Demonstrating The Economic Value Of An Acute Learning Disability Liaison Service Within Hywel Dda University Health Board

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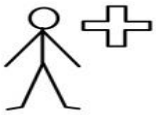
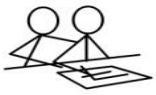
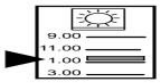
	**Easy Read Executive Summary**
	This project looks at how Learning Disability Liaison Nurses can help Hywel Dda University Health Board save money.
	It also looks at how they help other people including patients with a learning disability, their carers and ward staff.
2018	Hywel Dda does not have any Learning Disability Liaison Nurses at the moment. They will be in place by the end of 2018.
	This project looked at Liaison services in other places to see how they work.
	Learning Disability Liaison Nurses can help to make stays in hospital shorter. This can stop Hywel Dda spending extra money. It also means people can return home as soon as they are well enough.
	They can help to make sure people go to their hospital appointments. This will also save Hywel Dda money.
	They can help nurses on the ward to make "reasonable adjustments" so patients with a learning disability have care in the way they need it, and have their investigations and treatment on time.
	The Learning Disability Liaison Nurses will need to find out how many people they help so they can see how well the service is doing.
	Lots of people will be told about this project and how the Learning Disability Liaison service can help Hywel Dda, patients with a learning disability, their carers and ward staff.

Aim

The purpose of this economic assessment is to demonstrate the value of an Acute Learning Disability (LD) Liaison Service within Hywel Dda UHB. As this service is yet to be established, the assessment will be prospective and aims to identify data to later be collected from the liaison service to evaluate its economic impact.

The case study will be presented to the Hywel Dda executive board and then disseminated to key stakeholders, namely People First groups, Parent carer groups, All Wales acute bundle implementation group and the Acute and LD directorates within the Health Board.

The true economic cost of the service will be examined using Treasury guidelines. This will include both direct and indirect costs and will aim to identify the set up and running costs. Direct costs include staff costs for the liaison service, electronic tablets, mobile phones, and expenses for trainers. Indirect costs are the use of resources which have been funded from elsewhere e.g. office base, equipment, recruitment of the liaison nurses, clinical and managerial support and venues for training. It is anticipated the set up costs will be less than the running costs, as staff costs will have the biggest financial impact on the service.

It is anticipated the Acute LD Liaison service will bring many benefits across the Health Board and beyond. The aim is to increase the quality of care provided to people who have a learning disability when admitted to or attending hospital. It is hoped they and their families will enjoy an improved experience, spend less time in hospital and so be at less risk of a hospital acquired infection. Additionally, the LD liaison nurse may prevent premature death by ensuring all relevant investigations are carried out and prevent the individual being re-admitted to hospital. It is hoped the presence of LD liaison nurses will decrease the workload of acute ward staff and increase their confidence in caring for patients who have a learning disability. Having training on LD issues will also help staff meet their CPD or revalidation needs. Benefits to the Health Board include increased capacity due to decreased length of stays, reduced DNA's for outpatient clinics, prevention of inappropriate admissions and a reduction in litigation due to poor health care and outcomes. Other benefits may be increased confidence of paid staff and carers of the hospital care provided and the timely payments of additional support.

As the LD liaison service is not currently established, a baseline of care provided prior to the implementation of the service will be used to compare the costs and benefits. A service evaluation of staff knowledge and confidence of working with patients who have a LD was conducted in 2015. This looked at the experience of staff, patients who have a LD and their family or paid carers across the four general hospitals in Hywel Dda UHB. This audit tool can be used again to assess any change in experience.

Introduction

The most common definition of learning disability used in the UK is taken from Valuing People, the 2001 White Paper on the health and social care of people with learning disabilities. It states:

'Learning disability includes the presence of:

• a significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence), with;

• a reduced ability to cope independently (impaired social functioning);

• which started before adulthood, with a lasting effect on development' (DoH, 2001).

In Wales there are approximately 15,000 adults with learning disabilities who are known to social services and in receipt of services. It is estimated there are potentially at least 60,000 adults with milder learning disabilities who are not in receipt of services (Welsh Government, 2018). The nature of people's learning disability varies widely and will affect the kind of support that they may require. Many people with a learning disability will have a significantly reduced ability to cope independently in a variety of situations (including health services), to understand new or complex information, to learn new skills (whether practical things like tying shoelaces, or social skills such as holding a conversation or self-care), and they may have difficulty with generalising any learning to new situations. Some people with a learning disability may not have any effective verbal communication and need to find other ways of communicating with those around them. Some need help with everyday things like getting dressed or making a cup of tea, whilst others will live quite independently with minimal support. It is expected the number of people with a learning disability in the UK will continue to grow and there will also be a growth in the complexities of learning disabilities (Michael, 2008). This is due to people with learning disabilities living longer and also due to young people with complex disabilities surviving into adulthood.

People with learning disabilities may experience multiple co-morbidities and chronic health problems. For example, in the Confidential Inquiry (Heslop et al, 2013), 17 per cent of the sample had four or more health conditions. Due to their experiences of both acute and chronic illness, people who are learning disabled have an increased attendance and admittance to acute general hospitals and the demand from people with learning disabilities, their families and carers on specialist and general health service is expected to increase significantly in the future (Gates, 2011).

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 and 2012, Michael 2008, Heslop et al 2013, 2017). Recent data estimates 1,200 people die unavoidably in the NHS each year (Mencap, 2018).

The Learning Disabilities Mortality Review found that on average men with a learning disability die 20 years younger and women with a learning disability 27 years younger than those in the general population. Many of these deaths are considered avoidable and/or premature. The Confidential Inquiry (Heslop et al, 2013) identified the central issue was that of delays in the care pathways of people with learning disabilities, specifically relating to investigations, diagnosis and treatment. However, other factors enhanced the vulnerability of people with learning disabilities which include: a lack of reasonable adjustments, a lack of coordination across and between the different disease pathways and service providers, and a lack of effective advocacy.

In response to these reports and the death of a gentleman with learning disabilities in a Welsh hospital, the Welsh Government launched the "All Wales Learning Disability Acute Care Bundle" (Public Health Wales 2014). An all Wales Group has been established to co-ordinate work around the bundle and the 1000 lives improvement team are actively involved in promoting and supporting it (http://www.1000livesplus.wales.nhs.uk/learning-disabilities). This bundle also addresses the recommendations of the Confidential Inquiry (Heslop et al, 2013) by early identification of patients with a learning disability and providing a care pathway with improved communication, and reasonable adjustments.

The first learning disability liaison nursing service was established in Scotland in 1999 and involved highly experienced Registered Learning Disability Nurses working exclusively in general hospitals to support people with a learning disability and their families throughout pre-attendance, attendance, admission and discharge (MacArthur, 2015). The model has been implemented in many areas across the United Kingdom and in their *Getting It Right* campaign, Mencap (2010) produced a charter which called for all general hospitals to appoint learning disability liaison nurses. This model was further endorsed by the World Health Organisation (2010) and has been promoted by the Chief Nursing Officer for Wales and the Minister for Health (Welsh Government) at Welsh Health Conferences in 2018.

Research has endorsed the value of acute LD liaison services (MacArthur et al, 2009; Castles et al 2013). Michael (2008) states "there is preliminary qualitative support for the value of appointing staff, commonly called 'acute liaison nurses' to provide health facilitation or link working between and across primary and secondary specialised (acute hospital) care" (Caan, 2005 and Taylor, 2007, both cited in Michael, 2008). He also concludes "it is clear that learning disability nurses can have a really positive impact on the care people receive". The UK Chief Nursing Officers "Strengthening the Commitment" report (2012) highlights that liaison nurses are highly valued by people with a learning disability and their carers. This is further emphasised in the report by Heslop et al (2013) which recognises the crucial role LD liaison nurses undertake in facilitating access to health care. Mencap has long campaigned for better health care for people with a learning disability and launched a new campaign, *Treat me Well*, in 2018. This aims to transform the way the NHS treats people with a learning disability and highlights the important role of LD liaison nurses.

The LD liaison service

The Learning Disability Liaison Service is currently in the process of being set up in Hywel Dda. Four 0.5 WTE Band 6 LD Health liaison posts have been advertised, one part time post per general hospital in the Health Board. Once appointed the nurses will be line managed by the professional lead in LD Nursing and jointly supervised by the professional lead and the acute service nursing manager for each hospital. The liaison nurses will work across the age range and support paediatric services as well as adult and older adult services. It is expected they will work in all areas of the general hospital including outpatient clinics, A&E and inpatient admissions.

The role of the LD liaison service is based on the perceived need of the Health Board and evidence from other established LD liaison services, obtained from both literature and networking. Most LD liaison services have direct clinical support, education and practice development or strategic development as their main roles. Initially the service in Hywel Dda will be 75% educational and 25% clinical. The size of the educational role is anticipated to decrease over time, once staff have been trained. ABMUHB (Abertawe Bro Mogannwg UHB – a neighbouring health board) have developed their service as 50% clinical and 50% education and strategic/organisational development, however on discussion with their liaison nurses, they spend 75% of their time carrying out clinical work and for some months, particularly over the winter period, they are unable to provide any training due to their clinical demands. Education provided by the Hywel Dda UHB liaison service will involve recruiting and training "LD Champions" in each area to act as resources as the LD service will only operate on a part-time basis in each hospital. There is a current call for LD training to be mandatory for all health staff. This will be provided by the liaison nurses and people who have a learning disability, who have been trained in teaching others what it is like to have a learning disability. It is essential to have people with a learning disability deliver training as the benefits can not be disputed (Thacker & Crabb, 2007). Understanding quality of life from the patient's perspective gives a far better insight than a professional's opinion (Mencap, 2007).

A recent project undertaken in Hywel Dda UHB aimed to "improve the experience of general hospital care for patients with a learning disability". This was achieved by developing an educational training pack. Focus groups were held with people who have a learning disability and family carers of people with a learning disability to find what they though could make things better. The pilot ward, a surgical assessment unit in Glangwili General Hospital, was then approached and another focus group held to identify what information the ward staff actually wanted to improve things for patients with a learning disability. From the information obtained from the focus groups, a bespoke educational package was devised, and facilitated learning sessions were held during the hand over period for 6 weeks. A member of Carmarthenshire People First, who has a learning disability herself, was a valued member of the project team and was involved in the development and delivering of the training. Evaluation of the sessions by ward staff found an increase in knowledge of LD issues, better awareness of capacity and consent issues, increase knowledge of specialist LD services and an increase in staff confidence in nursing a patient who has a LD. It is anticipated the liaison nurses will

be able to use this teaching package and adapt to each ward and department to provide meaningful education to all hospital staff.

The clinical part of the LD liaison role consists of supporting individuals who have a learning disability whilst they are an inpatient, attending an outpatient appointment or A&E. Purely by being present on the ward and acting as role models, the liaison nurses will help acute staff develop confidence in meeting the needs of patients who have a learning disability. The liaison role will also include ensuring reasonable adjustments have been made e.g. their communication needs have been considered, they receive information in a way they can understand, information in their health passport has been addressed, and behavioural support plans are followed to minimise distress etc. The LD liaison nurses will work closely with ward staff to develop appropriate care plans to ensure all needs are met in a person-centred way. Discussion with a LD liaison nurse at Pennine Acute Hospitals NHS Trust and Salford Royal Hospital found that input at pre-assessment clinics is particularly valuable. This provides an opportunity to plan an admission and to ensure all consent issues have been addressed, which ensures there is no delay in treatment. It also ensures the right support is provided by the right people when the patient is admitted to the ward. The liaison role will also involve participation in the complex discharge of patients with a learning disability, to ensure timely and safe discharge to an appropriate setting which will meet their needs. Castles et al (2013) found that a "significant" amount of their work was involved in discharge planning. It was felt they were in the best position to arrange this due to their prior knowledge of services and placements available for people with a learning disability in the local community.

Set up costs

The set up costs have been calculated in line with Treasury guidance to provide the true cost of setting up the service. (See appendix 1)

The direct costs, i.e. the costs directly borne by the LD liaison service are:

- 4 x electronic tablets with accessible software (Microsoft Surface Grid 3)
  4x £480 = **£1,920**
- 4 x Mobile Phones
  4 x £50 = **£200**
  Making a **total of £2,120**

The indirect costs, i.e. the goods and equipment already in place or provided by the Health Board with no additional cost to the LD liaison service are:

- Appointing the liaison nurses
  Human resources for advertising the posts, recruiting, interviewing and appointing the liaison nurses
- Office bases and equipment
  Offices, desk, computer, printer, ink, laminator, laminating sheets and paper.

Running costs (See appendix 2)

The annual running costs have been identified as:

Direct costs

- Acute LD liaison Nurses - 4 x 0.5 band 6
  0.5 x £30,661 = 15,330.50
  15,330.50 x 4 = **£61,322** (x 22.5% on-costs for health service personnel) = **£75,119.45**
  In order to provide an accurate representation of staffing costs, the middle of band 6 salary has been used. 22.5% has been added to this cost to provide for pensions, sickness, supervision, management etc.
- Trainers from People First
  4 x 2 - ½ day training
  £250 per half day x 8 **= £2,000**
  Historically trainers from People First have provided LD awareness sessions as volunteers and have received no recompense for their time or travel. This has always been on an ad hoc basis with the professional ringing to see if anyone was able to provide training on a certain day. As the Learning Disability Awareness education appears to be becoming mandatory and the value of having a person with a learning disability providing the training is recognised, it seems only right that People First should receive payment. People First already provides training to the police force at £500 per day or £250 per half day. It is anticipated they will provide 2 x ½ day training per hospital at a total cost of £2,000. This money is paid to the People First organisation itself and not to individual trainers as people with a learning disability are likely to be in receipt of benefits and any payment could have an adverse effect. People First then use the money for the benefit of its members e.g. purchasing new kitchen equipment to develop cooking skills etc.
- Travel costs
  2 x 1000 miles
  2x 500 miles
  3000 miles at 45p per mile **=£1,350**
  Hywel Dda UHB covers approximately a quarter of Wales. Its four General Hospitals are spread out throughout the region with Glangwili and Prince Phillip Hospital being the two closest together at a distance of 23 miles apart. Due to the rural nature and poor road network, mileage costs can be high. Although the LD liaison nurses will be hospital based, they will be expected to occasionally conduct home visits for patients who may need additional support to ensure their admission/treatment is successful. Additionally they will need to travel to meetings for supervision, networking, and training for voluntary groups and care agencies etc. It is anticipated the LD liaison nurses at the two most distant hospitals, Withybush and Bronglais, which service a more rural and sparse population will

have higher mileage rates. Whereas the mileage for the liaison nurses based at Glangwili and Prince Philip hospitals which are on the M4 corridor and serve a more highly dense population will be lower. The mileage rate of 45p per mile has been obtained from the expenses department at Hywel Dda UHB.

- Mobile phone contracts
  4x £2.50 per month (Minimum of 24 month contract with each new phone)
  £2.50 x 12 = £30 per year 4 x £30 = **£120**
  Total Direct running cost per year =£78,589.45

Indirect costs

- Management and Supervision
  1 band 8a x 1hr per month x 4
  This will be provided as part of existing professional lead nurse role and will incur no additional cost to service. Supervision and clinical support from head of nursing in each area will be provided as part of established bi-monthly acute bundle implementation meetings and will again incur no additional cost.
- Office bases and equipment
  Offices, desk, computer, printer, ink, laminator, laminating sheets, paper
  These are already provided by health board and will incur no additional cost to service
- Training venues
  Large rooms, chairs, projector, computer, speakers
  This is already provided by health board and will incur no additional cost to service
- Refreshments
  Tea, coffee, milk, sugar, disposable cups, biscuits
  Course participants will be asked to contribute 20p per drink which will cover the cost of refreshments and incur no additional cost to service. This is a model which is currently used when LD nurses provide epilepsy training and appears to work well.
- Cost to release hospital staff to receive LD training
  This will involve no "back fill" costs and therefore has no additionality. It is expected that LD training will become mandatory for all hospital staff so there is a requirement for them to be released. Wherever possible this training will be provided at handover time on the ward to minimise any disruption to ward routine.

Once the direct and indirect costs have been considered, it can be seen the total cost for the set up and running the LD liaison service in Hywel Dda UHB in the first year will be a total of **£80,700.45.**

It has been very difficult to obtain data to establish a baseline of the number of people with a learning disability who are admitted to the general hospitals in Hywel Dda and who would therefore benefit from the LD liaison service.

In an attempt to find this information the deputy chief executive of the health board was contacted; however, the performance team was only able to provide information for what speciality the person

was admitted for. Other Health Boards across the UK have a ”flagging system” where people with a learning disability have an icon placed next to their name on the IT system which alerts clinicians to the fact the patient has a learning disability and may need reasonable adjustments. It is anticipated the LD liaison nurses will be able to “flag” individuals with a learning disability by adding names on to the system. Although they will not be able to diagnose a learning disability, from their clinical experience and expertise the LD liaison nurses will be able to identify patients who appear to present with a learning disability and can signpost on to be referred for assessment if needed.

As there is currently no way of identifying how many people with a LD are admitted to hospitals within Hywel Dda, alternative means of finding this information was sought. The community learning disability nurses were approached to identify how many people they had supported while in hospital over a six month period from Dec 17 to May 18. A questionnaire was sent to every community LD nurse in Hywel Dda asking for the number of people who have a learning disability had been admitted to hospital, their length of stay, if they were re-admitted and what support the LD nurse provided. Unfortunately from the 4 Community Teams, full responses were only obtained from 2. The other teams were unable to provide information due to staff sickness, secondments and pressure of work.

Hywel Dda UHB Dec’17 – May’18

	Ceredigion	Pembrokeshire	Llanelli
No of admissions	3	16	9
Length of stay range (days)	7-75	1-85	1-95
Average length of stay (days)	29	18.3	40.2

From the 2 teams that responded there was a far lower admission rate than was expected. In the Pembrokeshire team 16 patients were reported to have been admitted to hospital out of 336 known on LD GP registers (2017) and in Llanelli 9 people were reported to have been admitted out of 351 on the LD GP register. It is known that only about 25% of people who have a LD are known to social services (WG, 2018) and that Community LD nurses only support those individuals who have the most complex health needs. Therefore this sample will be highly under representative of the total number of people with a LD admitted to hospital.

Data from Betsi Cadwallader UHB (a Health Board in North Wales which has an established LD liaison service) identified that during a similar period (January 2018- July 2018):

Statistics	Wrexham	Ysbyty Glan Clwyd	Ysbyty Gwynedd
No of referrals	87	64	54
No of non-LD referrals	6	2	2
No of hospital days	309	209	230
Number of unplanned admissions	68	48	28
Average length of stay	7 days	5 days	6 days

The total population of people with a Learning Disability known on Learning Disability GP registers for 2017-2018 in Betsi Cadwallader UHB is 2,918. Although it is unknown if there are multiple admissions for the same patient, this is the best data available and with the caveat that this does not account for possible readmissions, it equates to approximately 14% of people with a learning disability being admitted to hospital in the first 6 months of 2018. (Admission rate data was not able to be used from ABMU as the liaison nurses only collect information for 2 of their 4 general hospitals).

Using the figures from Betsi Cadwallader UHB, 14% of the LD GP register were admitted to hospital Therefore as Hywel Dda has 1,993 people on the LD GP register, it is estimated there would be 142 admissions to their hospitals during the same period, 114 more than captured by the community nurses. This figure is an estimate based on the best available data, however it is acknowledged there are limitations as the comparators are not identical.

Benefits of the LD liaison service

As the LD liaison service is yet to be established in Hywel dda, the benefits of such a service are those anticipated through research and evidence from other services. The expected benefits of the LD liaison service will be felt by patients with a learning disability, carers, ward staff and Hywel Dda UHB (see appendix 3). These are themed as below:

Length of Stay

As can be seen the average length of stay in Betsi Cadwallader UHB is between 5-7 days, whereas in Hywel Dda UHB it is between 18.3 and 40.2 days. There are several different ways of interpreting the reason behind these figures. It could be due to the very small sample size in Hywel dda and the fact that all the patients were known to the community LD nurses implying they had the highest health problems. Therefore the length of stay would be deemed to be higher for the individuals who had the most complex needs. If the sample was much larger and included individuals not known to the LD nursing service, or may be not even on the social service register, the average length of stay may even out. Another possible explanation as evidenced in the literature is the fact that Betsi Cadwallader UHB has LD liaison nurses whereas Hywel Dda currently doesn't. Evidence at Norfolk and Norwich University Hospital indicates that 39% of people with learning disabilities had extended lengths of stay (across emergency and elective admissions) before a Liaison Nurse was appointed (NHS East of England, 2011).

The following case study illustrates the potential cost avoidance in timely discharge from hospital.

Miss A is a 59 year old lady with a mild learning disability. She generally enjoys good health but is morbidly obese and had become unsteady on her feet. She suffered a number of falls which resulted in a previous hospital admission for a fractured clavicle. Miss A lives in an adapted bungalow as part of a supported living scheme with two other ladies. They receive 24 hour care from support staff who have been trained to meet their needs.

Miss A suffered a stroke (also known as a cardiovascular attack or CVA) on 9th April 2018. She was admitted to a local General Hospital and nursed on a specialised stroke ward. She made slow but steady progress and regained her communication and cognitive skills to a pre-admission level. However, the CVA resulted in no active movement in the left side of her body.

At a multidisciplinary team meeting (MDT) meeting held on 21st May '18 it was agreed Miss A was fit for discharge. The occupational therapists from both the hospital and community learning disability team assessed her home and found additional equipment was required to manage Miss A's manual handling needs. This equipment was provided and training given to staff at the home in how to use it safely.

It was then anticipated Miss A would be discharged, however, there followed a series of DST meetings (Decision Support Tool Meetings where the primary need of the individual is assessed and the source of funding identified). The local authority and health board were not able to agree the primary need with each identifying it was the other's responsibility. The dispute was taken to panel and further information was requested. During this time Miss A remained on the ward. She received regular support from her carers and occasional visits from friends. However, she consistently asked to go home and at times would become frustrated and tearful when told she wasn't able to at that moment.

A referral was then received by the learning disability nursing service and a community learning disability nurse became involved. They visited Miss A on the ward and provided reassurance. They also ensured reasonable adjustments had been made to ensure all her needs were met in an appropriate manner. The LD nurse worked with the LD speech and language therapist to create a "social story" to help explain to Miss A that she had a stroke, was unable to use her left side and would be going back home to live. The LD nurse then requested a multi-disciplinary team meeting to discuss discharge. This was arranged as a further DST on 10th July '18 to obtain more information for the panel. The LD nurse attended the DST and contributed to the assessment. They also queried why Miss A was still in hospital as after taking advice from the learning disability community healthcare team found that funding issues should not affect discharge as the individual should be discharged with the same funding source as they were admitted with and decisions about who should fund it can be made after discharge. Miss A was finally discharged home on 13th July '18.

Miss A spent a total of 95 days on the ward. This is compared to the average length of stay for the consultant she was under of 18.9 days. It is reasonable to suggest that if a LD liaison nurse was present in the hospital, the discharge process could have been expedited and Miss A discharged when she was deemed medically fit. This would have happened on 21st May meaning she would have spent a total of 42 days as an inpatient and discharged 53 days prior to her actual discharge. Even if there was a delay in the arrival of assessed equipment and provision of manual handling training of the staff (estimated at 2 weeks from discussion with the occupational therapist) Miss A could have been discharged on 4th June, 39 days prior to her actual discharge. Any decrease in length of stay does not provide direct financial savings to the Health Board as the bed will be used for the next patient. It does however, allow for an increase in bed capacity. Figures obtained from the

finance department in Hywel Dda UHB state the financial cost per bed night including all overhead and associated costs is £452.75. Using a sensitivity analysis, it can be estimated in this episode of care a LD liaison nurse could potentially have avoided between 39 and 53 bed nights which has the value of between £17,657.25 and £23,995.75.

Before being admitted to hospital Miss A. received a package of care totalling 168 hours per week (including wake-in staff support) and 1 sleep in staff per night. This amounts to 168 hrs at £14.49 per hour = £2,434.32 plus 7 x £75.76 sleep-in = £530.32 which makes a total of £2,964.64 per week. During the hospital stay, Miss A.'s care providers visited 4 times per day to assist at meal times, and provide social input. This amounted to 10 hrs per day which includes travel time 10 x £14.49 = £144.90 per day x 7 = £1,014.30 per week. There were no additional mileage costs as Miss A.'s own vehicle was used. The whole of her hospital stay cost the local authority 95 days at £144.90 = £13,765.50. This compares to 168 hours per week = 24 hours per day at 95 days = £33,037.20 + £75.76 (x 95) = £7,197.20 = £40,234.4, a potential cost avoidance to the local authority of £26,468.90.

On discharge Miss A. receives a package of care which amounts to 158 hours per week. This is a decrease in support hours due to a change in circumstances of a fellow tenant and a change in the sleep hours to 9 hours per night from 11-7 to 10-7 due to European work directives. All the above hours and figures were provided by Miss A's home manger. There is the additionality of equipment costs at her home, Etac turning system and shower chair. However, these would have been needed regardless of the hospital admission. The admission can therefore be seen as an opportunity to get proper care at home and potentially avoid future adverse outcomes and costs.

Miss A now appears very settled and happy in her own home and continues to make improvement with her mobility. The argument over who should fund her care still carries on (as of 20th Sept.'18) so there is the possibility Miss A could still be in hospital now if the LD nurse hadn't intervened.

The above case study illustrates the benefit to the Health Board in the cost avoidance in one admission. Using the figures above from the limited but best available data it is fair to estimate that in 6 months 142 patients with a learning disability could be admitted to general hospitals within Hywel Dda UHB, which equates to 284 admissions per year. If the LD liaison nurses are able to reduce the length of stay for 39% of those patients (NHS East of England, 2011), then 111 patients will be discharged sooner. If every person is discharged one day earlier that would be a cost avoidance of £452.75 x 111 = **£50,255.23**.

A peer review discussion was held with other community LD nurses. It was felt that although Miss A's hospital admission is not a typical hospital admission for people with a learning disability, it is certainly not an isolated admission. As the population of people with a learning disability is getting older, and there are known health problems associated with obesity due to poor diet, exercise, lack of access to health education etc the risk of CVA's in this client group is likely to grow. On a scale of 0-10 where 0 was thought to be highly untypical and 10 thought to be very typical of admissions for people with a learning disability, it is thought Miss A's admission would score 3. It is therefore reasonable to suggest that Miss A's admission may be representative of approximately 30% of admissions for a learning disability. In Hywel Dda an estimated 111 patients could be discharged

earlier and 30% may have complex needs as seen with Miss A. Using the figures from the Miss A case study there could therefore be potentially an annual cost avoidance of between £17,657.25 x 33 = **£582,689.25** and £23,995.75 x 33 =**£791,859.75.** However it is acknowledged there is a big variation in the length of stay and the sample size is small, which both indicate caution should be exercised in the interpretation of these data.

Another benefit of decreased length of stay and the freeing up of available beds is that the health board will improve on the ability to meet Welsh Government targets. Current A&E targets aim for 95% of patients to be seen within 4 hours and 100% to be seen within 12 hours. Information obtained from the Hywel Dda UHB informatics service shows that from April '17 to March '18, across all General hospitals in Hywel Dda there were 13,472 A&E breaches due to no available beds. The Welsh Government target for referral to treatment time is 95% of patients should be seen within 26 weeks of referral. Again using the information obtained from the Hywel Dda informatics service 687 elective procedures were cancelled from April '17 to March '18 due to no available beds. A discussion was held with the General Manager of Hywel Dda UHB who said that if there is shown to be a reduction of 2,000 bed nights per year per general hospital within Hywel Dda, which is the equivalent of a 6 bedded bay, money can be obtained from the government for RTT (referral to treatment time). It is felt that the LD liaison service will not be able to achieve this alone, but may be able to feed into other schemes to reduce length of stays to secure the extra funding.

If the patient has a timely and safe discharge once medically fit, not only will there be economic benefits to the Health Board but the person themselves will also greatly benefit. They will return to familiar surroundings with people who know them well and will be able to enjoy their routine and return to their normal way of life. This is important for anyone, but especially so for a person who has a learning disability as being with loved ones, seeing pets, familiarity of the environment, food, smells, approach, possessions, ability to carry out rituals and routines etc can have a huge impact on their sense of wellbeing and mental health (Monitor, 2015). In addition, carers, especially family carers will be less stressed. They will be able to continue with their day to day lives without the burden of having to visit, cost of hospital car parking, and worry that their relative is not being looked after as well as they are able to.

There have been suggestions that the length of stay in hospital could itself be a cause of increased morbidity known as "Hospital- acquired harms" (Nuffield trust, 2015). Bed rest was first identified as being harmful to patient care in the 1940's as it puts patients at higher risks of skeletal muscle loss, falls, deep vein thrombosis, catheterisation and associated urinary tract infections, chest infections and pressure areas. Additionally, longer hospital stays increase the risks of hospital acquired infection (Hopkins et al, 2012). A total of 364 hospital acquired infections were reported in Welsh acute hospitals in 2016 (prevalence of 5.5%) (Public Health Wales NHS Trust, 2017). The top three most common infections within the acute hospitals were pneumonia (19.2% of infections), urinary tract infections (15.9%) and surgical site infections (11.3%). The health service has to bear the cost of diagnosis and treatment of these infections, the extended length of stay which often results, and the use of more expensive treatment that may be needed. Infection Control services must also be paid for and bed / ward closures and cancellation of operations / admissions that can result from these infections, are also a hidden burden for the health service. Immobility in general hospital care can

lead to particular problems for older patients. A study of healthy older adults found that 10 days of bed rest led to a 14% reduction in leg and hip muscle strength and a 12% reduction in aerobic capacity: the equivalent of 10 years of life (Kortebein et al, 2008). There is also anecdotal evidence from this research that older patients are more likely to suffer from falls in the unfamiliar hospital environment, and if they suffer from dementia are more likely to be confused. It would be fair to assume these principles would also apply to a patient who has a learning disability and is disorientated in a different environment. In addition, older patients are more likely to have complex long-term conditions, or to enter hospital with existing social care needs. This means that these patients are more likely to require step-down health or social care services on discharge, and experience delayed transfers of care (Oliver et al, 2014). Again, these issues of complex and long-term conditions and having social care needs also apply to people with a learning disability, highlighting the important role of the LD liaison nurse in discharge.

DNA rates

Hywel Dda UHB is currently working to reduce the rates of DNA (Did Not Attend – where the patient failed to turn up at their appointment). The assistant head of service costing for Hywel Dda UHB provided the current cost on average for each outpatient appointment as £140. This figure is from 2016-2017 as the figures to the financial year ending 2018 will not be available until October '18. Each outpatient appointment, whether new or follow up, varies in length, diagnostic testing required and the type of health care professional providing the care, depending on the specialty and clinical condition of the patient in question. Therefore, as the estimated costs of outpatient appointments vary, a median estimate of £140 is stated to provide a consistent message. There are fixed and variable costs associated with each outpatient appointment, whereby the fixed costs (cost which do not change) include staffing, estates and facilities used and variable costs, which change depending on the diagnostic tests and equipment used during the appointment. The fixed costs make up the majority of the total cost, therefore, an estimate of £140 is used to cover both new and follow up appointments. The range of costs varies from a new outpatient appointment at a rheumatology clinic at £539.84 to a follow up appointment at an Ear, Nose and Throat (ENT) clinic being £78.85. Hywel Dda UHB estimates the annual cost of DNA's for 2016-17 was £3,659,040. This figure excludes diagnostic services, DNA rates and planned procedures DNA's.

It is anticipated the LD liaison nurses will work with the outpatient departments to ensure patients with a learning disability receive information in a way they can understand. This will involve sending accessible appointment letters using symbols and widgits to tell them the date and time of the appointment, and where to attend. Easy read information to explain about the clinic and why they need to attend can also be sent to help alleviate anxieties about going to the hospital. Also contact details of the LD liaison nurses will be provided so there is a point of contact if there are any questions the individual or their carer may have. Through this project, initial discussions have been held with Improvement and Transformation Team within Hywel Dda UHB. Recommendations for sending reminders for outpatients' appointments for patients with a learning disability via audio text to landline rather than text to mobile phone due to difficulty in reading which many people with a learning disability experience have been made. Other LD Liaison services have found it beneficial to address capacity and consent issues prior to the appointment with the consultant. They can

establish if the person has capacity to make the decision about their investigation or treatment and if not arrange for a best interest decision to be made on the person's behalf. Prior to the LD liaison involvement, anecdotally it was found that consultants would have to arrange further appointments to discuss best interest decisions causing a delay in investigations, or the person would attend at clinic for the procedure and it would have to be cancelled as the correct consent had not obtained.

There is no known data available regarding the impact of LD liaison nurses have in reducing DNA rates but it is thought they will contribute to avoiding some of the cost currently experienced by the Health Board. This is an area the LD liaison service in Hywel Dda will be able to explore and gather evidence as to the impact the service may have.

Other benefits Hywel Dda UHB may experience from the LD liaison service include meeting the goals set out in the Quality Improvement Strategic Framework (QISF) 2018-2021. This strategy identifies 5 key quality improvement goals for the health board and includes

- No avoidable deaths
- Protect patients from avoidable harm from care
- Reduce duplication and eliminate waste
- Reduce unwarranted variation and increase reliability
- Focus on what matters to patients, service users, their families and carers and Health Board staff

LD liaison nurses have been shown to facilitate "reasonable adjustments" to ensure patients with a learning disability have timely investigations and treatment so reducing preventable and premature deaths. By decreasing the length of stay, the risk of harm from care is also reduced e.g. developing hospital acquired infections, pressure area damage, mobility issues and deconditioning of the patient etc. From the case study it can be seen that a LD liaison nurse would reduce duplication of DST meetings and eliminate waste by enabling an earlier discharge once the patient was medically fit. Having a LD liaison nurse in each of the four general hospitals in Hywel Dda will enable consistency of care across the health board. The whole ethos of the LD liaison service is patient centred, ensuring people with a learning disability get the right care which is provided in the way they need it. This also encompasses the needs of their families and carers. Additionally ward staff will be supported to provide this care, and their learning and communication needs addressed. There may be additional cost implications for meeting reasonable adjustments. However, these are necessary and equality of access outweighs resources. This will be monitored by the LD liaison nurses to quantify impact and benefits.

<u>Patient experience</u>

The impact LD liaison nurses may have on the experience of the patient who has a learning disability is evidenced from the literature. The study undertaken by Brown et al (2012) demonstrated the LD liaison nurses provided greater access to and patient compliance with investigations and treatments, thereby ensuring health needs were better addressed. This co-ordination of care and consideration of communication and sensory needs by the LD liaison nurses is seen as an important outcome, as is the education and role modelling to acute staff. General hospitals are complex environments which coupled with busy clinicians who have limited knowledge and experience of the needs of people with a LD can result in poor care and premature death (Mencap, 2007 & 2012, Heslop et al, 2013,

Leder 2017). Patients also commented the LD liaison nurses were "*helpful and friendly*" and "*listened to them, visited them and understood them*" (Castles et al, 2013).

Not only is there a financial cost to DNA's but also a human cost as shown in the following Case study which is taken from the Confidential inquiry (Heslop et al, 2013).

"*Alan lived alone with daily support. He was 'fast track' referred for a colonoscopy by his GP when he had lost a significant amount of weight and was found to be anaemic. He was expected to have the investigation within 2 weeks. Three months later his GP was concerned that Alan had not had the procedure. On investigation by the GP it transpired that 2 appointments had been arranged but that Alan had sent the hospital transport away on each occasion, because he had diarrhoea and he had not understood that the special drinks he had taken in readiness for the procedure would give him diarrhoea. The lack of reasonable adjustments for him resulted in a 14-week delay between referral and diagnosis and contributed to his premature death*".

Carer experience

Patients with a learning disability may be supported by paid carers or family carers. Castles et al (2013) found that many carers reported how in past admissions they had not been listened to, and the experiences had been 'more complicated'.

One carer stated: "*these episodes filled us with dread and was just not a positive experience at all*". However, when reporting upon more recent experiences, they felt the liaison nurses had more experience and felt confident they were working in the patients' best interests (Castles et al, 2013). Family and formal carers particularly valued adjustments that promoted understanding, safety, comfort and reduction in anxiety (MacArthur, 2015) Carers gave examples of the liaison nurses influencing adjustment of outpatient appointment times and waiting areas "*She phoned up or she spoke to the staff in the outpatients, explained what his needs were, what would be causes of anxiety. For instance, rather than him waiting in the general waiting room, they were able to say 'well there's a quiet room to the side, you can wait there'. That made a big difference*".

Also, for some carers, knowing that the liaison nurse had handed over messages also provided reassurance that everything was in hand during their absence. One mother commented:

I just felt I did not have to rush to the hospital every morning to make sure my daughter was ok (Castles et al, 2013).

One role that Community Learning Disability Nurses are often asked to undertake is completing the risk dependency assessment tool when their clients with a learning disability are admitted to hospital. This identifies if the patient requires additional support whilst they are in hospital, and who is best to provide that support. Some patients with a learning disability require no support whereas some may require additional support to assist with managing their anxieties or communication issues. If a patient has a care package of individual support, that support can be provided even when the person is in hospital e.g. 6 hours of support per day enables the paid carer to be with the

patient, provide meaningful activities or social engagement during the day, explain what is happening, provide help with meal times etc. However if the risk dependency assessment identifies the patient needs extra support and that familiar carers are best placed to provide this which is in additional to the persons individual package e.g. the person may be living in a group home with care shared between 3 people, then the care company provides this care and the hospital will pay for it. In Hywel Dda UHB there have been occasions when invoices for additional care have submitted retrospectively and so care providers have had to wait many months to be reimbursed. It is thought that this will be a role for the LD liaison nurses, to ensure the risk dependency assessments are completed on admission to the ward and there will be timely payment to care providers.

Ward Staff

It has been found that LD liaison nurses raised the confidence of general hospital ward staff in working with people with a learning disability, and reassured that legislation and policies were being adhered to. Also, to some degree they were able to *'take the pressure off'* (Phillips, 2012). Importantly, there was also recognition that through effective preparation with both patient and hospital staff they increased the likelihood of investigations and treatments actually taking place and being successful, with benefits for the patient as well as the organisation in relation to appropriate early discharge and financial savings (Brown et al, 2012). Many of the ward staff interviewed by Castles et al (2013) considered that the role of the liaison nurse was to support them in the care they provided to patients with learning disabilities, to liaise with other professionals involved in the patient's care and to assist them with discharge planning. Some ward staff felt they had insufficient time to spend with these patients, and that the time the liaison nurse could offer proved productive for all parties. One ward sister reported: "*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*". Nurses, doctors, physiotherapists, speech and language therapists and carers described numerous examples of individual patient outcomes that were directly influenced by the liaison nurses. These included co-ordinated care, successful investigations and treatment, reducing and managing challenging behaviour, increasing staff confidence, fostering autonomous decision-making and ensuring compliance with capacity and other safeguarding legislation (MacArthur et al, 2015).

The following comments are taken directly from patient feedback forms for Hywel Dda UHB as part of the baseline audit undertaken in 2015. It is expected these themes will be addressed by the LD liaison nurses and will therefore improve the experience and outcomes for patients, their carers and ward staff. By improving patient experience and outcomes it is anticipated there will be less opportunity for complaints and potential litigation.

Individuals with a learning disability
"I get lost in hospitals and get panicky" "Doctors talk to my carers and not to me" "I was scared and nervous and left on my own to go to surgery" "The MRI scan was very scary" "I was only allowed 2 visitors to come and see me" "I didn't like being in bed all the time" "I was scared"

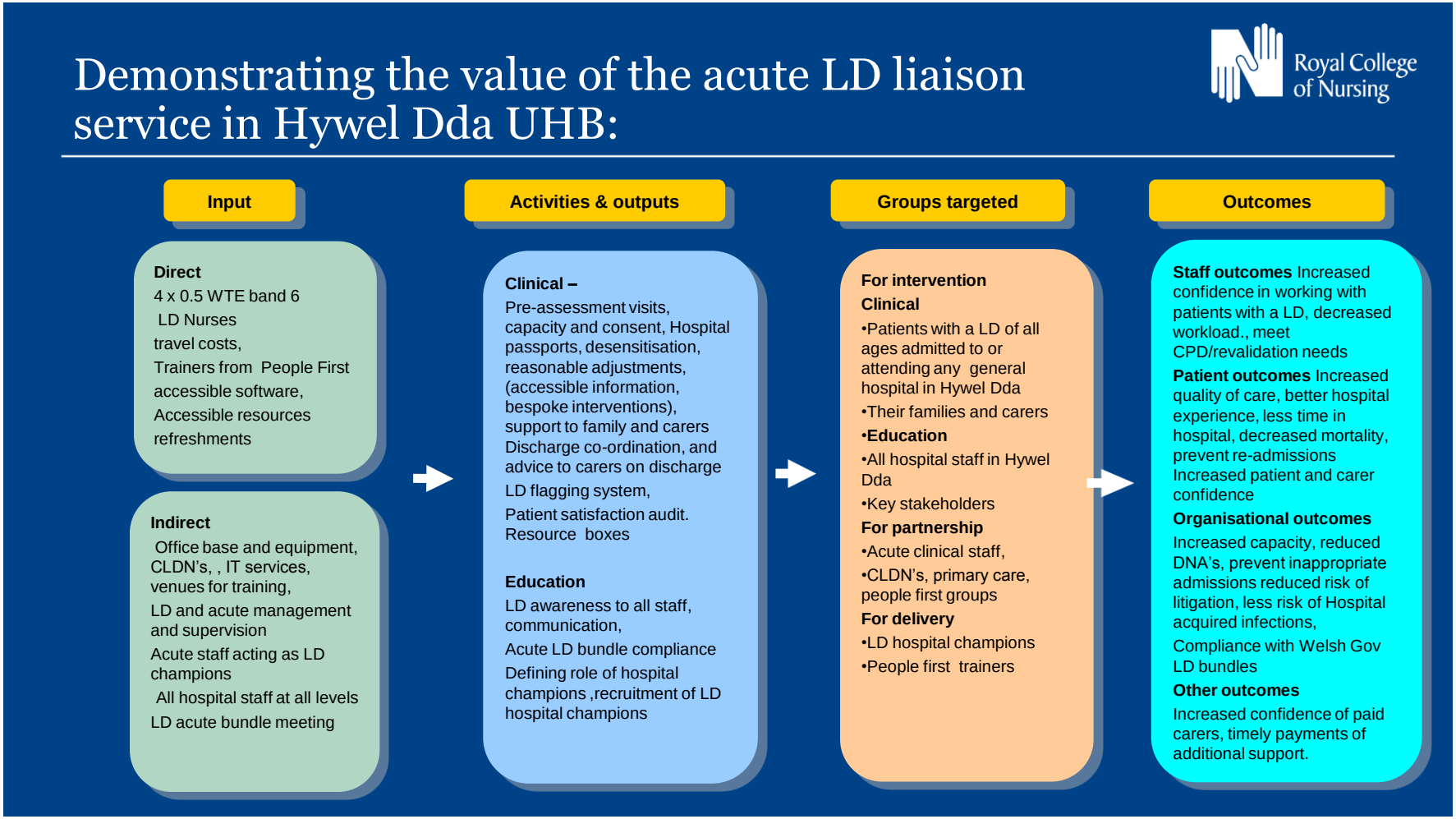
Carers
"Not being listened to when I'm the expert in my daughter!"

Ward staff

"Better communication (own personal skills)" "Resource boxes" "More training days" "More information on learning disabilities"

Demonstrating the value of the acute LD liaison service in Hywel Dda UHB:

Royal College of Nursing



Conclusion

From the work undertaken it can be seen the true economic cost of a learning disability service including set up and running costs for the first year is **£80,700.45.** The total direct running cost for subsequent years will be **£80,554.19** (which includes an additional 2.5% which is added each year to allow for inflation).

If the LD liaison service operates as evidenced in other areas there can be potential benefits to the health board, patients with a learning disability, their carers and ward staff. Reducing the length of stay provides cost avoidance for the Health Board. A conservative estimate using research and proxy data of reducing the length of stay for 39% of patients with a learning disability by one day provides a cost avoidance of **£50,255.23** per year. However, using the case study and information from the peer review discussion, the potential cost avoidance could be between **£582,689.25** and **£791,859.75** per year. Additionally the reduced length of stay will free up available beds which will help Hywel Dda UHB improve on meeting the targets for A&E and referral to treatment times which have been set by the Welsh Government.

The LD liaison service will also have an impact in reducing the number of DNA's which is currently estimated to cost Hywel Dda £3,659,040. Discussions have already taken place with the Improvement and Transformation Team within Hywel Dda UHB as to how this may happen.

Although no monetary figures have been attributed to the quality benefits a LD liaison service can bring patients with a learning disability, their carers and ward staff caring for them, its value can not be underestimated. Liaison nurses are thought to prevent premature and avoidable deaths of patients with a learning disability by ensuring all necessary investigations and treatment are carried out in a timely manner. They can also help to improve the hospital experience for people with a learning disability and their carers enabling further admissions to run more smoothly. LD liaison nurses have been shown to increase ward staff knowledge of learning disability issues and improve their confidence in nursing a patient with a learning disability.

It is important to remember that the LD liaison service is not yet established in Hywel Dda, however this project has highlighted areas of data which needs to be collected by the service for audit and evaluation.

One unexpected outcome of this project is the personal benefit it has brought to the author. The concept of the evaluation has been challenging and I have been really stretched at times, however, on completion I have a great sense of achievement. As a community learning disability nurse and also a mother to a child with a profound learning disability and complex health problems, I am passionate about learning disability care. Working on this project has enabled me to meet with executives of the health board and raise awareness of LD issues at the highest level. I have also obtained support from directors of services and other teams within the health board which I previously had not known had existed e.g. performance analysis team. Meeting with senior managers and directors had initially been daunting, but as the project has progressed so my confidence has increased. I feel I have been able to make a difference to the health board as data

produced within this report is being acknowledged and is being acted on (use of audio text messages for appointment reminders). Additionally, I am keen to obtain one of the LD liaison posts and feel this project will not only increase my chances of securing the position, but has also provided a deeper understanding of the value this role will bring.

Recommendations

The following recommendations are made in light of this economic report

- This report has highlighted the importance of a "flagging system" to identify the numbers of people with a learning disability accessing general hospital services. It is imperative this system is addressed as a matter of urgency by Hywel Dda UHB.

- Present project finding to health board and stakeholders – The completed project will be presented to the executive board at Hywel Dda UHB. It will also be presented at heads of services meeting at both acute services and learning disability services. It will be presented to local People First groups and an accessible summary will be produced. Invitations have already been secured to present the project at Mencap family carer groups.

- Collect data and evaluate service - The LD liaison nurses will collect data and evidence their input. This information will include the number of referrals, reason for attendance/ admission, length of stay and number of training sessions provided. This will be reviewed after 12 months to evaluate the liaison service in Hywel Dda UHB. The baseline audit undertaken in 2015 should be repeated to compare patient, carer and ward staff experience following the implementation of the liaison service.

- Network and share good practice with other Health Boards in Wales and nationally - The information collected will feed into all Wales data collection to compare how Hywel Dda UHB is performing against the other LD liaison services in Wales. Support will be obtained from more established LD liaison services across the country to aid the implementation of the service in Hywel Dda.

- Publish findings - It is anticipated this report to demonstrate the economic value of a LD Liaison Service in Hywel Dda UHB will be published in national journals. This will inform a wider audience of its impact and the value of undertaking such a project for their service.

- Present findings at national conferences - an invitation has already been secured to present this project at a national learning disability nursing conference, "Positive Commitments" in April 2019. Opportunities to present at other conferences will also be explored.

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RCN Demonstrating Value: Applying the principles of economic assessment in practice
Appendix 1 - Template 3: Identify, quantify and monetise set up costs

	Set up costs		
Direct	Identify	Quantify	Monetise
1.	Accessible resources	4 x electronic tablets with accessible software (Microsoft Surface Grid 3)	4x £480 = **£1920**
2.	Mobile Phone	X4	4x £50= **£200**
3.			**Total Direct costs = £2120**
4.			
Indirect	Identify	Quantify	Monetise
1.	Office base and equipment	Office, desk, computer, printer, ink, laminator, laminating sheets	These items are already supplied by the Health Board and will therefore incur no additional cost
2.	Appointing the liaison nurses	Human resources for advertising the posts, recruiting, interviewing and appointing the liaison nurses	This is already provided by the Health Board and will incur no extra cost to the service

RCN Demonstrating Value: Applying the principles of economic assessment in practice
Appendix 2 - Template 3: Identify, quantify and monetise set up costs

Running costs per year			
Direct	**Identify**	**Quantify**	**Monetise**
1.	Acute LD liaison Nurses	4 x 0.5 band 6	0.5 x £30,661 = 15,330.50 15,330.50 x 4 = £61322 (x 22.5% on-costs for health service personnel) = **£75119.45**
2.	Trainers from People First	4 x 2 - ½ day training	£250 per half day x 8 = **£2000**
3.	Travel costs	2 x 1000 miles 2x 500 miles	3000 miles at 45p per mile =**£1350**
4.	Mobile phone contracts	4x £2.50 per month Minimum of 24 month contract with each new phone	£2.50 x 12 = £30 per year 4 x £30 = **£120**
			Total Direct cost =**£78589.45**
Indirect	**Identify**	**Quantify**	**Monetise**
1.	Management and Supervision	1 band 8a x 1hr per month x4	This will be provided as part of existing role and will incur no additional cost to service
2.	Office base and equipment	Office, desk, computer, printer, ink, laminator, laminating sheets	These are already provided by health board and will incur no additional cost to service
3.	Training venues	Large room, chairs, projector, Computer, speakers,	This is already provided by health board and will incur no additional cost to service
4.	Refreshments	Tea, coffee, milk, sugar, disposable cups, biscuits	Course participants will be asked to contribute 20p per drink which will cover the cost of refreshments and incur no additional cost to service

Demonstrating The Value Of An Acute LD Liaison Service Within Hywel Dda UHB

Inputs

Investment/Resources

Direct
4 x 0.5 WTE band 6 LD Nurses
Travel costs,
Trainers from People First
Accessible software,
Accessible resources
Set up costs=**£2,120**
Running costs=**£78589.45**
Total =£80,700.45 (for first year)

Indirect
Office base and equipment,
IT services,
Venues for training,
LD and acute management and supervision
Acute staff acting as LD champions
All hospital staff at all levels

The Service

Clinical

Pre-assessment visits, capacity and consent, Hospital passports, desensitisation, reasonable adjustments, (accessible information, bespoke interventions), support to family and carers Discharge co-ordination, and advice to carers on discharge
LD flagging system,
Patient satisfaction audit. Resource boxes

Education

LD awareness to all staff,
communication,
Acute LD bundle compliance
Defining role of hospital champions,
recruitment of LD hospital champions

Summary of Benefits

Patients with a learning disability

Increased quality of care, better hospital experience, less time in hospital, decreased risk of hospital acquired harm, decreased mortality, prevent re-admissions Increased patient and carer confidence

Ward Staff

Increased confidence in working with patients with a LD, decreased workload., meet CPD/revalidation needs

Hywel Dda UHB

Increased capacity, meet WG targets, reduced DNA's, prevent inappropriate admissions reduced risk of litigation, less risk of Hospital acquired infections Potential estimated cost avoidance of between **£50,255.23 and £582,689.25 to £791,859.75**

Other outcomes

Increased confidence of paid carers, timely payments of additional support.