on experiences or whether carers who had an average experience were not motivated to respond. There appeared to be no significant differences observed between the responses from family carers or paid carers in terms of experiences of hospital care, as both groups provided positive and negative responses. A common theme that emerged from the data across all hospital sites was that the hospital passports were not being used by ward staff. Also, comments were made that hospital staff should receive training to have a better understanding of learning disability issues. Some of the comments taken directly from the questionnaires can be seen below:

“Nursing staff and doctors should learn how to deal with learning disability as they didn’t have a clue”
“The hospital did everything well”
“Staff on the ward had obviously not read the hospital passport before caring for the individual. She was asked if she had children or does she walk etc. and seemed unaware of
**Project group meetings**

Monthly project group meetings were held initially with the project lead and 3 learning disability nurses. However, as the project progressed so the group expanded and included a person with a learning disability and an independent health advocate. Carer representation was sought however this was difficult to arrange. Instead the Mencap carer group was kept informed by updates through minutes which were taken at each project meeting.

A variety of facilitation methods and approaches were used in the project meetings. These developed as the project proceeded to meet the ongoing requirements, and different ways of working were needed at different times. Initially a values clarification exercise (Manley et al., 2011) was undertaken to develop a shared vision. This exercise involved sharing individual experiences of supporting people who have a learning disability in hospital and discussing how each team member felt about it. We agreed the ultimate purpose of the project would be that everyone who has a learning disability would receive the best possible experience of using general hospitals in Hywel Dda University Health Board. This provided us with a shared vision to build our action plans on. The values clarification exercise also highlighted the different strengths of the project team members as some were more passionate about researching the issues, or teaching ward staff, or petitioning managers in meetings to achieve the goal. This provided a sense of direction and promoted collaborative working within the project, for without a shared sense of purpose it would be difficult to elicit any change in practice. Other facilitation methods used in the project meetings included the use of critical reflection to explore and learn from the team’s actions (Rolfe et al., 2001). Reflection enabled the project team to change the approach when things didn’t work out. It was through reflection that an alternative source of engaging with acute hospital staff was found. Also, it was a way through which the enormity of the project was identified and the project scaled down. Through discussion with the FoNS practice development facilitator, it was agreed to change the emphasis of providing a development programme for two ward areas, to an approach of facilitating a learning experience to help change culture and practice on one ward.

The project was evaluated as it progressed and achievements or difficulties documented along the way. Celebrating the successes or “Golden Moments” was used to keep the momentum of the project going when things were slow to happen.
As previously mentioned, successes or “Golden Moments” have been used in the evaluation of the project. One such “Golden Moment” was the first stakeholder event. An afternoon tea was held in the offices of Carmarthenshire People First. 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 2 of the local hospitals, learning disability nurses and other professionals. Also in attendance were the family of Paul Ridd, the gentleman who had a learning disability and died in a neighbouring Health Board. It was due to Paul’s death that the Welsh Government launched the Acute Care Bundles, which was where the impetus for improving the care of people with a learning disability had come from. His family shared their story with those at the afternoon tea and had a big impact, especially on the acute staff. Feedback comments received on the day included “very good – feel inspired to provide better patient care”, “today was a pleasure, we were so glad we made the effort to come. Your enthusiasm is inspirational. We all have a common goal and hopefully will make things better together”.

A second afternoon tea stakeholder event was held at the end of the project to provide feedback and outcomes of what was achieved.

**Focus groups**

Focus groups were instrumental in informing the direction of the project. Skills learnt during the FoNS workshops were used to facilitate the focus groups. These included active listening, giving and receiving constructive feedback and asking enabling questions.
With people with a learning disability

One group was held with members of Carmarthenshire People First who all have a learning disability. Quality refreshments were provided to help the members feel valued and to show that their contribution was appreciated. A claims, concerns and issues (CCI) exercise (Guba and Lincoln, 1989) was undertaken but adapted to meet the needs of individuals with a learning disability. Three questions were written on separate flip chart paper and put on the wall. These questions were; what is good about being in hospital, what is bad about being in hospital and would make being in hospital better. Members were given post its and help was offered to those who couldn’t write or had difficulty in expressing themselves. Each person was then invited to place their post it on the relevant flip chart paper (see Table 2 below). Members felt that they were able to have a voice and that their suggestions would make a difference.

Table 2: Results from focus group with people with a learning disability

<table>
<thead>
<tr>
<th>Comments from individuals with a learning disability</th>
<th>What is good about being in hospital</th>
<th>What is bad about being in hospital</th>
<th>What would make things better</th>
</tr>
</thead>
<tbody>
<tr>
<td>“Nurses were nice and helpful”</td>
<td>“Nurses were kind to me”</td>
<td>“Greet me with a smile”</td>
<td></td>
</tr>
<tr>
<td>“Had my own room and privacy”</td>
<td>“I felt safe”</td>
<td>“Staff need to explain what you can and can’t do in hospital eg. Going for a walk and to the toilet”</td>
<td></td>
</tr>
<tr>
<td>“Lots of people came to visit me”</td>
<td>“Things were explained to me”</td>
<td>“Allow me to have more than 2 visitors at a time”</td>
<td></td>
</tr>
<tr>
<td>“I liked the food”</td>
<td>“Nurses were nice”</td>
<td>“Doctors should take extra care of you and show you some respect – talk to you not just your carers”</td>
<td></td>
</tr>
<tr>
<td>“The bed was comfortable”</td>
<td>“Mami held my hand”</td>
<td>“Be on time”</td>
<td></td>
</tr>
<tr>
<td>“My carers were with me”</td>
<td>“Paramedics were nice”</td>
<td>“Let family know when you are coming out of theatre so you are not by yourself”</td>
<td></td>
</tr>
<tr>
<td>“I was scared”</td>
<td></td>
<td>“Temperature controls on ward as it can be very hot”</td>
<td></td>
</tr>
<tr>
<td>“My grandmother died in hospital so I’m afraid to go by myself”</td>
<td></td>
<td>“To have a dayroom or equivalent as I don’t like being in bed all the time”</td>
<td></td>
</tr>
<tr>
<td>“I get lost in hospitals and get panicky”</td>
<td></td>
<td>“More information in a way I can understand especially about my tablets”</td>
<td></td>
</tr>
</tbody>
</table>
With family carers
Two other groups were held with family carers of people who have a learning disability, one at the Mencap carers meeting in Carmarthen and the other at their meeting in Llanelli. The same approach was used in providing quality refreshments and undertaking a CCI exercise. It was decided to keep the questions the same for ease of theming the results (see Table 3 below). Again carers were enthusiastic to contribute to the exercise expressing the wish that their experiences would make a difference.

Table 3: Results from family carers of people with a learning disability

<table>
<thead>
<tr>
<th>Comments from Carers focus group</th>
<th>What is Good about being in hospital</th>
<th>What is bad about being in hospital</th>
<th>What would make things better</th>
</tr>
</thead>
<tbody>
<tr>
<td>“Can’t praise the nurses enough – very helpful and supportive”</td>
<td>“Can’t praise the nurses enough – very helpful and supportive”</td>
<td>“Cannot be listened to when I’m the expert in my daughter!”</td>
<td>“Dedicated LD liaison nurses based in the hospital”</td>
</tr>
<tr>
<td>“Great to have had a dedicated LD nurse when my daughter was in Bristol Hospital”</td>
<td>“Great to have had a dedicated LD nurse when my daughter was in Bristol Hospital”</td>
<td>“Not being listened to when I’m the expert in my daughter!”</td>
<td>“Being able to stay in hospital 24 hrs a day with our severely disabled daughter is a must”</td>
</tr>
<tr>
<td>“Nurses are very reassuring”</td>
<td>“Nurses are very reassuring”</td>
<td>“Having to wait a very long time for treatment”</td>
<td>“Volunteers with a LD working on the ward so LD is seen every day as something not to be scared of”</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>“Wifi internet connection”</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>“Doctors need to treat patients according to their size, weight and abilities – not purely in an age appropriate way”</td>
</tr>
</tbody>
</table>
With the ward staff
Monthly focus group meetings were also held on the ward with key members of staff and the project group. Cleddau Ward is a 15-bedded surgical ward which includes a 6-bedded assessment unit that may care for individuals with a learning disability when they are admitted for any surgical intervention. It is newly established and fully staffed, which was hoped to ease attendance at meetings etc. The focus group meetings were held from 2.15pm to 2.45pm during the handover period and quality refreshments were provided. The refreshments were not only for those who attended but were taken back to colleagues to ensure everyone felt included and the profile of learning disability issues was raised on the ward. Again, a variety of facilitation methods were used depending on the situation. A values clarification exercise was undertaken to find out how ward staff perceived patients with a learning disability. Also a claims, concerns and issues exercise was undertaking asking the same 3 questions that were posed to individuals with a learning disability and to their carers (see Table 4).

Table 4: Results from the focus group with ward staff

<table>
<thead>
<tr>
<th>Comments from Ward staff focus group</th>
<th>What is Good about being in hospital</th>
<th>What is bad about being in hospital</th>
<th>What would make things better</th>
</tr>
</thead>
<tbody>
<tr>
<td>“Able to communicate with patients and understand their like and dislikes”</td>
<td>“Time (9 surgical beds, 6 assessment beds with 1 nurse and 1 NA)”</td>
<td>“Better communication (own personal skills)”</td>
<td></td>
</tr>
<tr>
<td>“Having carers with them”</td>
<td>“Passport not being up to date (recent difficulty with a patient’s mobility)”</td>
<td>“Up to date passports or where to get up to date information from”</td>
<td></td>
</tr>
<tr>
<td>“Good rapport with carers”</td>
<td>“Difficult carers – not giving information”</td>
<td>“Contact numbers for CTLDs”</td>
<td></td>
</tr>
<tr>
<td>“Carers able to stay with patient”</td>
<td>“Quality of carers – may be support workers or bank staff who do not know the person well”</td>
<td>“Resource boxes”</td>
<td></td>
</tr>
<tr>
<td>“Having familiar items with them”</td>
<td></td>
<td>“More training days”</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>“More information on learning disabilities”</td>
<td></td>
</tr>
</tbody>
</table>
The project group examined the responses from all the focus groups. It was very interesting to see that all groups (people with a learning disability, carers and ward staff) had the same concerns and all felt that further information and development in these areas would improve patient experience.

**Facilitated learning sessions**

The results of the focus groups were taken back to the ward meeting and staff asked what development was needed to address the issues raised. From these discussions, a series of facilitated learning sessions entitled “My Health My Stay” was developed. (See below and see Appendix 2).

This learning sessions consisted of 6 sessions:

- Communication
- Reasonable adjustments
- risk dependency assessment
- Challenging behaviour
- Specialist roles
- and a final session to recap and advise re how to contact LD services

Each session lasted 30 minutes and was held during the hand over period between 2.15pm – 2.45 pm. Initially further sessions were arranged at the end of each session to accommodate maximum attendance due to staff rotas etc, however it was found the timing was ad hoc, the gaps were too long and the momentum was lost. In January 2017, it was decided to facilitate the sessions on a regular fortnightly basis which ended up working very well. The project team facilitated the sessions, which consisted of learning disability nurses and the member who has a learning disability who was supported by the health advocate. Each session started with teaching “sign along” core signs to re-enforce the importance of communication and which acted as an ice-breaker. The key issues were addressed in an interactive style with the ward staff being engaged directly in the activity e.g. completing a risk dependency assessment with support. They were also asked to complete activities following each session e.g. identifying accessible information relevant to procedures carried out on the ward or completing a reflective account of supporting a patient with a learning disability who exhibited challenging behaviour. Wherever possible, the same ward staff attended allowing for continuity of training, and included a mixture of qualified and unqualified staff.
Following the six learning sessions, the staff who had participated were invited to complete questionnaires. As they were anonymous, it was not established if the same staff completed both pre- and post-training questionnaire so individual changes in knowledge and confidence could not be identified. Eight questionnaires were returned this time (for full results see Appendix 3).

Some of the comments staff made were:

“The learning sessions provided good insight into what to do when caring for patients with a disability”

“Following the sessions I feel it has broadened the knowledge of staff on the ward. It has also allowed us to develop a good rapport with staff from the LD team and also allowed us to have access to who we need to contact and how to fill in risk assessments”

“Very informative helpful sessions regarding nursing patients with learning disabilities. The sessions have addressed aspects I have not been aware about. Thank you”

“I have benefited a lot from the training with regards to providing the best care possible for people with learning disabilities E.G communication (sign language)”

It must be noted however, that the questionnaires were all self-reported and although the ward staff may feel that the service provided to people with a learning disability has improved, there has not been opportunity to seek the opinion of people with a learning disability themselves or their carers because no people with a learning disability were admitted to the ward following the training. However, patient and carer questionnaires have been left on the ward and will be used to add evidence to the standard of future care provided.

**Presentations at a conference**

Another golden moment occurred in November 2016 when the project was presented as a poster at a national learning disability conference in Cardiff. It was well received with very positive feedback and the poster (see below) won best in conference. The poster was judged by people with a learning disability who found it easy to understand.
The project has also been presented at another national learning disability conference, “Positive Choices 17” where the project team hosted a “whirlwind café” informing learning disability students about the initiative. There has also been a poster presentation at a local “Innovations in Health Care” conference.

**What the future holds**

However, the most encouraging success of the project has been the feedback and evaluation from the ward following the learning sessions. Staff were asked to evaluate the project, which was filmed with their consent ([https://www.youtube.com/watch?v=-OxuRzs3nSg](https://www.youtube.com/watch?v=-OxuRzs3nSg)). The ward sister felt the patients first project had changed the culture on the ward and improved staff’s 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.

The project has been disseminated via report distribution within the directorates in Hywel Dda UHB. Its progress has been discussed at regular management meetings both in learning disability services and acute services. A regular joint meeting between acute and learning disability services has taken on board the findings of the project and continues to progress the recognition of the needs of people with a learning disability within acute services.

The project has been presented at national learning disability conferences, “Strengthening the Commitment” and “Positive Choices 17” and also at local conferences. The project has
been discussed with the Programme Manager of the Learning Disability Transformation Programme in the Health and Social Services Group of the Welsh Government. They would like to be kept informed of any future progress, positive outcomes and next steps for the project and have asked if it can be used as a case study to illustrate issues to ministers.

Discussion
As can be seen above, the facilitated learning sessions for the Cleddau ward staff appear to have made a difference. The areas of concerns raised in the focus groups were all addressed. The results showed a marked improvement of staff’s reported ability to communicate effectively, recognise pain or discomfort in a patient with a learning disability, manage challenging behaviour appropriately, apply the Mental Capacity Act to decisions made in respect of care and how to contact and involve specialist learning disability services. There was also an improvement in the perceived level of care provided on the ward with all staff feeling the care patients with a learning disability receive on Cleddau ward is above average or excellent.

Contact details have been left on the ward of specialist learning disability services who can provide advice and support around individual patients as required. The positive involvement of people with a learning disability in delivering the learning sessions cannot be underestimated. It delivered a positive message to ward staff of capability and challenged preconceived attitudes of ‘handicap’ and ‘inability’ indeed the quality cakes were baked by the member of the team who had a learning disability and tasted better than any the other members of the team could make. This involvement also meant that some of the fears and preconceived ideas were challenged in a non-threatening manner purely by getting to know an individual with a learning disability. Unexpected benefits of the project have included positive changes in the project team, confidence has increased with project members feeling more able to challenge practice on wards. Members of the team have overcome nerves and presented to large conference, the group’s facilitation skills have increased and the team have bonded to the extent that they are now looking to see how they can develop the work and continue to meet. The relationship forged with our learning-disabled member has also increased her confidence to the extent that she taught an entire conference how to sign “hello my name is...”. She has also stated that she enjoyed working with the project and has liked helping the nurses.

This Patients First initiative has been the first project the team has undertaken. It has been a steep learning curve and has only been successful due to the support of the skilled practice development facilitator from the Foundation of Nursing Studies.

If the team were to repeat the project, it would plan to concentrate on changing practice and culture in one area. Initially the plan was to target 2 sites in 2 hospitals with HDUHB, however, this was scaled down to 1 pilot ward which was more achievable in the time frame.

Another change which would be undertaken is to arrange the dates of the development programme in advance with the ward sister. The first date was agreed and then subsequent dates were arranged at the end of the session. This was so the rota was available in order for the project team to co-ordinate diaries and accommodate ward staff off duty etc.
However, the dates were ad hoc, there were long gaps between each session and the momentum was lost. It was then agreed to provide the sessions on a fortnightly basis which worked much better and in fact had a higher attendance rate.

Recommendations
Due to the positive feedback from the ward and key stakeholders, it is recommended that the learning sessions are repeated on every wards and department throughout each hospital within HDUHB. The success of the project has come from asking the ward staff what they feel would improve the experiences of people with a learning disability on their ward and by working alongside them to implement the changes. The issues and culture of each area will be different and so focus groups will need to be undertaken to identify the claims, concerns and issues of each area to provide development programmes specific for each ward and department.

The project has been undertaken by community learning disability nurses, however providing this would not be a sustainable part of their role. Instead it is envisaged that it could be provided as part of the acute learning disability liaison nurse role once the posts have been established within the health board.

This project has evidenced the crucial role of collaboration in raising learning disability awareness and has improved the culture and practice on the pilot ward. If it repeated on wards throughout each hospital site, it will improve the experience of acute hospital care for people with a learning disability within Hywel Dda University Health Board

References


**Acknowledgements**

Many thanks to Professor Ruth Northway for suggesting the Patients First programme and for her support of the project, and also to Caroline Williams for her help in the application process.

The project team would also like to take the opportunity to thank the staff working on Cleddau ward, Glangwili Hospital for their collaboration and support of the project.

And finally thank you to the Foundation of Nursing Studies and the Burdett Trust especially Jo Odell for supporting the project as part of the Patients First Programme
Appendix 1: A report on the experiences of people with a learning disability and their carers when using acute hospital care within the Hywel Dda University Health Board

Introduction
This report examines the findings of an audit of people who have a learning disability (LD) and their carers about their experience of hospital care within the four general hospitals in Hywel Dda University Health Board. This information was needed to provide a baseline for the patients first project and give direction to the areas that require improving.

Method
A sample of 40 individuals with LD were selected across four Community teams in HDUHB. Community Nurses in each CTLD were asked to identify 10 individuals from their locality who had recently received general hospital care. In addition to this, participants were recruited by the Independent Health Advocate, and via the Mencap carer service. Each person was sent a service user questionnaire and carer questionnaire. These were validated audit tools taken from the National Audit of Learning Disability Feasibility Study (Royal College of Psychiatrists, 2014). The questionnaires were sent out to participants in Feb 2016, each had a prepaid envelope and were asked to return them by the 18th March 2016.

Results
15 Carer questionnaires were returned. The results are illustrated in the tables below.
11 questionnaires were returned by people with a learning disability. The results are shown below.
Below, are some direct quotes from participants that have been taken from the questionnaires broken down into hospital localities.

Glangwilli Hospital

“Staff did not take on board the provisions carefully laid down to make the visit as stress free as possible- lots of time and energy went into this and the passport was locked away in the cupboard even though they knew it was there. Staff would not allow family carer to help prepare patient for some of the observation that needed to be done, thus causing unnecessary stress and anxiety. No compassion for the person’s needs”.

“We waited in A&E for 4 hours on chairs with no help in the middle of the night with no information, support and in pain although you had been informed we were coming. The treatment was excellent but everything was difficult for P because of the lack of understanding from both sides. 1:1 support was provided by our staff throughout but no one completed a support assessment to see if this was required so getting our costs back is difficult”.

“Spoke in English to a Welsh speaking patient which was not appropriate. The oncologist judged capabilities and made her decision on first meeting the patient. These judgements were wrong and seemed to coerce the patient to agree by possibly the presentation of the options”.

“All nursing staff on the ward were more than happy to help. Couldn’t have wished for more than the staff gave”.

“The hospitality team were very friendly and spoke to the patient in Welsh to comfort her. The anaesthetist and another Doctor were very person centred, singing the stereophonic while trying to find a vein and talking about the patient interests. However, there was lack of knowledge about personal care and correct positioning of pads and the discharge was sprung on us, not much info re meds and no prescription given”.

Bronglais Hospital

“My daughter is severely mentally and physically handicapped and blind and is unable to communicate in any way. I was involved and kept informed of her treatment. All staff were very sympathetic and helpful in every way. She moved to Tregaron hospital and then to permanent residential care”.

Would it be Okay to stay in this hospital again?

<table>
<thead>
<tr>
<th></th>
<th>Yes</th>
<th>Sometimes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>6</td>
<td>5</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>4</td>
<td>3</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>2</td>
<td>1</td>
<td>0</td>
</tr>
</tbody>
</table>
“I can’t speak too highly of Bronglais Staff and Tregaron. We are lucky to be so near”.

Prince Phillip Hospital

“Very caring and supportive staff – was able to visit at any time of day”.
“There was a student nurse called Steffan who was very attentive and remembered the patient from a previous visit so was reassuring. However, passport not read, Support staff’s opinions were rarely listened to in respect to finding veins (as per person centred care plan). The individual’s parents were not informed of treatment eg bringing out of an induced coma”.
“All nurses should read the hospital passport. This never happened and they were unaware of A’s needs. When support staff tried to explain to nurses about A, it was like talking to a brick wall”.
“Steffan the student nurse spoke to me about birds, Jeff my nurse was very friendly”.
“I don’t like the curvy beds (airflow mattress) I felt bored”.
“Need a better understanding on how to support someone with a LD”.
“Doctor gave my mum time to explain my history with migraines, I would like to speak more for myself and how I feel”.
“Doctor good and very understanding. Still waiting for communication from this appointment”.
“The hospital did everything well”.

Withybush

“Nursing staff and Doctors should learn how to deal with LD as they didn’t have a clue”.
“Treatment in ICU was excellent”.
“Staff on the ward had obviously not read the hospital passport before caring for the individual. She was asked if she had children or does she walk etc. and seemed unaware of her severe LD”.
“Explain things easier, use the hospital passport more, more understanding and training in disabilities”.
“More training about what the hospital passport is”.
“I am very happy to have…. my LD Nurse as she is so lovely and kind and I am very happy since starting with me she has been able to help and explain things about health and chase up outstanding appointments”.

Conclusion

As can be seen the data examined from the questionnaires, appeared to give mixed responses from Individuals and carers about their experience of hospital care. The majority of individuals relayed it was not easy to ask their Doctor questions, with just under half of participants confirmed that they did not understand why they were in hospital. This lack of understanding, may have contributed to the high number of individuals who felt unable to ask their Doctor questions about their health during their stay. Unfortunately, when asked “Would it be okay to stay in this hospital again”, only five individuals said “yes”.
The carers of people with a LD usually consist of family members, unpaid carers or paid carers. Out of the data collected the majority of responses were collect from paid carers. When analysing the data collected, the results appear to be polarised with either very positive or very negative feedback. It is uncertain if this is an accurate reflection on experiences or whether if carers had an average experience they were not motivated to respond. There appeared to be no significant differences observed between the responses from family carer or paid carers experiences of hospital care, as both groups provided positive and negative responses. A common theme that emerged from the data across all hospital sites was that the hospital passports were not used by ward staff. Also, comments were made that hospital staff should receive training to have a better understanding of learning disability issues.

It must be noted however that since the audit in Spring 2016, a number of recommendations from the LD acute care bundle have been implemented, such as LD resource boxes on each ward. Also, there have been visits to each hospital by the Paul Ridd Foundation and so ward staff are becoming more familiar with learning disability issues. It is recommended that Service user and carer questionnaires are added to the resource box and patients with a learning disability and their carers are asked to complete the forms on their discharge. This will provide ongoing evaluation of their experience and the care provided.

Lynsey Davies & Linda Phillips
Community Learning Disability Nurses
9th May 2017
Appendix 2

**TEACHING PLANS**

*Me, the same as you*

**You can make the difference to my stay**

- **Hospital Passport**
  - Communication

- **Engage with me**

- **Adjust**
  - Reasonable Adjustments

- **Learn about me**

- **Talk to my Carers**
  - Risk Dependency Assessment

- **Management plan**
  - Challenging Behaviour

- **Your challenge, not mine**

- **Support to speak up**
  - Our Roles- LD Nurses/Advocacy

- **Trained to support**

- **Advocacy**

- **Your local CTLD**
  - Contact

---

**Session 1: Communication**

1/2 hour session.
2pm arrival.
2.15pm start

**Ice breaker**

Core signs to learn:
1. Hello, my name is.......  
2. My role is.............  
3. Have you got a Health Passport?

Go through Health Passport
Go through Hospital Communication Book
Re-cap of core signs
Sign post to the Easy health resource website that can be accessed via intranet.
**Work Book Task:**
Develop a communication aid that is relevant to your ward area.
For example- ask staff to come up with a list of pictures that can be made into a key ring to hang at the end of patient’s beds i.e. objects of reference

<table>
<thead>
<tr>
<th><strong>Session 2: Reasonable Adjustments</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>1/2 hour session.</td>
</tr>
<tr>
<td>2pm arrival.</td>
</tr>
<tr>
<td>2.15pm start</td>
</tr>
</tbody>
</table>

**Ice breaker**
Core signs to learn:  1. Happy/Sad  
  2. Scared  
  3. Anxious  
  4. Hot/Cold  
  5. Pain

What is a Reasonable Adjustment? (Give Definition), what is the legislation?
Mention time, Mental Capacity Act & Best Interest decisions.
**Case Study** (Laura) – 1 simple, 1 complicated
**Patient Story** (re: Sleep Systems & Autism) – link to challenging behaviour also.
Re-cap of core signs

**Work Book Task:**
What reasonable adjustments can you see being needed on your ward?  
How would you do it?

<table>
<thead>
<tr>
<th><strong>Session 3: Risk Dependency Assessment</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>1/2 hour session.</td>
</tr>
<tr>
<td>2pm arrival.</td>
</tr>
<tr>
<td>2.15pm start</td>
</tr>
</tbody>
</table>

**Ice breaker:**
Core signs to learn:  1. Hungry/Thirsty  
  2. Walk  
  3. Toilet  
  4. Carers  
  5. Eat/Drink  
  6. Carers

Go through Risk Dependency Assessment Form- emphasise that non-qualifieds can also complete.
Give examples of where it has worked/not worked (example from Linda)
Refer to Resource Box/Admission Process for People with a Learning Disability
Re-cap of core signs

**Work Book Task:**
Using the scenario, complete a Risk Dependency Form for the patient.

<table>
<thead>
<tr>
<th><strong>Session 4: Challenging Behaviour</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>1/2 hour session.</td>
</tr>
<tr>
<td>2pm arrival.</td>
</tr>
<tr>
<td>2.15pm start</td>
</tr>
</tbody>
</table>

**Ice breaker**
Core signs to learn:  1. Pain
2. Angry
3. Scared
4. Anxious
5. Calm down

Take staff through- what is a behaviour management plan? known triggers i.e. not doing them, understanding what their baseline is, anxiety linked with hospital, behaviour always has a function, don’t personalise behaviour etc.

“Tool Box Talk”- Laura
Angie/Ffion to act out role play
Re-cap of signs

Work Book Task:
Scenario/ or think of a time you’ve experienced working with someone with challenging behaviour- complete a reflection on this.
Or
Role Play: Give us a scenario and see how we would respond to it.

Session 5: Our Roles (Advocacy/LD Nurse)
1/2 hour session.
2pm arrival.
2.15pm start

Ice breaker:
Core signs to learn: 1. I want my ‘Advocate’
2. What is an ‘Advocate’? i.e. Voice, Choice, Control
3. Home

What is an Advocate, how can they help & when to call them
What do LD Nurses do? How can the LD Nurse support you?
Talk through the admission process
Planned/Un-planned admissions- how we can help
Re-cap of signs

Work Book Task:
Checklist for discharge planning- come up with things to do/consider
What can delay discharges?

Session 6: Who to Contact?
1/2 hour session.
2pm arrival.
2.15pm start

Ice breaker:
Re cap of all signs from the sessions
Re-cap of the last 5 sessions
My Health, My Stay
Grab sheet of contact details

Work Book Task:
Bring a file to put all teaching resources together.
Appendix 3: An evaluation of the learning sessions facilitated for Cleddau Ward

Introduction
This report examines the findings of an audit of staff knowledge and confidence in nursing patients who have a learning disability on Cleddau ward in Glangwilli Hospital, Hywel Dda University Health Board. The audit was carried out as part of the Patients First Project, supported by the Foundation of Nursing Studies which aimed to “Improve the experience of acute hospital care for people with a learning disability within Hywel Dda University Health Board”. Questionnaires were also distributed to people with a learning disability who had recent hospital admissions and to their carers to capture their experiences of hospital care.

Cleddau ward is a 15 bedded surgical ward including 6 assessment beds. In February 2016 it was identified by the acute service manager within the hospital as being most suitable to use as the pilot ward due to being newly established, with a full staff compliment who would be eager to embrace any training or suggestions to help improve care. Also, as it has the surgical assessment unit, all people requiring surgery would go through the ward so would capture admissions of people with a learning disability. It was explained that people with medical conditions are now having nursing care provided at home and so only the very ill would be admitted to hospital and would then go to the ward of expertise eg cardiac, respiratory etc. so other wards may not have the volume of patients with a learning disability admitted.

Method
In April 2016, Cleddau staff were invited to complete staff questionnaires to establish a baseline of knowledge and confidence of nursing people with a learning disability. This audit tool was taken from the Royal College of Psychiatrists, National Audit of Learning Disabilities Feasibility Study and had previously been used to obtain data from across Hywel Dda Health Board. 12 questionnaires were returned and the results are shown below. This exercise was repeated with staff on Cleddau ward who had an interest in learning disability issues and became part of the project group. The responses were themed and it was found the same issues were raised across all the focus groups. These results were taken back to the project group meeting and staff asked what were the learning needs that the issues raised. From these discussions, a development programme was devised to specifically address the concerns of ward staff. (see appendix 2)

At the end of the 6 sessions, staff questionnaires were again distributed. As they were anonymous, it was not established if the same staff completed both pre and post training questionnaire. Also, individual changes in knowledge and confidence could not be identified. 8 questionnaires were returned this time and the results are shown in the graphs below. Some of the comments staff made on the questionnaire are also noted.
Results

**Flexibility to Allow extra time for patients**

- Pre-training
- Post-training

---

**Enough staff to allow sufficient time**

- Pre-training
- Post-training

---

**Clear Guidelines around capacity**

- Below average
- Average
- Above average
- Excellent

---

**Understand and recognise the needs of patients with a LD**

- No
- Yes

---

**Communicate effectively with people with a LD**

- Strongly disagree
- Disagree
- Undecided
- Agree
- Strongly agree

---

**Recognise pain or discomfort in patients with a LD**

- Strongly disagree
- Disagree
- Undecided
- Agree
- Strongly agree

---

30
Comments from staff:
Pre-training
“The patients I have come across so far with learning disabilities have had good quality of care, although I do believe further training would increase the quality of care and understanding of learning disabilities”.
“Despite the lack of training provided to care and provide treatment for people with learning disabilities, I feel our ward team still does its best to deliver an above average standard of care within our capabilities”.

31
Post-training
“The training provided good insight into what to do when caring for patients with a disability”
“Following the 5 sessions I feel it has broadened the knowledge of staff on the ward. It has also allowed us to develop a good rapport with staff from the LD team and also allowed us to have access to who we need to contact and how to fill in risk assessments”
“Very informative helpful sessions regarding nursing patients with learning disabilities. The sessions have addressed aspects I have not been aware about. Thank you”
“I have benefited a lot from the training with regards to providing the best care possible for people with learning disabilities E.G communication (sign language)”

Conclusion
As can be seen above, the training sessions provided to Cleddau ward staff appear to have made a difference.

The areas of concerns raised in the focus groups were all addressed through the training. The results showed a marked improvement of staff’s reported ability to communicate effectively, recognise pain or discomfort in a patient with a learning disability, manage challenging behaviour appropriately, apply the Mental Capacity Act to decisions made in respect of care and how to contact and involve specialist learning disability services. It is also seen there is an improvement in the perceived level of care provided on the ward with all staff feeling the care patients with a learning disability receive on Cleddau ward is above average or excellent.

It must be noted however, that the questionnaires were all self reported and that the results may not be indicative of how patients and their carers feel. Patient and carer questionnaires have been left on the ward and will be used to add evidence to the standard of future care provided.

It was interesting to see that even following the training sessions most staff felt further training would help them deliver better care. Contact details of specialist LD services have been left on the ward who can provide advice and support around individual patients as required.

It is hoped that due to the success of the training on the pilot ward, this training can be repeated on other wards across the hospitals through Hywel Dda University Health Board.

Linda Phillips
Community LD Nurse
5th May 2017