Portsmouth Hospitals NHS
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A service evaluation: Has the implementation of a Learning Disability Liaison Service improved the experience of patients with learning disabilities, and their carers, within an acute hospital setting?

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Introduction

This paper reports on a service evaluation that has been undertaken on the Learning Disability Acute Liaison Service which has been recently developed within a large acute hospital in Hampshire. The purpose for conducting this evaluation was to establish whether this new service within the locality proved to be of benefit to patients, and if so to identify ways to further improve the service. In addition, it was felt important to establish whether users of the service understood the liaison role and if so identify how it may benefit them and improve their future hospital experiences. This evaluation also wanted to establish if the liaison role has increased the confidence of hospital staff in meeting the needs of this patient group and to establish whether or not the service had helped to meet carer's needs. There is little research about the effectiveness of this type of service and hence such an evaluation is a timely and important contribution in understanding this new service.

Background and review of literature

People with learning disabilities have the same health needs as the general population; however the prevalence of certain conditions among people with learning disabilities is higher, as are mortality rates for this group of people. It is estimated that people with learning disabilities are 58 times more likely to die before the age of 50 than the general population from illnesses that are preventable and treatable, indicating that some of these deaths are avoidable (Michael, 2008; DOH, 2009a; RCN, 2011a). Despite these well known statistics, there is evidence to suggest that people with learning disabilities are living longer; therefore healthcare services will see a growing number of people coming through their doors with learning disabilities (Emerson *et al*., 2011 and RCN, 2011b). However there is a wealth of evidence that has highlighted that people with learning disabilities have poorer access to mainstream services, and when they do access mainstream services, they are more likely to receive poorer standards of care than the general population (Emerson *et al*., 2011, Gibbs *et al*. 2008, Glasby, 2002, Mencap 2007, Mencap 2012, Michael, 2008, Parliamentary and health services Ombudsman, 2009).

A rapid scoping of the existing literature was undertaken which searched for studies that examined the effectiveness of acute hospital learning disability liaison nurses. Although only one research study on this specific topic was found (MacArthur et al, 2010), some of the other studies that explored the experiences of people with a learning disability when in hospital have provided useful and relevant information. A recent study using interviews with people with learning disabilities accessing hospitals in Liverpool found cases of people with learning disabilities being outraged at their treatment and their specific learning disability needs not being met. Those participants that were generally satisfied with their treatment within this study were outpatients (Dinsmore, 2011). There have been many reasons highlighted for negative experiences such as these, some being that many health professionals do not understand the needs of people with learning disabilities which results in diagnostic overshadowing (Mencap, 2007); a lack of partnership working; not

listening to families and carers (Guidelines and audit implementation network, 2010 and Ombudsman, 2009); people being part of a lower socio-economic group (Disability Rights Commission, 2006; Kerr, 2004; Mencap, 2004); and hospital staff not being aware of the legal framework in which they should work, for example the Mental Capacity Act 2005 and the Disability Discrimination Act 2005 (this has now been superseded by the Equality Act 2010) (Mencap, 2007, and Michael, 2008). Many of these reports have consistently highlighted the action necessary to overcome such issues.

The Improving Health and Lives: Learning Disabilities Observatory (IHaL) was established specifically to obtain information on the health of people with learning disabilities, with one aim being to help hospitals understand better the needs of this population and their families and carers (IHaL,2011). Turner and Robinson (2011) in their IHaL report, highlighted that, despite the legal requirement to make service access equal to all by making reasonable adjustments, some NHS services are not providing this to a sufficient standard. They also identified that the most common solution used to provide reasonable adjustments is to rely on professionals with specialist learning disability training to act as a liaison with all involved.

Many professional bodies have called for the development of learning disability liaison roles within the acute hospital setting (DOH, 2007; DOH 2009a; DOH 2009b; and RCN, 2011b) as part of highlighting the need for learning disability nurse's to help tackle the inequalities faced by people with learning disabilities by either being employed directly within services or from an external supportive role. Northway (2006) has emphasised the uniqueness of learning disability nurses in being the only professional group trained specifically to work with this client group. The Dinsmore study (2011) found that people wanted hospitals to employ learning disability specialists to provide themselves and nursing staff with advice and support.

Acute learning disability liaison nurses, whose role is to support people with learning disabilities and their families/carers during their episodes of care in hospital settings, including support with communication tools and decision making, have been shown to improve services for people with learning disabilities (MacArthur et al 2010; DOH, 2010a; Foster, 2005 and NHS QIS 2009). Particular areas of improvement have been highlighted as preventing challenging behaviour, reduced length of stay, reduced readmissions to hospital, ensuring compliance with legislation, highlighting the needs of people with learning disabilities, and providing solutions to poor practice.

This review of literature found only one piece of research that has focused on the learning disability liaison service (MacArthur et al. 2010). The objective of this piece of research was to identify the impact of a learning disability liaison service on the healthcare experiences of people with a learning disability accessing general hospital care. The authors found that the benefits highlighted were those that directly impacted on care outcomes; the ability to promote effective communication, pre-admission planning, supporting patient compliance, providing support to families and carers and making recommendations for reasonable adjustments. It also outlined that the liaison

nurse has an important part to play in improving the status of people with a learning disability within a general hospital. The study highlighted some shortcomings in the service, however these were linked to the resources rather than the individuals themselves and included the service only being available during office hours; the awareness of the role within the hospital as some staff said they were not aware of the liaison service until they had direct contact; and the fact that the actual staffing levels within the liaison teams were, at times, stretched. Also highlighted within the report are the characteristics of a successful liaison nurse and service, as well as some recommendations for service development including covering evenings and weekends, placing an alert system on patient records, increased promotion of the services, providing a skill mix within the liaison team including a health care support worker, and maintaining commitment for permanent funding of the roles. The researchers of this study emphasise that in the future, when examining the outcomes of liaison services, a range of measures should be used including the contribution of liaison nurse's to individuals, teams and the organisation as a whole but that priority should be given to patient and carer experiences.

The Portsmouth study

The study undertaken in Portsmouth focused on a learning disability liaison service based across a large acute hospital site. The Learning Disability Liaison Service was set up in June 2011, initially consisting of two learning disability nurses employed by Solent NHS Trust. Later, in the September of the same year, a third nurse joined the team employed by a neighbouring NHS Trust. The hospital site is the Queen Alexandra Hospital which is a part of Portsmouth Hospitals NHS Trust, therefore making the service a partnership between three local organisations.

The service runs Monday to Friday 08.30-16.30, and each nurse is part time with another part time role within their respective Learning Disability Service. When working as a liaison nurse, the nurses have an office based on the hospital site. Currently the nurses only work with adults, but are looking into developing a care pathway with paediatric services to work with those in the stage of transition between children and adults services. The only referral criteria is that the patient has a learning disability and is over 18, and referrals can be made by anyone in a variety of ways such as email, telephone calls or face to face, this is to make it as easy as possible to refer.

During the initial set up of the service, the nurses were orientated to the hospital and introduced to key members of the hospital staff such as Matrons of the Clinical Service Centres, Duty Managers, Operational Flow Managers and the Integrated Discharge Team. As the service has developed, the liaison nurses have made introductions with other key members within the hospital and are slowly introducing themselves across the whole range of departments and services. There has been much advertisement of the service within the hospital, aided by the nurses creating a Liaison Service poster which was distributed throughout the hospital and across a wide range of community services.

Aims

The aim of this project was to establish whether the implementation of the Learning Disability Liaison Nurse Service improved the patient and carer experience within the hospital. The research nurse completing the project was employed by Solent NHS Trust, supervision was provided by the Lead Nurse within the Learning Disability Service of Solent NHS Trust and academic support was provided by colleagues from the Centre for Learning Disability Studies at the University of Hertfordshire.

Methods

There were two parts to the data collection, one collecting quantitative data from the liaison nurses' referral records including information such as; how many referrals they received on a monthly basis, the source of the referrals, how many of the referrals were for emergency or elective patient admissions, and how long it took for a referral to be made. This data was collected on a monthly basis for 6 months.

The other part to the data collection involved the use of semi-structured interviews with patients who had a learning disability, one of their carers (paid or a family member, although a community nurse or care manager was interviewed in cases where there were no carers involved) and one member of the hospital staff team who was involved in their care. Due to time constraints, these interviews were not recorded and transcribed, but answers were recorded verbatim onto the interview schedules.

Portsmouth Hospitals NHS Trust and Solent NHS Trust Research Departments were informed of the study, and decided that it could be classified as a service evaluation, meaning that it was therefore not necessary to gain approval from an ethics committee.

However in order for the person with a learning disability to be included within this study, they had to meet certain inclusion criteria these included; being able to consent to taking part in the interview, and having had more than one contact with the liaison nurse. For those patients who could not consent to taking part in the interview but had received more than one contact from the liaison nurse, their carer and a member of hospital staff were still interviewed. This was important as it ensured that some details of the experiences of those patients were captured. The interviews were carried out over a period of 5 months, and 36 people took part including; 12 hospital staff, 7 patients with learning disabilities and 17 carers.

Patients and their carers were approached to take part in the study either during their contact with the liaison nurse, or alternatively the research nurse contacted them after their discharge from hospital. The research nurse completing the study was also one of the liaison nurses within the service being evaluated; therefore some of the patients and carers had been in contact with the research nurse prior to their interview. All participants were

given an information sheet outlining the aims and details of the study and these were also developed into an easy read format.

Originally the researcher anticipated interviewing 40 patients with learning disabilities as well as their carers and a member of ward staff. In total however only 36 people were interviewed even though over the 5 months 115 referrals were made to the service. This was due to a number of factors; the majority of the referrals did not meet the inclusion criteria, many patients with learning disabilities that had more than one visit could not consent resulting in a low representation from this group, and some of the referrals were for the same patient over the 5 months and as they had already been interviewed they were not interviewed again. Four people also declined to take part, three of these being patients with learning disabilities.

Due to time constraints some participants preferred to complete the interviews on their own, therefore taking more of a questionnaire approach, and they sometimes did not return the questionnaire. Some participants, when originally asked at the hospital, agreed to take part but when the researcher approached them again, they did not always return the researcher's calls or emails and it was felt from an ethical view there was a fine balance between approaching a person to take part one or two times and pestering someone. Due to the sensitive nature of the situation for some patients and their family carers, it was felt inappropriate to approach them to take part. Five patients passed away during this project, however some of their carers and ward staff were still willing to participate and be interviewed.

There were two stages to the data analysis. Firstly there was the quantitative data collected from the liaison nurses records which were collated and these have been presented in graphic form. Secondly, a thematic approach to data analysis was adopted to analyse and interpret the qualitative data collected during the interviews (Cresswell, 1998). A thematic approach was considered necessary to uncover salient aspects of the liaison service as experienced by patients with learning disabilities, carers and ward staff. Further, thematic data analysis was an appropriate method given the relatively new research focus and was found to be a useful methodology to analyse data to find themes within the textual data. Using the constant comparative approach data collection and data analysis happened alongside one another to identify commonalities, differences and contradictions (Cresswell, 1998). During the last few interviews, once the researcher was aware of themes already identified, at the end of each interview the researcher then discussed with the participants the current themes to see whether the participants found these themes to be true to their experiences. This was done to improve credibility of the findings (Carpenter and Streubert, 2003). As well as the main researcher completing data analysis the researcher's supervisor also completed data analysis to verify the themes identified.

Quantitative data findings:

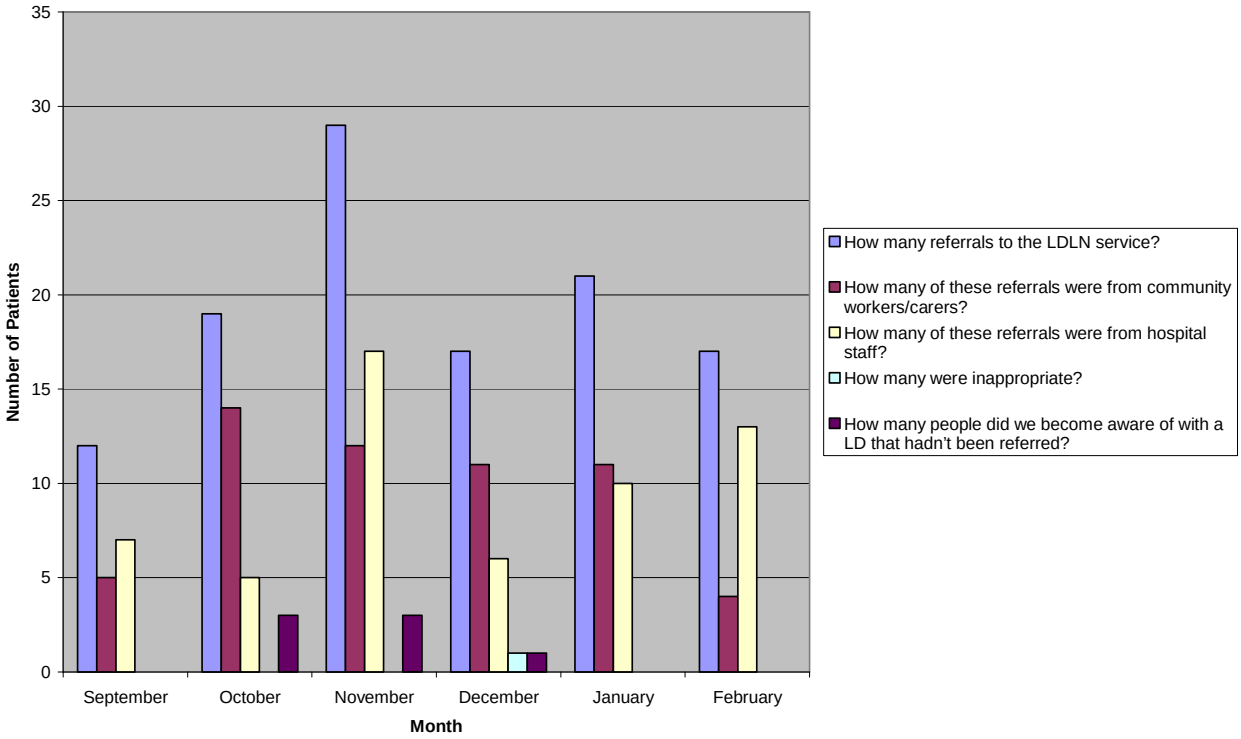
As this liaison service had only been in operation three months when this evaluation commenced, it was felt to be useful to collect the number of referrals made to see if these were increasing.

Table 1 Data on referrals made to the liaison service

	September	October	November	December	January	February
How many referrals to the LDLN service?	12	19	29	17	21	17
How many people did the service become aware of that had not been referred?	0	3	3	1	0	0
How many of the patients were emergency admissions?	7	15	12	12	16	14
How many of the patients were elective admissions?	5	7	20	6	5	3

There is not a continuous increase in referrals but this may reflect how busy the hospital was during those times; however they have never dropped below the amount in September. This may be explained because as time goes on and the service becomes more known, a steady number of referrals are received. The rise in November's referrals is explained by an increase in the number of referrals for elective patients, this was partly down to advertising the service with staff within the pre-operative assessment department of the hospital and the surgical flow managers. The data shows that the majority of the referrals are emergency admissions

Graph 1 A graph to show number and source of referrals to LDLN service

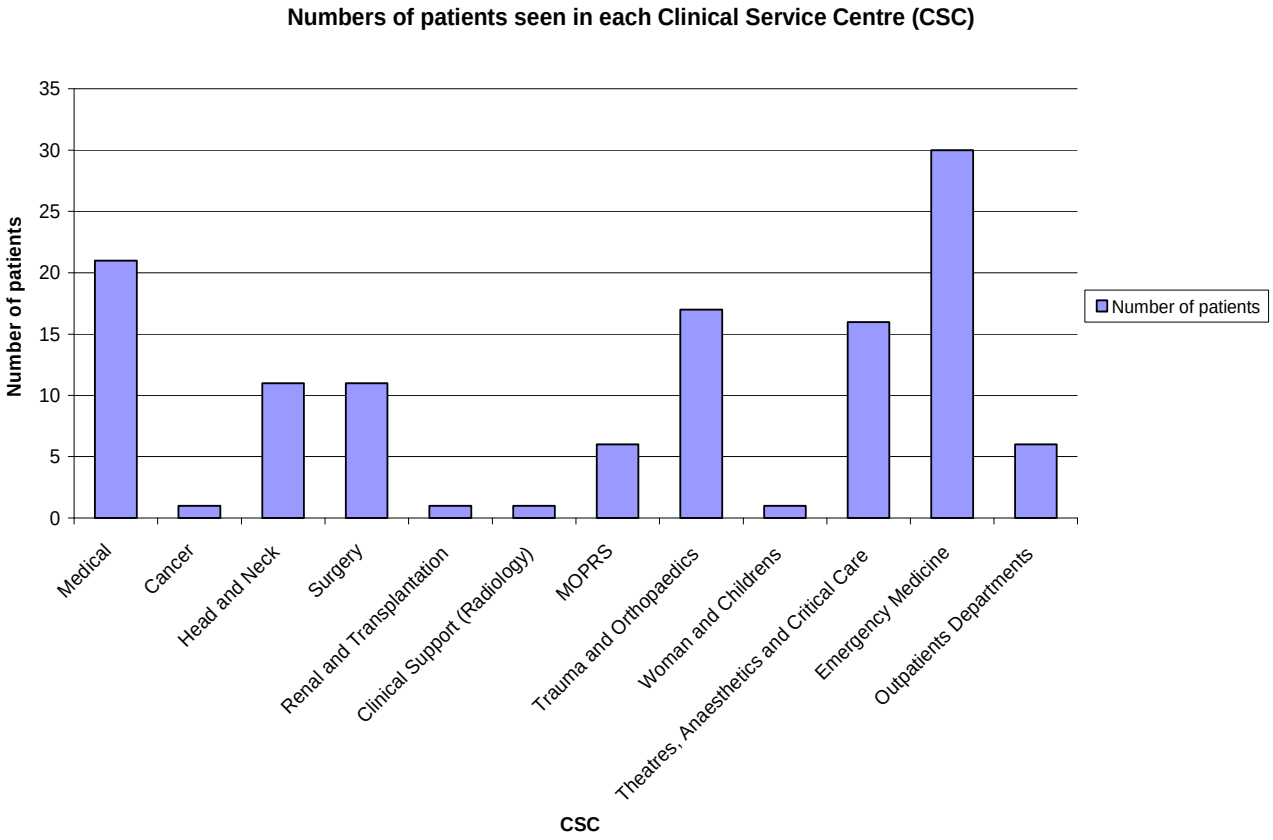


Graph 1 shows the number of referrals on a monthly basis. This is further broken down to identify the source of referral in order to establish whether the hospital staff referred more than the carers.

Graph 1 also shows that the number of inappropriate referrals to the service has been very low. This will be further explained later within the qualitative data that users of the service are aware of the role of the liaison nurse's and with whom they work. However what is shown is that the liaison nurses became aware of patients within the hospital that had not been referred at all by anyone. These patients were found when the liaison nurse was visiting a ward and would come across them. Further exploration would be needed to clarify why these patients have not been referred. A few hypotheses are that they were not recognised as having a learning disability, there was no perceived need for the liaison nurse, or the people involved in their care were not aware the liaison service existed, something that will be discussed later in the qualitative data.

There does not appear to be a marked difference in who refers more, the monthly differences may be explained by how busy each group may be but this would require further exploration. February, however, was a busy time for the hospital with a build up in winter pressures; therefore this could explain why the hospital staff referred more this month.

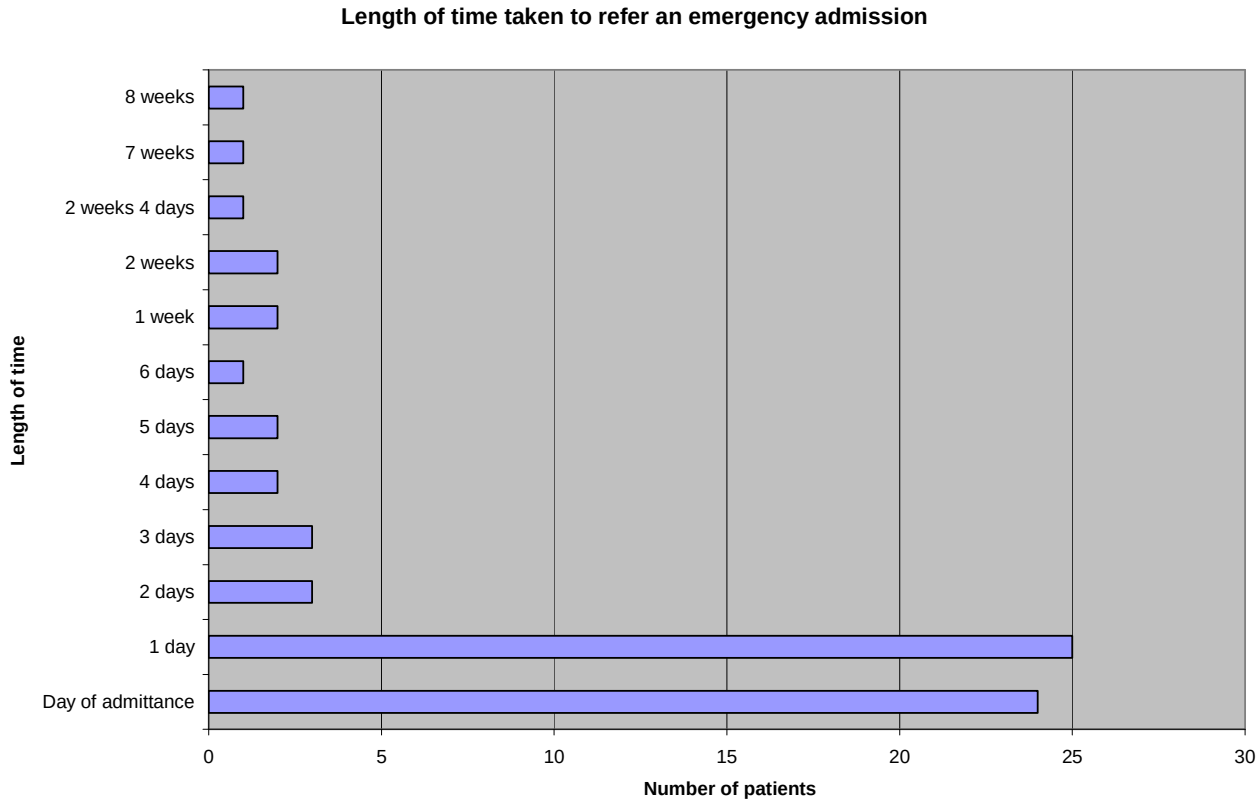
Graph 2 Clinical service centres most used by people with learning disabilities



Graph 2 shows the number of patients over a six month period that used each clinical service centre (CSC). Some of these patients may go through one or more of the CSC's, therefore both services have been counted within the data as some patients will go through emergency medicine then on to another CSC. After emergency medicine it is perhaps not surprising that the medical CSC has the second highest number of patients with learning disabilities as the two leading causes of death for patients with learning disabilities are respiratory conditions and cardiology difficulties (Emerson, 2011).

When completing the interviews, although not identified as a theme, a couple of participants mentioned that if the liaison nurse had been involved earlier it may have changed the outcome such as the patient being able to get home to die. Therefore within the quantitative data the length of time taken to refer an emergency admission was collected. This is represented in Graph 3.

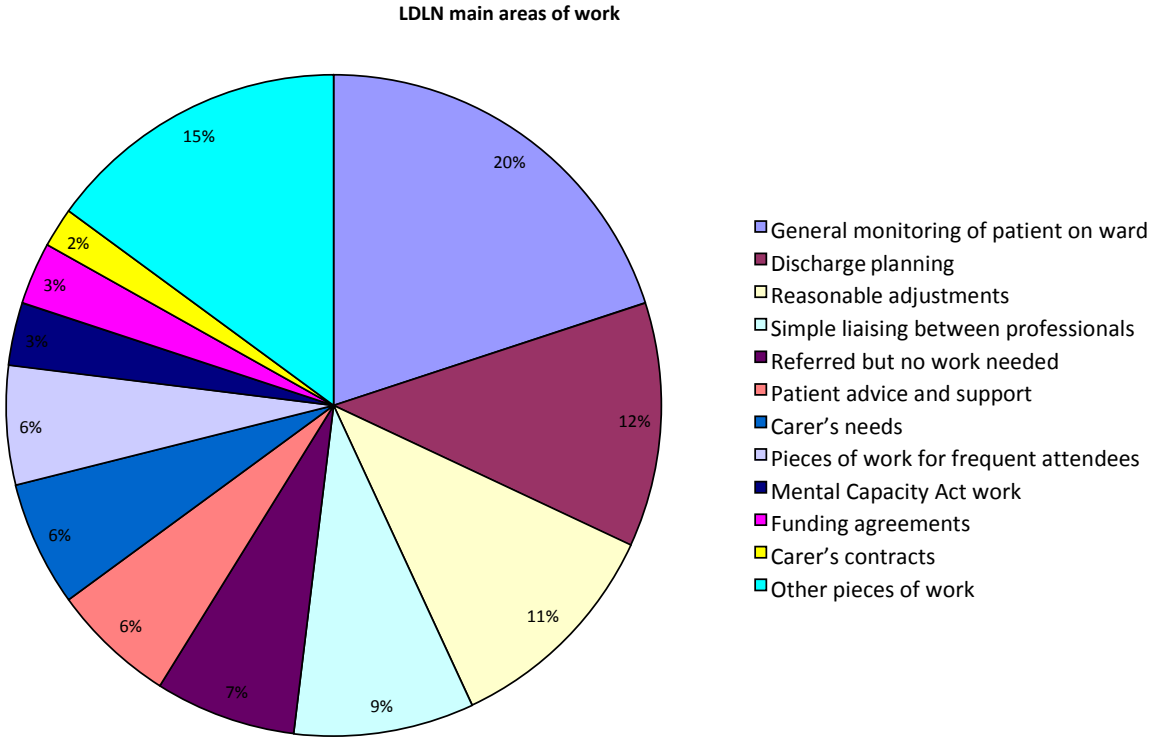
Graph 3 Number of days taken to refer a patient to the liaison service



Graph 3 shows that the majority of emergency admissions are referred either on the same day as being admitted or the following day. For one of those people who said that the referral to the liaison nurse should have been made earlier, two weeks passed before the referral was made. This patient was receiving end of life care and did not get home in time to die. Therefore although the majority of patients are referred quickly, the liaison service needs to highlight the importance of referring more promptly. As part of the liaison nurse's role includes discharge planning and good practice shows discharge planning should happen on admission (DOH, 2010b), if the patient is not referred to the liaison nurse early enough there is a risk that discharge planning will happen too late if hospital staff have not already started the process.

Data was not collected on the time taken to refer a patient coming for elective surgery as the comparison would be the date they found out they required an elective admission and this data was not available. In elective cases it is just as important to refer early because, in those cases where the referral was late, surgery has often been postponed. This was due to other elements not being in place prior to the liaison nurses involvement such as appropriate assessment of capacity and best interest's decisions, as well as putting in place reasonable adjustments.

Graph 4 the types of work the liaison nurses complete for referrals



Graph 4 highlights the main areas of the liaison nurses work. Again, for some patients, there was more than one element and each was counted. For all patients there is liaison between professionals, however 'simple liaison' has been when a referral is simply for the liaison nurse to make sure the hospital staff have everything in place that has been handed over to them by the carer, or passing on a message to the carer from hospital staff.

A number of the carers interviewed said that the liaison nurses helped them to communicate more effectively with hospital staff by listening to what they had to say and passing that information on in a meaningful way to hospital staff. The researcher of this project, as mentioned before, is also one of the liaison nurses and when reflecting with the other liaison nurses upon their role, a large part of it is seen as being an interpreter. They are able to understand what the patient and carer are saying, as well as the hospital staff, and are able to relay this to each party in a way they understand. Also, for some carers, knowing that the liaison nurse had handed over messages was also providing reassurance that everything would be fine in their absence. One mother said 'she just felt she did not have to rush to the hospital every morning to make sure her daughter was ok', and that based on this admission, where the liaison nurse had been involved, communication was much improved.

The liaison nurse's also felt that when they are relaying certain pieces of information to carers, the carers trust the liaison nurse. For example, when a patient is ready for discharge, the carers are assured that this is accurate information when it is relayed by the liaison nurse as they have trust in them.

It is felt in some cases, when they hear this from the hospital staff, they may disagree because they may believe the hospital are trying to discharge too early.

When 'general monitoring' without any specific intervention has been the main piece of work for a referral it is usually for patients who are not known to any service within the community, or who aren't being supported by any familiar carers. Therefore they do not have anyone to advocate for them if required and so the liaison nurse continues to visit and monitor the situation to ensure the patient's stay goes to plan.

Discharge planning has been the main piece of work for 12% of the liaison nurses patients and is a large and important part of the liaison nurses work. This is because the liaison nurse has the understanding of the placements available in the community that the hospital staff do not and an idea of the support that can be provided within these placements. For some patients, when they come into hospital, they cannot return to the placement they were admitted from due to a change in their health needs. Hence the liaison nurse works with the care managers and the hospital social services departments as well as the hospital's discharge planners to aid the discharge process.

Case Study of liaison nurses involvement in discharge planning

The liaison nurses were liaising with the carers of a gentleman named Chris who had moderate learning disabilities, and ward staff, to plan a safe discharge home as he was medically fit for discharge. They agreed to hold a discharge planning meeting the following day as it was felt that his current care package may not have been sufficient.
However when the liaison nurse visited Chris on the ward that afternoon the nurse noticed Chris was becoming increasingly agitated and was saying that he wasn't staying for dinner on the ward as he was going home that afternoon. He was threatening to hurt the nursing staff if they stopped him. Chris did not have the capacity to understand the risks related to this unplanned discharge.

The liaison nurses role here was to implement a plan immediately to facilitate a planned and safe discharge home that evening, because he was not going to stay and was becoming increasingly agitated. The liaison nurse worked with the ward nurse to plan this, with the ward nurse arranging his medications and the liaison nurse liaising with the care manager and home manager to ensure they could implement enough staffing as an emergency for Chris to come home. It was also agreed that the care manager would continue to reassess his level of need once at home. The discharge meeting was still held after Chris had been discharged. So although not ideal, Chris was discharged that evening in a safe manner. The liaison nurse had to make sure the carers were comfortable with Chris coming back last minute but also make them understand that in Chris's mind he was not going to stay in hospital and nothing was going to stop him from returning home.

When interviewed the ward nurse involved in this case study said that the liaison nurse had made the process of planning the discharge much easier, and also made her aware of the patient's agitation. It was also this nurse's first experience of working with a patient with learning disabilities on the ward.

Another important part of the liaison nurses role is ensuring carer's needs are met including; breaks, arranging cheaper car parking fees, and reclining chairs or a bed for use if staying overnight. The liaison service has created a document which outlines the accepted roles and responsibilities of carers when they are supporting a person with learning disabilities in the hospital. This helps to clarify specifically the role of the carer and the role of the ward staff in relation to the care provided to the patient whilst in hospital, as it was reported at times to the liaison nurses that certain elements of care were being missed due to the misconception of who was responsible.

The liaison nurses have also developed written funding agreements. These involve permission being given by the Head of Nursing for the relevant CSC to pay familiar carers to support the patient in hospital. To ensure this is used appropriately and there is a clear rationale for the use, the agreement must outline; why the ward staff are asking for the support, what would happen if the hospital did not pay for this support, how many hours are being paid for and what the hours are to be used for. This came about when the liaison nurses started to receive referrals from ward staff because the patient was refusing food, fluid and medication from the ward staff. In these circumstances the patients paid carers were not insured to provide any care or did not have permission to use the patients social care hours to provide support in the hospital. Usually, within the hospital, they would supply an agency member of staff for when a patient is requiring extra support; however this is still not someone familiar to the patient. It was felt that without the hospital paying the patients familiar carers to provide this care then the patient's needs would be compromised.

On reflection upon these findings, it has become apparent that the liaison nurses role is varied, and very much appreciated by those who have used the service. For some hospital staff they have highlighted how vital and important they see the role, saying that

"The liaison nurses see different things to us, look at the patient's symptoms differently and identify reasons for things that we might not have".

One ward sister said;

"Prior to the liaison nurses being employed I would have asked the hospital trust to employ some but now we have you and it has been an extremely helpful service".

The data collected has shown the number of referrals and the main elements of work but what it has not shown is the complexity and time spent on each referral.

Due to the limited time period of this service evaluation, there was not time to collect data prior to the liaison service being in place. For example the number

of patient and carer complaints, average length of stay, and the number of patients with learning disabilities who had delayed discharges. If we had allowed sufficient time, it would have been beneficial to see whether the numbers of these had dropped since the implementation of the service to try to make a link to whether or not the service has impacted on these figures.

Qualitative data findings

A total of 36 participants took part in this study, 7 were patients with learning disabilities, 12 were hospital staff and 17 were carers. Table 2 outlines the background of the participants and how many from each took part. It shows that there was a variety of hospital staff members, and variety of carers including parents and paid carers.

Table 2 A breakdown of the participants that took part in the study

	Total number who took part
Patients with learning disabilities	7
Hospital staff nurse	5
Hospital senior nurse	4
Hospital support worker	1
Hospital physiotherapist	1
Hospital discharge planner	1
Parent carer	5
Paid carer	5
Community Learning Disability Nurse	5
Community Learning Disability support worker	1
Care manager	1

When completing the thematical analysis of the transcripts, it was decided to analyse the carers, patients and ward staff transcripts individually, and then group them altogether and analyse again to see whether there were themes as one group about the liaison service.

<u>Patients Themes</u>
For the patients with learning disabilities that took part their presenting illnesses to hospital included frequent falls, chest pains and hip replacement. These patients had varying levels of support from carers within the hospital and required varying input from the liaison nurse such as discharge planning, general monitoring and liaison with other professionals.

Understanding the role
The patients interviewed did have an understanding of the role of the liaison nurse and considered that the role was to listen to the patient and help them understand their care in the hospital. The patients described that the liaison

nurses listened to them, visited them and understood them although were not able to describe more specifically what the liaison nurse did for them. This is felt to be because a large part of the liaison nurses work can happen in the background away from the patient. For example the liaison between carers and ward staff or advice to ward staff. This may also be due to the inclusion criteria for this service evaluation requiring patient consent to participate in the interviews. Those who could consent and take part could generally make their needs known on the ward and therefore, did not always require complex input from the liaison nurses. However, for those who could not consent, their carers and ward staff were still interviewed.

A need to enhance communication in the hospital
When patients were asked if there were any improvements the hospital could make, they wished to be kept more up to date. It was reported that the liaison nurses were frequently able to obtain answers on behalf of the patients and listened effectively to the patient.

One patient, Jennifer, whilst waiting for a scan, felt that the ward staff could have been more open about what was happening. When the liaison nurse arrived, they found out for Jennifer that the scan was no longer required and Jennifer was able to go home. Jennifer also suggested that the hospital could be more specific about medication and aftercare advice, using less jargon.

Alan, a gentleman who frequently visits the hospital, also stated that the ward staff needed to keep him up to date with information. However all of the patients commented that the nurses at the hospital on the wards including paediatrics and in the discharge lounge were very friendly.

Although not found as a theme, it would be remiss to leave out some important points made by the patients. One being that their discharge was delayed because they had to wait for their medication. A second point was that a particular patient was admitted to the emergency medicine department and subsequently moved to another ward. This meant that she saw different doctors who gave her different answers within each department.

<u>Carers themes</u>

Enhancing effective communication
A common theme reported was a presence of a communication barrier within the hospital, but the liaison nurse was able to overcome this barrier. The carers reported that they were not always listened to, that there was too much use of medical jargon, and that they experienced difficulties in getting updates and the correct information. Mencap's (2012) recent report highlights families who also report not feeling listened to. For these families they felt the death of their relative may have been avoided if staff had listened to their information.

One community nurse described the liaison nurses presence as bridging the gap between community services and the hospital, being able to get information quicker and understanding one another's language and expectations. For some family carers, they expressed an interest in wanting to

be more involved in ward rounds, reporting that they were never asked to attend. For some patients this would be vital because they cannot relay information to the doctors or the patient does not understand enough to be able to relay to the family what was said. Another family felt that they could only visit during visiting hours and therefore did not attend ward round as it was outside of visiting hours. It was suggested by one parent that the doctor could arrange a set time to meet with the family to discuss patient issues.

Some of the parents described how the liaison nurse relieved some of the stress of communicating with health professionals and being able to translate the families' views into medical language. One parent felt that if the liaison nurse had not been involved, they would have come across as aggressive resulting in not being listened to and further breakdowns in therapeutic relationships.

The liaison nurse promotes a holistic approach to care

Carers reported that the liaison nurse was there to raise awareness of the patient's needs; learning disability needs and their associated health needs. It was felt that the liaison nurses supported the patients stay by ensuring the ward staff were aware of the patients needs, acting as an advocate and bringing together the views of all to promote a holistic approach to care. As mentioned earlier in the report, learning disability nurses are unique in being the only professionals trained to work with people with learning disabilities, and it has been emphasised that learning disability nurses need to be the profession to shape the future for people with learning disabilities by addressing the barriers they face in health care (Northway, 2006). The learning disability liaison nurses fulfil this role effectively within the hospital setting.

<u>Ward staff themes</u>

Understanding the role

Many of the ward staff interviewed considered that the role of the liaison nurse is to support them in the care they provide to patients with learning disabilities, to liaise with other professionals involved in the patients care and to assist the ward with the discharge planning. This does reflect the nature of the work as shown in Table 4. Some ward staff felt they had insufficient time to spend with the patients and that the time the liaison nurse could offer proved productive for all parties.

Lack of knowledge on learning disabilities

When asked what the definition of a learning disability was, many of the hospital staff found this difficult to answer, some being unaware there was a formal definition. It was generally described as a difficulty in learning and/or understanding, and there being a broad spectrum in the way a learning disability can manifest. One member of hospital staff was able to define accurately the definition. It may be of importance to highlight that this staff member had spent time shadowing the liaison service.

When asked what the hospital should be doing for patients with a learning disability, the ward staff requested more training be provided to the staff about learning disabilities. Currently there are training sessions included in the corporate induction, patient experience training, nurse preceptorship, junior doctors training, medical assessment unit training sessions, health care support worker workshops, and bespoke training delivered as requested. These are undertaken by community learning disability nurses and the liaison nurses. There are also resources on the staff intranet and in the past there have been resource folders taken to the wards. In light of all of this training provision, further exploration is needed regarding this ongoing request for training. It may be that hospital staff are not aware training is in place, low attendance at the sessions, or the information presented is not useful and applicable. However, what is reassuring is that the hospital staff are aware that they have limited understanding of learning disabilities. It has been recommended within Healthcare For All (Michael, 2008) that undergraduate and postgraduate courses included mandatory training in learning disabilities and should involve people with learning disabilities in the training.

Themes as a whole group

The transcripts from all three groups were then grouped together and analysed to see whether there were similarities in their answers.

Lack of awareness of the service

When completing the analysis of all participants as one group, it was apparent that a large number of participants did not know the liaison service existed. The majority of those that were not aware were patients and family carers. Although the service has been advertised, on reflection it was mainly with the nurses on the wards and the community teams. One family suggested that details of the liaison service were included in the initial hospital appointment letter, so that patients and their carers could contact the liaison nurses prior to the appointment. The technicalities involved in this process require further exploration.

It would be expected that with more advertisement would come an increase in referrals. It could be possible that the liaison service would have limited capacity to meet an increase in demand, risking criticism that the service is not providing what it set out to do.

Necessity of the service

Many of the participants highlighted the need for the liaison service to remain in existence. Ward staff described the service as ‘a valuable resource’ and stated that ‘the system would fail without it’. Patients described the nurses as ‘helpful and friendly’. For carers, it was helpful that the nurses were on site and many stated that they ‘would not be able to do without the service’.

All participants were asked if there was anything the liaison service could improve upon and a regular response was to ask for more of the nurses or for the current nurses to cover more hours. There are always going to be patients with learning disabilities using the hospital as research shows it is a growing population, therefore there could be a growing demand on the service (Emerson, 2011). Some people felt the nurses were not always available

when they were needed. All three liaison nurses work part time hours therefore there are only two days a week when two nurses are in on the same day. Cover may be limited if there is any sickness, annual leave or it is a weekend. Availability can also be affected by other commitments such as training sessions, meetings, and having a complex case in the hospital which is requiring a lot of the liaison nurses input.

The Access 2 Acute network (an online network of acute learning disability liaison nurses) has recently reported to Mencap that liaison nurses usually cover insufficient hours or are on short term contracts (Mencap, 2012). This recent report calls for all acute services to employ learning disability liaison nurses as they have a major role to play in providing reasonable adjustments and providing specialist support to the hospital staff.

All carers and patients were asked if they had had a past experience of being in the hospital without the assistance of a liaison nurse. Mainly the carers were able to recall experiences for many they did not have a positive experience. For a few parents they were very keen to take part in the evaluation to be able to compare their experiences. One mother who provides 24 hour support to her son in hospital was unable to during one admission as she was not allowed to provide over night support on a shared male ward. Now, with the support of the liaison nurse, her son is provided with a private room and the parents provided with reclining chairs to sleep on.

A community nurse who had supported a patient reported how the gentleman received poor care and was ‘neglected’ as well as losing some of his possessions.

For another carer they reported how they had had difficulties in obtaining a dairy free pureed diet for their service user, but on a more recent admission the liaison nurse was able to arrange this for the patient. For many carers they reported how in past admissions they had not been listened to and the experiences had been ‘more complicated’. For one carer they stated “these episodes filled us with dread and was just not a positive experience at all”, however when reporting upon their recent experience, they felt the liaison nurses had lots of experience and felt confident they were working in the patients best interests.

As mentioned previously we were unable to obtain quantitative data from before the liaison service was established and therefore it cannot be quantitatively concluded that the liaison service has improved patient and carer experiences within the hospital. However participant’s comparisons of admissions from before and after the liaison service were established and these could reflect that the service has made some progress in improving hospital experiences for all involved in the care of a person with learning disabilities.

The liaison service was introduced to improve patient experience and, as this was a new role for this acute hospital, the liaison nurses had to develop their service and identify their roles within the hospital. Therefore, as has been

shown in this report, key users of the service understand the role and are clear what support the liaison nurses can offer and provide. This must therefore be a sign of success.

Conclusion

The liaison service was established in June 2011 and the quantitative data shows a steady number of referrals from both carers and hospital staff. There have been a very low number of inappropriate referrals and a small number of people with learning disabilities not referred at all. Within the data the importance of a prompt referral was highlighted and data shows the majority of patients are referred within one day of emergency admission. The liaison service set out to establish itself and promote the role within the acute setting and the study shows that all users of the service have an understanding of the role and therefore this must be seen as a success on the liaison nurses' behalf. It is agreed by all the role of the liaison nurse is varied but important and highly regarded by all users of the service. The liaison nurse is viewed by patients and carers as the person that listens to them and enhances communication between all parties, bridging the gap between the community and hospital setting. The majority of people that used the service were not aware of its existence prior to coming into the hospital, but feel it is a necessity to have.

Although there is already a large proportion of learning disability training provided within the hospital, hospital staff still lack an awareness of what a learning disability is but are aware of this and have asked for more training. From this small study we can conclude that, although there has not been a service audit prior to the introduction of the liaison nurses, from carer's experiences and/or to compare these with their current experience. The liaison nurses have made an improvement on the experiences of patients with learning disabilities and their carers. It could also be concluded from the ward staff comments that the liaison nurses have improved their experiences of caring for a patient with learning disabilities. There are still areas of improvement the liaison nurses would like to make and there are improvements highlighted by participants, therefore some recommendations have been made as a result of this study.

Recommendations

1. There needs to be more advertisement of the service, but advertisement in places where people with learning disabilities and their carers visit, such as; Day services, GP practices, Care Agency groups, local Community Learning Disability Teams waiting areas, local newsletters and maybe even in the local news.

2. The possibility of adding the Liaison Service contact details to letters to people with learning disabilities should be explored, as this may be impacted upon by other processes that may not be in place such as a flagging system.

3. The effectiveness of the current training provided to hospital staff on learning disabilities needs to be explored, with consideration given to whether it would be suitable to include people with learning disabilities and their carers in providing the training.

4. The liaison nurses need to emphasise the importance to hospital staff, where appropriate, to provide a handover to carers who wish to be kept informed bearing in mind legislation such as consent from the patient to share information, confidentiality and information governance. This could be included in the training as well as on an individual basis.

5. The liaison nurses to make hospital staff aware that carers can often feel ignored and frustrated at not being listened to. They also need to highlight that, to establish effective communication, the hospital staff should use less jargon and medical language when speaking with patients and carers. This again could also be addressed in the training, especially if the training is provided by carers and patients, but also on an individual basis.

6. This study shows an increase in referrals but cannot reflect the complexities and the length of time each referral can take in liaising with and between different services. Therefore it needs to be considered whether there is a demand for more hours and cover by the liaison nurses. There could be a risk of criticism if the liaison service cannot provide what it set out to do.

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