

Nurse education: valuing the contribution of people with a learning disability. An economic assessment

Ruth Wyn Williams, School of Health Sciences, Bangor University

Acknowledgment: Thank you to all the members of Mencap Môn for their engagement with this project and to David Allsup and Jason Devereux, my learning disability nursing colleagues at Bangor University for enabling me to engage in this work.

Introduction

“If a measure of a society is how it cares for those who are vulnerable, the poor health outcomes of people with learning disabilities in general healthcare settings indicate that we have a long way to go” (Beacock et al., 2015, p. 4).

As a learning disability nurse working within a Higher Education Institute (HEI) in Wales there is a responsibility to ensure that the future nursing workforce is fit for purpose and has the skills and knowledge to work in partnership with some of the most vulnerable individuals in our society.

Recent reports such as The Learning Disability Mortality Review (LeDeR) Programme Annual Report December 2017 (LeDeR, 2018) still highlight the inequality that many individuals face when accessing healthcare. Although NHS England commissioned the LeDeR programme the recommendations should be considered across health and social care. This case study outlines an economic assessment of the contribution of individuals with learning disability to the undergraduate Bachelor of Nursing (Adult) course. By identifying the value of this contribution across all stakeholders, the intention is to inspire other HEI's to consider working with individuals with learning disability in the teaching and learning of nurse education.

The inequality that individuals with learning disability persistently face in accessing mainstream healthcare is evident (LeDeR, 2018). Reports indicate that individuals with learning disability die prematurely with repeated problems of delayed diagnosis, poor identification of needs and inappropriate care (Emerson et al., 2012; Emerson et al., 2016; Heslop et al., 2013; Krahn et al., 2006; Mencap, 2007; Michael, 2008; Scottish Government, 2012). However, such complex inequality requires a multifaceted approach. This case study highlights the possible role of healthcare education in tackling this inequality.

Future nurses commence their education within HEI's that work in partnership with health services to provide clinical experience. Providing direct clinical experience for large cohorts of adult nurses in working with individuals with learning disability may be difficult for some HEI's. Therefore, it is important to provide opportunities for adult nursing students to work in partnership with individuals with learning disability within the HEI setting. Enabling adult nursing students to gain skills and knowledge from a 'workshop' activity with people with learning disability is proposed as an approach to ensure future nurses are prepared to work with all individuals. Hence, future nurses have an introduction to working with a range of needs, thus building insight into the importance and challenges of equal access to mainstream health services for all.

Intended audience:

- Individuals with a learning disability.
- Organisations that support individuals with a learning disability.
- Current and future nursing students.
- Nurse lecturers from other fields of practice (i.e. not RNLD).

- HEI's that deliver nurse education.

Background

- Some evidence (small scale studies), policy and guidance to support including the 'voice' of service users in all levels of healthcare provision (see review Boudioni et al., 2017).
- Increased evidence to support service user involvement in healthcare education (Rush & Barker, 2006; Gutteridge & Dobbins, 2010; NMC, 2010; Scottish Government, 2012).
- Limited evidence that explores how effectively to include people with learning disability in nurse education (Bollard et al., 2012).

Enabling an inclusive educational approach in learning disability nursing can be understood from the wider context of 'nothing about us without us' (DoH, 2009 *Valuing People Now*) and the growing recognition that people with learning disability and their families are 'experts by experience'. By working in partnership with people with learning disability as 'experts by experience', 'co-lecturers', 'co-facilitators of learning' we are also influencing the context of education and enabling all individuals involved to develop new skills and knowledge. (*Experts by Experience are people who have experience of using (or caring for someone who uses) health and/or social care services. – Care Quality Commission - <https://www.cqc.org.uk/about-us/jobs/experts-experience>).*

Involving service users in healthcare is not a new concept. It is 28 years since the World Health Organization (WHO, 1991) stated that patient involvement would offer 'a contribution by people to their own health and healthcare, the development of organisational structures that promote participation, and effective empowerment of patients and their organisations and advocates, so that their voice is heard and not assumed'. Furthermore, policies in the UK specifying that hearing the 'voice' of individuals that use services is a method to prevent failings in healthcare quality (Francis, 2013).

Within the UK there are policies that aim to improve the quality of life of people with learning disability. The broad themes of the UK policies are:

- citizenship
- empowerment
- having choices and making decisions
- having equal rights and opportunities
- social inclusion (RCN, 2013).

Although policies exist, people with learning disabilities die, on average, 15-20 years sooner than the general population, with some of those deaths identified as being potentially amenable to good quality healthcare (LeDeR, 2018).

The Equality Act 2010 states that services must think about people with disabilities. Thus, the reasonable adjustments duty under the Equality Act 2010 requires services to take into account the needs of people with learning disabilities and ensure adjustments are made to the service and care they provide in order to meet their needs. The legal duty for health services is 'anticipatory'. This means that health service organisations are required to consider in advance what adjustments people with learning disability will require, rather than waiting until people with learning disability attempt to use health services to put reasonable adjustments into place (Hoghton et al., 2003).

Providing reasonably adjusted services for people with learning disability is a legal requirement (Equality Act 2010). Thus, services have to ask: 'What extra things do we need to do, so people with learning disability can get health services as good as other people?'

Furthermore there is a clear legal framework that supports the involvement of 'experts by experience' in all services. E.g.

- Human Rights Act, 1998
- Adults With Incapacity (Scotland) Act, 2000
- Mental Capacity Act, 2005
- Mental Health Act, 2007
- UN Convention on the Rights of Persons with Disabilities, 2008
- Equality Act, 2010
- Social Services and Well-being (Wales) Act 2014
- Well-being of Future Generations (Wales) Act 2015

Also within nursing education the recently published Nursing and Midwifery Council (NMC) Standards for pre-registration nursing education (NMC, 2018) advocate the involvement of 'experts by experience':

"1.12 ensure programmes are designed, developed, delivered, evaluated and co-produced with service users and other stakeholders" (NMC, 2018. *Standards framework for nursing and midwifery education* p6).

"We believe that involving our service users and members of the public in the planning and delivery of curricula will promote public confidence in the education of future nurses. We encourage the use of supportive evidence and engagement from people who have experienced care by adult, children's, learning disabilities or mental health nurses to inform programme design and delivery for all fields of nursing practice". (NMC, 2018. *Programme standards: Standards for pre-registration nursing programmes* p5).

Involvement of 'experts by experience' in nurse education is advocated internationally as Happell et al. (2011) evaluation in Australia suggests. Happell et al. (2011) identified the benefits of involvement and noted that 'experts by experience' 'challenge the traditional power base apparent in much health professional education, which tends to privilege clinical perspective over individual experience' (Scammell et al., 2015, p 54). Scammell et al's (2015) systematic review of "published studies on service user involvement in undergraduate, preregistration general nursing education" highlights that the majority of research considers the 'value of participation' rather than the 'impact' of involvement.

The benefits highlighted from the student nurses perspective are noted as a transformative experience that instigates reflection on practice (Christiansen, 2011; Rhodes, 2013), further suggesting that the involvement of experts by experience bring an element of reality to nurse education (Bollard et al., 2012). From the experts perspective Rhodes and Nyawata (2011) and McKeown et al. (2012) reported that the service users found the experience rewarding. McGarry and Thom (2004) and Torrance et al. (2012) identified that lecturers perceived the involvement as a method to enhance education and practice. Thus, individual published case studies, small scale research outline the benefits of involvement, however the concept analysis conducted by Rhodes (2012) recommends that longitudinal research is required because there is a lack of evidence on the actual impact of involvement.

Charities are also pressing for equality of access to healthcare for people with learning disability. 'Treat me well' is Mencap's campaign that aims to transform how the National Health Service treats people with a learning disability in hospital. Mencap advocates that simple changes in hospital care can make a big difference, focusing reasonable adjustments around better communication, more time and clearer information for individuals (<https://www.mencap.org.uk/get-involved/campaign-mencap/current-campaigns/treat-me-well>).

In Wales, Mencap Cymru and the Paul Ridd Foundation are working together to raise awareness of the issues people with learning disability face when accessing healthcare. In collaboration with local health boards they help to deliver 'Learning Disability Champions' training to all NHS Wales staff. (<http://paulriddfoundation.org/the-care-bundle/learning-disability-champions/>). Furthermore, the 1000 Lives Improvement team in Wales are working to improve people's lives through focusing on three core areas; that is, Health Equalities Framework (HEF); Annual Health Checks and better experiences and outcomes for people with learning disabilities in general hospitals.

Thus, there are clear drivers for change and improving the access to the health service for individuals with a learning disability. From the Mencap report 'Death by indifference' in 2007 to the recent Learning Disabilities Mortality Review Programme publications (Heslop et al., 2013; LeDeR, 2018). There is also support from School level strategy, for instance the 'Public Engagement Strategy 2016' (<https://www.bangor.ac.uk/health-sciences/public-engagement.php.en>) at the School of Health Sciences, Bangor University. Such public engagement is also advocated by organisations, for instance:

- INVOLVE - a UK wide organisation that helps people to learn more about becoming involved in healthcare research <http://www.invo.org.uk>
- Health and Care Research Wales is an organisation that aims to bring together people who are interested in getting more involved in research. They also offer training and support across Wales <http://www.healthandcareresearch.gov.wales/>
- Participation Cymru is an all Wales network that offers training and opportunities to network across public services including education, government and third sector organisations. <http://www.participationcymru.org.uk> (National Principles for Public Engagement).

Description of service – Nurse Education

The School of Health Sciences is based within the College of Human Sciences at Bangor University. The School works across two campuses: Bangor and Wrexham. The School's mission statement states: "To engage with health care research, scholarship, teaching and learning that is of the highest possible standard, quality and value to service users, practitioners and stakeholders whilst maintaining language and cultural competence relevant to local, national and international partners". The aims of the School are:

- To promote a high quality of teaching and learning experience for both students and staff, whilst adopting the most appropriate teaching and learning methods that offers students choice, flexibility and inter-professional opportunities.
- To prepare and support healthcare practitioners to engage with lifelong learning and reflective practice that will promote high standards in evidence based practice.
- *To work in partnership with service users, health care providers and agencies mainly in the local region of Wales, but also nationally and internationally on health care research, education and scholarship.*
- To engage with scholarship and research applied to health care policy and practice, in order to evaluate, develop and wherever possible improve professional practice.

- To instil language and cultural competence in healthcare practitioners.
- To embed language and cultural awareness in healthcare research and practice and respond sensitively to the language needs of Welsh speakers.

The School offers undergraduate degree programmes that lead to registration with the NMC in one of the four fields of nursing practice: learning disability, mental health, child or adult. In line with the third aim of the School, this case study outlines the input of people with a learning disability to the adult nursing undergraduate programme. Creating opportunities for adult student nurses to gain skills and knowledge of working in partnership with learning disability is an integral element of the curriculum.

However, the economic assessment identifies and quantifies the additional cost of moving away from a didactic traditional lecture to an interactive session with the student nurses. The innovation in teaching moves away from a model of imparting knowledge to considering the impact of an interactive session and the possibility of influencing future behaviour and practice. Thus, this case study will outline an economic assessment by identifying the additionality of an interactive session to the traditional lecture and identify the possible immediate and future benefits to practice.

The cost consequence approach

The aim will be to outline the additional cost of introducing an interactive teaching session for third year adult nursing students and secondly to analyse whether an interactive session has consequences for future adult nursing practice. The cost analysis is taken from a nurse education perspective; that is, identifying the additional cost to the traditional didactic lecture format. A set fee is given as a donation to the 'experts by experience' thus detailing individual cost of the input of individuals with learning disability and their families is not highlighted in this case study. Apart from imparting knowledge the interactive session was expected to influence the skills of adult student nurses and impact on their future practice.

As HEI's work in partnership with local health services to provide undergraduate nursing courses there is a responsibility to impart knowledge that also influences and shapes practice. The Kirkpatrick's evaluation framework is one method that demonstrates how doing things differently in nurse education may impact future nursing practice. By making the impact (in cost and benefit) of the interactive session as transparent as possible it will enable other educators within HEI's to consider allocating resources to involving 'experts by experience' in nurse education. Thus, the information on the economic value of alternative teaching may provide HEI's with data to inform decisions about future allocation of resources to enable 'experts by experience' to contribute to nurse education.

Cost

As an employee of Bangor University my teaching role is clearly outlined in the job description, for example:

- Plan, prepare and deliver lectures and tutorials, responding effectively to a variety of student backgrounds, learning styles and class sizes.
- Motivate students to proactive engagement in learning, and provide meaningful and constructive feedback on the quality of their work.
- Keep abreast of new professional, educational and related social, economic and technological developments.

The cost outlined in the economic assessment will be the additional cost of teaching differently. For clarification a 'theory of change' model for the traditional lecture was completed (see Figure 1), termed here as a 'Pathways to Outcome'. This can be used as a comparison to the Pathways to Outcome (see Figure 2) that details the requirement of the interactive session led by 'experts by experience'.

Pathways to Outcome: Lecture (didactic model) versus Interactive Workshop (experiential learning)

The Pathways to Outcomes tool enables the mapping of the teaching activity, systematically identifying the requirements for the teaching to be delivered successfully and articulating the intended outcomes.

Figure 1 (Pathways to Outcome) identifies the input and outputs in relation to using a didactic model of teaching. This method of teaching does not identify any additional cost to the University and meets the current requirements of the curriculum. However, having reviewed the literature and policies, delivering an awareness session in isolation without the input of individuals with learning disability is contrary to the value base of learning disability nursing and person centred care.

With clear evidence, policy and guidance to recommend that all adult nurses require skills and knowledge to work in partnership with people with learning disability, how this is interpreted and achieved in undergraduate programmes is unclear. Although Beacock et al.'s (2015) report does offer some examples of activities within HEI's. For this case study Figure 2 (Pathways to Outcome) outlines the requirements of the interactive session and the intended outcomes. By comparing both Pathways to Outcomes (Figure 1 and 2) the additional cost, benefit and intended outcomes can be specified.

Costing the inputs

To enable others to replicate an interactive teaching session that is led by 'experts by experience' it's important to clearly identify the total costs of the intervention. Appendix 1 identifies, quantifies and monetises the set up cost of the interactive session. These are the one-off non-recurring costs required to establish the new way of working in the first year. Working in partnership with individuals with learning disability and their families takes time and investment in building a therapeutic relationship. The direct and indirect costs are identified in the table presented in Appendix 1 (Identify, quantify and monetise set up costs V1, 13.04.18). However, by working in partnership with an existing group of individuals with learning disability it appears to be a cost effective method of involving people with learning disability in teaching and learning.

Set up cost:

- contact with a 'experts by experience' group
- build relationship with individuals and family / carers
- build relationship with the organisation that supports individuals
- time (£499.02) and travel (£43.20) for one lecturer to meet with 'experts by experience' group on 6 occasions over a period of 10 months.

Additional time is required to build a relationship with individuals with a learning disability and their families/carers and make contact with the organisation that supports the individuals. In this case study, the time and travel for one lecturer to meet with individuals on six occasions over a period of ten months is costed. Setting up a new group to deliver the workshop would require further time

and investment, thus it is recommended that HEI's initially consider involving individuals with learning disability that are members of an existing group, similar to Mencap Môn.

Bollard et al. (2012) also noted that additional time and investment was required to ensure that any development of teaching activities would match the abilities of the individuals involved. However, Minogue et al. (2009) recognises that defining involvement can be difficult and some individuals will take part, whilst others will lead teaching activities. Thus adequate preparation, support and development of 'experts by experience' is advocated (Rush, 2008). The total set up costs were identified as £542.22.

Running cost of interactive workshop (additionality – the activity being additional to expected role):

- lecture contact time with experts by experience group between teaching (Time £332.69 & Travel £43.20)
- 1 x lecturer (£249.52) for supporting experts by experience during interactive workshop
- stipend - donation to the charity that supports the experts by experience (Total=£400 (£200 per teaching session)).

The running costs are outlined in Appendix 2: Identify, quantify and monetise running costs V1 13.04.18. The total running costs were identified as £1025.41 per academic year.

In essence the change in teaching style from lecture base to interactive workshop that included individuals with learning disability should not be 'seen' as additional cost to the HEI. However for clarification the running cost are identified in order to highlight the extra input required to run such a workshop. The main cost would be to have an additional lecturer for the purpose of supporting the 'experts by experience' rather than supporting the nursing students; and the agreed fee / stipend paid to the charity that the individuals are members of.

Figure 1

Pathways to Outcomes V1 22.05.18 (Ruth Wyn Williams)

Nurse education: valuing the input of people with a learning disability to BN(Hons) Adult programme – COMPARISON example

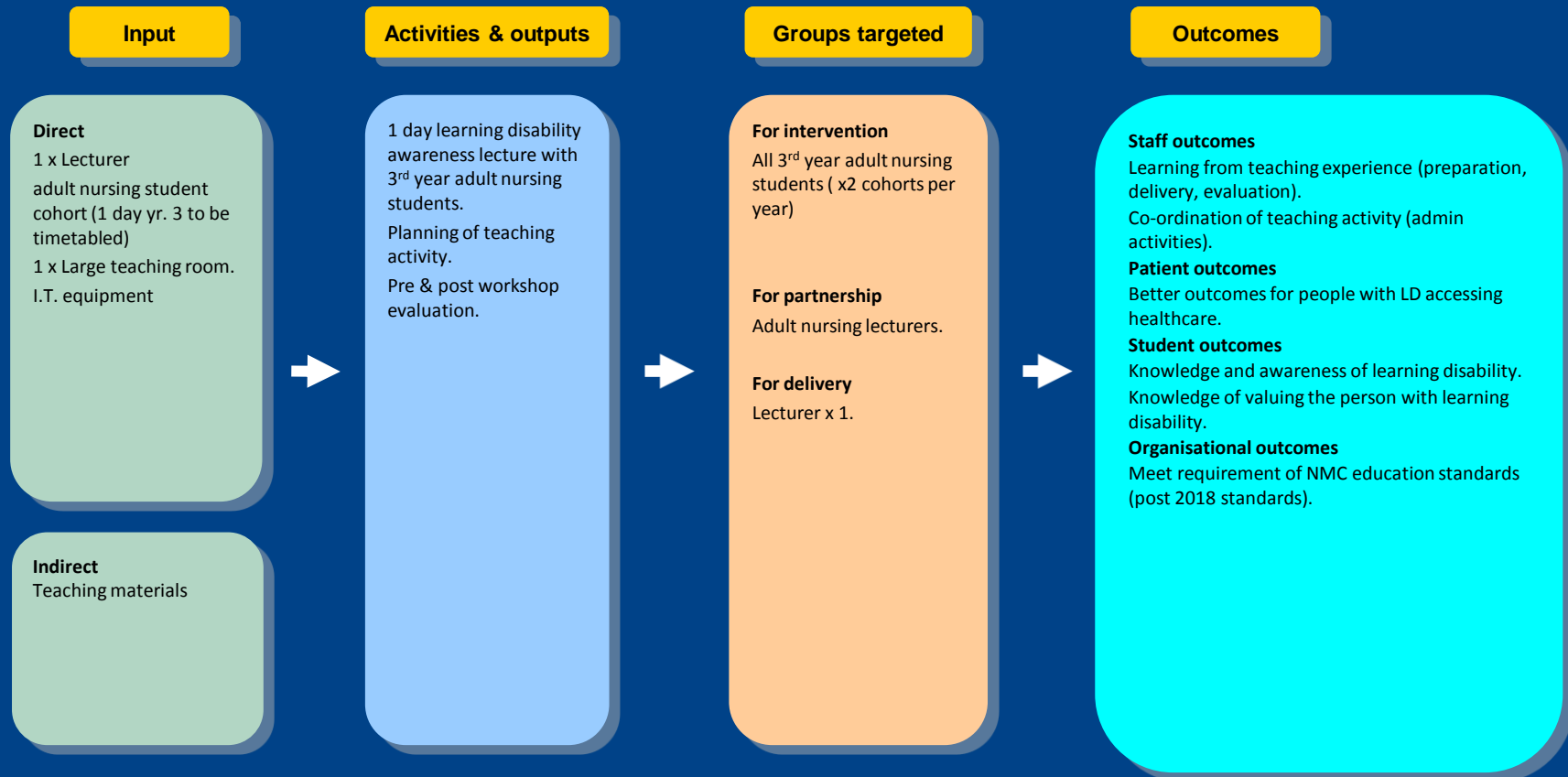
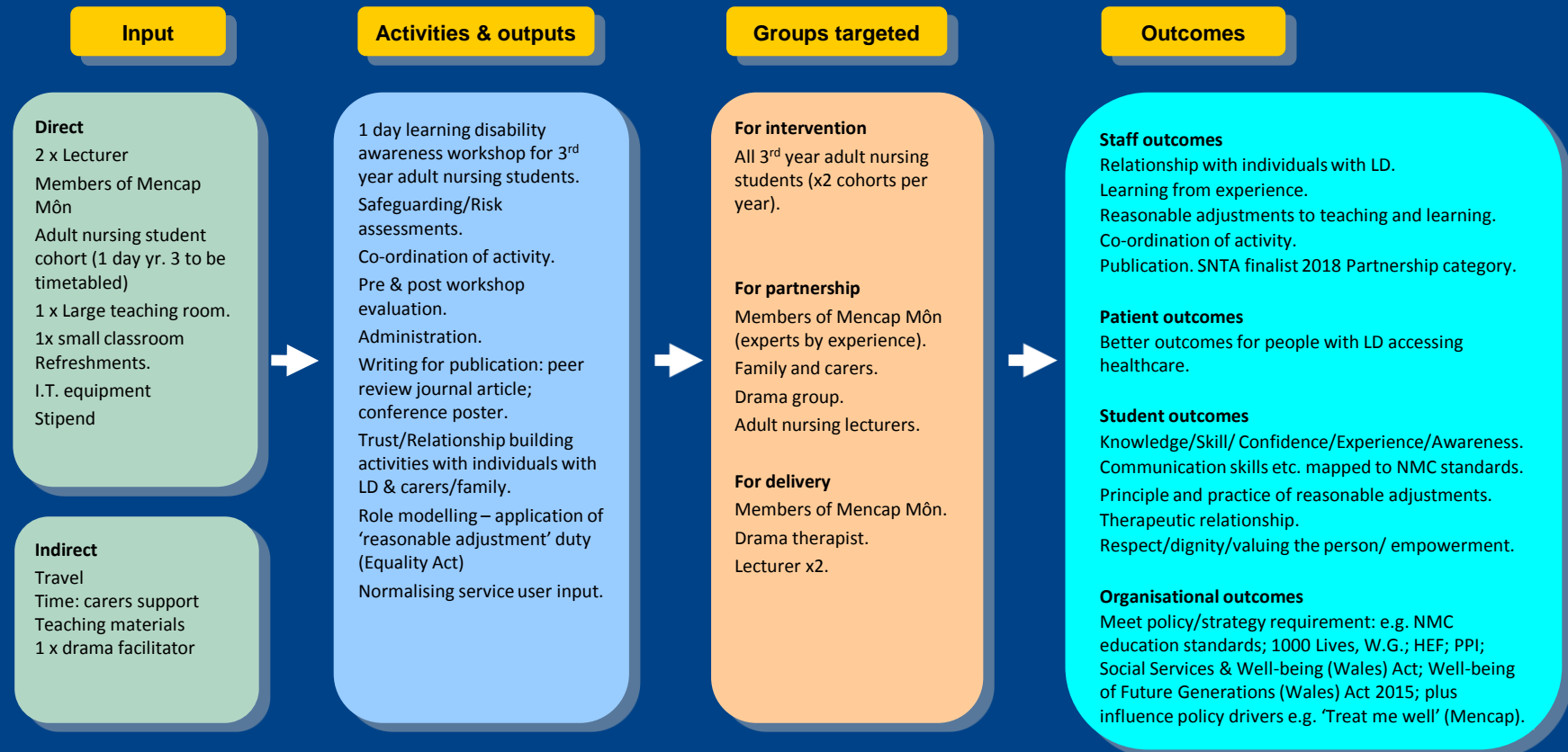


Figure 2

Pathways to Outcomes V4 16.05.18 (Ruth Wyn Williams) Nurse education: valuing the input of people with a learning disability to BN(Hons) Adult programme – interactive workshop



Benefits

The benefits of working in partnership with individuals with learning disability in the planning, delivery and evaluation of nurse education has the potential to impact on HEI staff, students, the organisation and patient outcomes within healthcare. However, long-term evidence that demonstrates the impact of such involvement in nurse education is limited and the research available are small scale and focus on specific projects or case studies mainly in social work practice and mental health nursing. Developing an economic assessment of service user involvement highlighting the benefits and cost adds to the growing body of evidence.

It is important to identifying the benefits from the perspective of the individual to the wider organisation. The identified benefits are stated (see Appendix 3). The benefits are categorised into five areas: individuals with learning disability and their family/carers, patients with learning disability, adult nursing students, HEI staff, the organisation (HEI).

Ultimately, the fundamental long-term benefit would be for individuals with learning disability to have equal access to healthcare although the impact of one aspect within healthcare education to this goal would be difficult to attribute. However, considering the benefits across the five areas will provide some evidence towards the long term goal of equity in healthcare.

Although the recent LeDeR report (2018) identifies that 64% of people with learning disability died in hospital, compared with 47% in the general population (n=1,244) is disheartening. However, monetising the benefits is difficult as equal access to healthcare is a multifaceted issue. One aspect would be to consider the cost of hospital stay for people with learning disability as compared with the general population. Iacono et al. (2014) identified that the data gathered regarding the cost of hospital stay by individuals with intellectual disability, physical disability, and or acquired brain injury, from 2005–2010 in Australia was higher than the general population. Iacono et al. (2014) conclude that it “would seem, then, that people with intellectual disability are high frequency and costly users of hospital services” (p. 506).

In the UK it seems that reporting of negative experiences of healthcare are the main drivers rather than identifying cost. For instance, a UK population-based confidential inquiry revealed that avoidable deaths, preventable or amenable through good quality care were more common among people with learning disability than the general population: 37% vs. 13% of avoidable deaths (Heslop et al., 2013).

The main focus of the benefits is improved health outcomes for individuals with learning disability. As Tuffrey-Wijne et al. (2013) note, the evidence suggests that ward culture, staff attitudes and staff knowledge are crucial in ensuring that hospital services are accessible to vulnerable patients. Thus role modelling the principle of reasonable adjustment and normalising the contribution of ‘experts by experience’ in nurse education is one aspect that could influence future nurse practice.

The direct benefits are noted on in Appendix 3 (Benefits: Nurse education: valuing the input of people with a learning disability to the BN (Hons) programme V1 05.06.18).

Individuals with learning disability and their family/carers - Members of Mencap Môn:

- Valued role - Experts by experience.
- Genuine partnership.

Patients with learning disability:

- People with learning disability accessing health care can expect better health outcomes.

Adult nursing students:

- Skills and knowledge to apply the principle of 'reasonable adjustment' (a duty under the Equality Act 2010) to nursing practice.
- Practice communication skills.

HEI Staff:

- Role model in practicing the principle of 'reasonable adjustment'.
- Normalising contribution of service users in nurse education.
- Relationship with service users and family.

Organisation:

- Meeting and delivering on NMC requirements Standards of Education, requirements of validating new curriculum to commence 2020.
- Public and patient involvement policy agenda.
- Avoidance of a negative.
- Enriching student experience.
- Creating a shared culture of equality.
- Partnership that reflects, respect, enabling, and a shared vision of an improved healthcare experience for people with learning disability.

Evidence of impact - Employing Kirkpatrick's evaluation framework

Evaluating the impact and effectiveness of teaching is essential to recognising the strengths of any teaching session and identify ways of improving the experience for all involved. Kirkpatrick's model of evaluation emphasises that evaluation should be conducted on four different levels from valuing the feedback of the students to an attempt to measure organisational impact and change (Rouse, 2014). Reio et al. (2017) state that 'from individual to organizational performance, the four levels represent a sequence or continuum of complexity.

Moving from one level to the next, the evaluation process becomes more difficult and time-consuming, but it also provides increasingly more valuable information' (p. 36). Although a complex journey, it is important to evaluate the impact and value of the contribution of individuals with a learning disability to higher education. Furthermore, HEIs question if 'outside' facilitators meet their objectives in a cost-effective manner too (Ellis & Hogard, 2006). Thus, the challenge when facilitating teaching sessions is to measure whether a change has occurred in the students' response to the session (Clark et al., 2013). Kirkpatrick's model offers a framework to examine the immediate impact of the session on the students but also on their future practice.

Evaluating the sessions demonstrates an openness to be scrutinized and a willingness to share the findings with stakeholders. Indeed it is hoped that feedback gained will help to improve or maintain the sessions. And lastly disseminating the evaluation by highlighting the learning points, the challenges and benefits of supporting individuals with a learning disability to facilitate teaching session with nursing students might enable other HEI's to replicate.

The four levels identified in the Kirkpatrick model for evaluation are: a) reaction; b) learning; c) behaviour; and d) results (DeSilets, 2018).

a) Reaction.

This first level considers the 'reaction' of the nursing students to the session through gaining feedback about the teaching style, presentation, materials, setting and learning activities.

b) Learning.

The second level of evaluation involves determining the extent to which learning has occurred during the session.

c) Behaviour.

Kirkpatrick's third level of evaluation is defined as 'the extent to which a change in behaviour has occurred because a participant has attended the educational or training program' (Kirkpatrick & Kirkpatrick, 2006, p. 22). Thus considering the transfer of learning from the classroom to the healthcare setting and the willingness of student nurses to apply their new knowledge and skills. For knowledge to influence behaviour change Kirkpatrick and Kirkpatrick (2006) identify four characteristics an individual must have:

1. The person must have a desire to change;
2. The person must know what to do and how to do it;
3. The person must work in the right climate; and
4. The person must be rewarded for changing (p. 23).

d) Results.

Yardley and Dornan (2012) identify that the fourth level of evaluation in healthcare has two elements, that is, an evaluation of the shift in practice and the improved outcomes for patients / clients. Such improvements should be attributed to the educational input.

Within the time scale of this case study levels 1 and 2 of Kirkpatrick's model was achievable; with proposals for level 3 and 4 evaluation outlined and supported by examples of current practice.

Reaction - Level 1, Kirkpatrick model of evaluation.

Following the teaching session the students are asked to write the first word (their 'reaction') that describes the teaching session. Figure 1 is a word cloud of one group's reaction. The words are in Welsh and or English as students are encouraged to use their preferred language to engage in the learning. Mainstreaming Welsh language into healthcare education is a way of preparing future workforce with appropriate knowledge, skills and attitudes to deliver 'active offer' of bilingual services (Welsh Government, 2016). The words suggest that the students thought the session was 'fun' and 'interactive', that it was 'educational' as well as 'an eye opener'. Thus, the student nurses' initial reaction to the session facilitated by individuals with learning disability was overall positive.

When the students were asked "What did you think about the session overall" again the comments received were encouraging. For instance:

"Fun interactive, a pleasure to be amongst service users and to learn about their needs"
"I really enjoyed the day, prior to the session I had little experience communicating with people with LD and this would make me feel a lack of confidence in the hospital environment – today has changed that and I will now feel more confident and I hope to get the opportunity to help a patient with LD in the future"
"Brilliant session! One of the most important and valuable sessions we've had at University"
"It was really good, useful and I thoroughly enjoyed it and learned a lot"
"Loved it, amazing session wish I had more over my 3 years"
"I thought the session was brilliant, very beneficial in helping adult nurses feel more confidence interacting with people who have a learning disability"
"Mencap were brilliant in enabling me to understand the communication needs of people with learning disability and allowing me to realise the specific issues affecting people with a learning disability within our local health board"

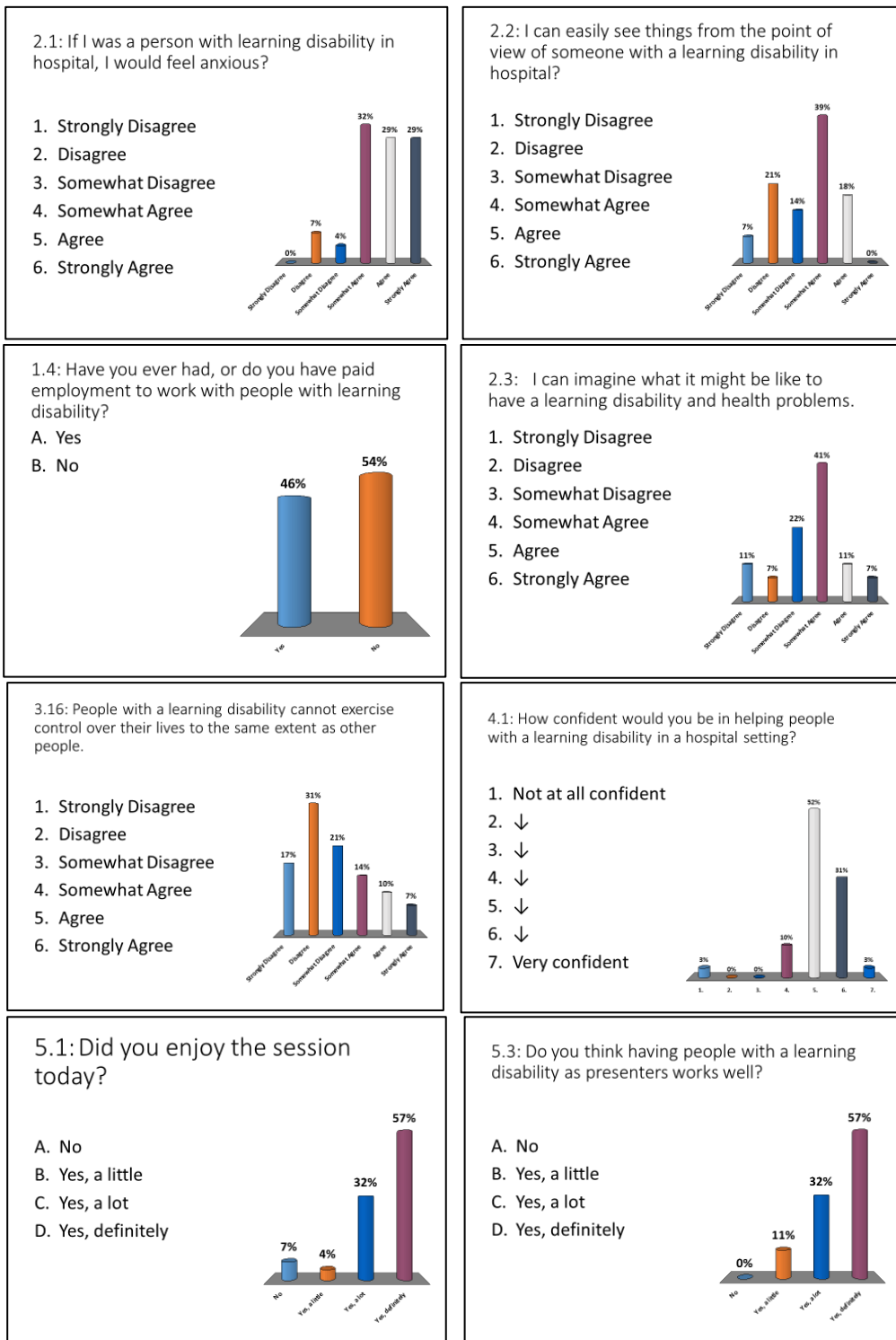
Again the students' comments are positive, emphasising on learning through a fun, enjoyable and interactive session.

Figure 1: Students initial reaction to teaching session.



Figure 2 illustrates some of the responses to set questions given to the students at the end of the session. The questions were presented via an audience response system within Microsoft PowerPoint. The evaluation consisted of 5 areas of questioning: demographic data; empathy and understanding from the perspective of individuals with learning disability; attitude and expectation; impact on future practice; and evaluation of session. It's interesting to note that 46% of the student nurses in this particular cohort specified that they had prior experience in working with individuals with a learning disability. This might have influenced their confidence level in working with individuals (noted on slide 4.1). However, the notion of an individual with a learning disability exercise control over their lives to the same extent as other people produces a mixed response (see Figure 2, slide 3.16).

Figure 2: Examples of the replies to the evaluation questions at end of session via audience response system.



Learning – Level 2, Kirkpatrick model of evaluation.

Following the session, students were asked to identify three things that they had learnt. See Table 1 for examples of response. Recurring themes that the students identify are the importance of communication and the need to think differently and sometimes find other solutions when nursing an individual with a learning disability.

Table 1: What have I learnt from the session – example of student nurses response

<i>'How to communicate with individuals with a learning disability'</i>
<i>'Think more in patient perspective'</i>
<i>'...value the job of listening to and learning about the patient'</i>
<i>'think outside the box'</i>
<i>'try to improvise with regards to time management when dealing'</i>
<i>'the difference between learning disability and learning difficulty'</i>
<i>'how vital communication is when caring for someone with a learning disability'</i>
<i>'the importance of being flexible and to make reasonable adjustments to provide patient centred care'</i>
<i>'everyone is different and therefore the care we provide needs to be tailored to suit that persons needs'</i>
<i>'to take time and prepare yourself to communicate'</i>
<i>'if they don't understand what you're trying to say, say/explain in a different way'</i>
<i>'I have learnt not to judge people with learning disability at first sight'</i>
<i>'always explain yourself in a way they understand'</i>
<i>'I learned about common issues and prejudices faced by people with learning disability in the acute sector and how we can help change that'</i>
<i>'I learnt that it was easier to communicate with people with learning disability when I was relaxed and comfortable as this helped them to feel more confident talking to me'</i>

Within the time scale of the case study conducting a level 3 and 4 evaluation was not feasible. However an outline of the proposed evaluation is included. The examples from practice therefore cannot be directly attribute to a specific session with led by 'experts by experience'.

Behaviour – Level 3, Kirkpatrick model of evaluation.

"...sometimes it is the service users' presence, which can change the behaviours of people"
(Chambers & Hickey, 2012, p.50).

Literature supports the notion that including service users in teaching activity is useful on many levels. Turner et al. (2000) found that students valued hearing the 'lived experience' of users and the experience resulted in a positive impact on students (Ottwell et al., 2006). After the session the students are asked to write a 'pledge' - a statement of future practice / behaviour that they as nurses will endeavour to achieve. Although writing a 'pledge' doesn't necessarily demonstrate future behaviour it does however identify intent at the time of writing. For example:

"I pledge to always take into account that some people might have a hard time processing information"
"I pledge to always listen and adjust care for what patient or patients' families need"
"I pledge that the care I give learning disability patients is equal to the rest of my patients. That I will take time to deliver the appropriate care that they feel comfortable and reassured in my care as a nurse"

"I pledge to make reasonable adjustments in my role to ensure that people with learning disability receive services as good as other people"

"I pledge to give more time to patients with a learning disability and to treat them as individuals"

"I pledge to listen to the family and carers"

In their pledges the student nurses identify behaviours such as listening, time, involve family/carers, adapting their practice as future ways of working.

The last cohort of students to attend the session were contacted via university email at the end of their course, (that is, six months after the session) to ask for examples of practice. That is:

Excerpt from correspondence to students:

I am keen to gather any evidence that highlights that this session with Mencap Môn made a difference to your clinical practice whilst on placement recently. For example, do you have an example from your clinical practice where you had to think of 'reasonable adjustments'? No identifiable details should be included in an example to ensure confidentiality. As a framework, you may think of:

- 1. What was the nature of the clinical activity?*
- 2. What 'reasonable adjustments' took place?*
- 3. Did the experience change/develop your practice?*

To date no response was received and as the students are on placement it was difficult to find a time that they would be attending University to speak directly to them. HEI's across the UK are preparing to meet the new 'Future nurse: Standards of proficiency for registered nurses' published by the NMC (2018). This creates an opportunity for service users to be integral in the planning and delivery of the new curriculum thus moving away from the involvement seen as a one off event to a continuing process across the curriculum. For the first time in the nursing curriculum the term 'reasonable adjustments' appear in the learning outcomes. That is:

2.4 identify and use all appropriate opportunities, making reasonable adjustments when required,... (p. 11)

3.7 understand and apply the principles and processes for making reasonable adjustments (p. 14)

7.9 facilitate equitable access to healthcare for people who are vulnerable or have a disability, demonstrate the ability to advocate on their behalf when required, and make necessary reasonable adjustments to the assessment, planning and delivery of their care (p. 26).

Where people have special communication needs or a disability, it is essential that reasonable adjustments are made in order to communicate, provide and share information in a manner that promotes optimum understanding and engagement and facilitates equal access to high quality care. (p.27)

2.2 use clear language and appropriate, written materials, making reasonable adjustments where appropriate in order to optimise people's understanding of what has caused their health condition and the implications of their care and treatment (p. 28).

Where people are disabled or have specific cognitive needs it is essential that reasonable adjustments are made to ensure that all procedures are undertaken safely (p. 31).

This commitment from the NMC to ensure that at the point of registration that all registered nurses have the skills and knowledge to make reasonable adjustments is welcomed. There is an opportunity here to link future 'expert by experience' led sessions to the NMC 2018 educational standards.

Results - Level 4, Kirkpatrick model of evaluation.

Attributing that a particular teaching session has made an impact on the future practice of nurses and on the healthcare of people with learning disability was not feasible within this six month project. However, following the session the students are asked to comment on 'what challenges do you expect to face when putting any of what you learnt into action?' (see Box 1). Students identified their ability to adapt their communication skills could be a challenge, alongside having enough 'time' on 'busy wards'. They also suggested that the work 'culture' and a lack of 'understanding' by other professions could be barriers to future practice.

Box 1: What challenges do you expect to face when putting any of what you learnt into action?

"Learning disability can be extremely varied and what works for one person might not for another"

"Finding the time to give the most effective care"

"Other people in work setting not understanding and maybe not agreeing with certain decisions due to lack of understanding"

"Communicating and meeting the needs of people with a learning disability"

"Nursing culture – 'old school nurses'"

"Accessing advice as few learning disability nurses in the acute setting and they are only available Monday to Friday"

"To challenge nursing culture and treat everyone as an individual"

"Time on the ward"

"May not notice or misdiagnosing a learning disability"

"Doctors maybe uneducated in the needs of people with a learning disability"

"Finding time on the busy wards to give the patient with learning disability the care they deserve"

"Other practitioner's long-standing views on learning disability"

Data available regarding the learning disability population, the number of individuals accessing healthcare and the cost of that care is difficult to source. The Welsh Government have started to collect data on the healthcare people with learning disability receive within acute hospital services and examples of good practice. See Appendix 4 for July 2018 interim report of referrals received by the Learning Disability Acute Liaison Service at Betsi Cadwaladr University Health Board.

The data should be read with caution as not all individuals with a learning disability admitted into hospital are referred to the Learning Disability Health Liaison Service and not all individuals with a learning disability are identified in mainstream services. Therefore currently, individuals with a learning disability cannot be reliably identified from the nationally collected inpatient data set. Several health boards in Wales have put in place ways of 'flagging' individuals with a learning disability in their Patient Administration Systems, however it is too early to know if this is a reliable method.

According to the Interim Report (see Appendix 4) the total population of people with a learning disability known on Learning Disability General Practitioners registers for 2017-2018 within the local health board (BCUHB) is $n=2918$. However, on accessing data via Daffodil (<http://daffodilcymru.org.uk/>), a web-based system developed by the Institute of Public Care for the Welsh Assembly Government, prevalence estimates based on Emerson and Hatton's (2004) work suggest that the number of people with a learning disability within the local health board (BCUHB) was 13,130 in 2017 (see Table 2).

Another source of data is the Learning Disability Quality and Outcomes Framework (<https://statswales.gov.wales/Catalogue/Health-and-Social-Care/NHS-Primary-and-Community-Activity/GMS-Contract/patientsonqualityandoutcomesframework-by-localhealthboard-diseaseregister>). The baseline data identified for Learning Disability (that is; $n=3426$ in 2016-2017)

within BCUHB is smaller than the estimate given via the Daffodil web based system. The disparity and the lack of reliable data produces challenges when attempting to seek clarification on actual population we are seeking to help access healthcare. Thus, the data to cost the average stay of a patient with learning disability compared with the cost of the general population is difficult to source.

Although there are significant gaps in data and evidence regarding hospital admissions it is acknowledged that enabling individuals with a learning disability to have equal access to healthcare is a complex issue and nurse education needs to consider ways to arm healthcare professionals with skills and knowledge to tackle health inequalities and health inequity.

Table 2: produced on 15/08/18 14:34 from www.daffodilcymru.org.uk version 7.0

	2017	2020	2025	2030	2035
Betsi Cadwaladr: People aged 18-24 predicted to have a learning disability	1,510	1,419	1,368	1,501	1,498
Betsi Cadwaladr: People aged 25-34 predicted to have a learning disability	2,073	2,157	2,110	1,932	1,964
Betsi Cadwaladr: People aged 35-44 predicted to have a learning disability	1,876	1,874	2,057	2,229	2,190
Betsi Cadwaladr: People aged 45-54 predicted to have a learning disability	2,294	2,158	1,914	1,847	2,027
Betsi Cadwaladr: People aged 55-64 predicted to have a learning disability	2,046	2,157	2,251	2,120	1,888
Betsi Cadwaladr: People aged 65-74 predicted to have a learning disability	1,886	1,889	1,802	1,945	2,046
Betsi Cadwaladr: People aged 75-84 predicted to have a learning disability	1,023	1,134	1,365	1,402	1,382
Betsi Cadwaladr: People aged 85 and over predicted to have a learning disability	421	464	566	714	917
Betsi Cadwaladr: Total population aged 18 and over predicted to have a learning disability	13,130	13,251	13,432	13,691	13,912

As Yardley and Dornan (2012) identify, the fourth level of evaluation in healthcare has two elements, that is, an evaluation of the shift in practice and the improved outcomes for patients. A long term project may be able to track the student nurses practice from nurse education to clinical practice as registered nurses. Appendix 5 gives an example of good practice in relation to applying the principle of reasonable adjustment in acute hospital care. Claire Johnson is a registered adult nurse and works at the Arrivals Lounge at a district general hospital. In her presentation (see Appendix 5) she outlines the care she delivered in partnership with the individual with learning disability and their family. Such good practice should be published to enable other professionals to see how the principles of reasonable adjustments can be implemented.

Mapping the improved outcomes for patients with learning disability requires reliable data. Such improvements at this time could not be attributed to the educational input outlined. However there is a campaign nationally to ensure that learning disability awareness training becomes mandatory for all healthcare professions with an assumption that this would improve the equality of access to mainstream healthcare (see <http://senedd.assembly.wales/mgIssueHistoryHome.aspx?IId=23618>).

Thus one could anticipate that increasing healthcare professional's awareness of learning disability and associated health needs would result in improved outcomes for individuals.

Conclusion

Creating meaningful opportunities for individuals who use healthcare services to contribute to undergraduate nurse education enables education to reflect the needs and priorities of people with learning disability. Current evidence highlights the health inequality that individuals with learning disability face every day. Designing opportunities for involvement with individuals with a learning disability in nurse education is an attempt to influence the healthcare individuals will receive from the future healthcare workforce.

The term 'involvement' can be problematic as it implies a situation where individuals are invited into the professional educational 'world'. However, within the workshop activity outlined in this case study the individuals do lead and control the teaching. Hence, across all aspects of teaching and learning within nurse education, involvement and participation should be seen as a continuum not as a one off activity.

By identifying the cost and benefit of service user involvement in nurse education, the aim is to ensure that such involvement would become an integral part of nursing curriculum. As universities across the UK progress with their curriculum planning to meet the new Standards of proficiency for registered nurses (NMC, 2018), HEI's are also encouraged to consider models of involvement to enrich nurse education for the students but ultimately to ensure better healthcare for all.

Key features

Ensure that through innovative teaching and learning approaches that reasonable adjustments are normalised in nurse education and ultimately in healthcare services for people with learning disability.

This is a bespoke approach to engagement that is not necessarily common practice in nurse education within HEI's.

Role model within HEI's in championing meaningful involvement of individuals who use services.

Normalising and celebrating the contribution of people with learning disability to nurse education.

References

- Adults With Incapacity (Scotland) Act, 2000 asp4*. London: The Stationery Office.
- Beacock, S., Borthwick, R., Kelly, J., Craine, & Jelfs, E. (2015) *Learning Disabilities. Meeting Education Needs of Students*. London: The UK Learning and Intellectual Disability Nursing Academic Network and the Council of Deans of Health.
- Bollard, M., Lahiff, J., Parkes, N. (2012). Involving people with learning disabilities in Nurse Education: Towards an inclusive approach. *Nurse Education Today*, 32 (2), 173-177.
- Boudioni, M., McLaren, S., & Lister, G. (2017). A critical analysis of national policies, systems, and structures of patient empowerment in England and Greece. *Patient Preference and Adherence*, 11, 1657–1669. <http://doi.org/10.2147/PPA.S144028>
- Branfield, F. (2009). *SCIE Report 29: Developing user involvement in social work education*. London: Social Care Institute for Excellence.
- Chambers, M. & Hickey, G. (2012) Service user involvement in the design and delivery of education and training programmes leading to registration with the Health and Care Professions Council, HCPC. Available at: <http://79.170.44.111/socialworkeducation.org.uk/wp-content/uploads/2012/11/service-users-involved-in-delivery-of-education-and-training-programmes.pdf>
- Christiansen, A. (2011) Storytelling and professional learning: a phenomenographic study of students' experience of patient digital stories in nurse education. *Nurse Education Today* 31, 280–293.
- Cooley, A. & Lawrence Z. (2006). *Reward and Recognition: The principles and practice of service user payment and reimbursement in health and social care. A guide for service providers, service users and carers*. Leeds: Department of Health.
- Clark, C. M., Ahten, S. M., & Macy, R. (2014). Nursing graduates' ability to address incivility: Kirkpatrick's level-3 evaluation. *Clinical Simulation in Nursing*, 10(8), 425-431. Available at: <http://dx.doi.org/10.1016/j.ecns.2014.04.005>
- Department of Health. (2009) *Valuing People Now: a new three-year strategy for people with learning disabilities Making it happen for everyone*. London: DoH.
- Developers of User and Carer Involvement in Education (DUCIE) Network. (2009) *Involving Service Users and Carers in Education: The Development Worker Role – Guidelines for Higher Education Institutions*. Mental Health in Higher Education, Available at: www.mhhe.heacademy.ac.uk/themes/ducie-guidelines
- DeSilets, L. D. (2018). An update on Kirkpatrick's model of evaluation: Part two. *The Journal of Continuing Education in Nursing*, 49(7), 292-293.
- Ellis, R. & Hogard, E. (2006) The Trident: A Three-Pronged Method for Evaluating Clinical, Social and Educational Innovations. *Evaluation*. 12(3), 372-383.
- Equality Act 2010, c. 15*. London: The Stationery Office.
- Emerson, E.; Glover, G.; Turner, S.; Greig, R.; Hatton, C.; Baines, S.; Copeland, A.; Evison, F.; Roberts, H.; Robertson, J. & Welch, V. (2012). Improving health and lives: The Learning Disabilities Public Health Observatory. *Advances in Mental Health and Intellectual Disabilities*. 6, 26-32.
- Emerson, E.; Hatton, C.; Baines, S. & Robertson, J. (2016). The physical health of British adults with intellectual disability: cross sectional study. *International Journal for Equity in Health*, 15:11.
- Francis, R. (2013). *Report of the Mid Staffordshire NHS Foundation Trust Public Inquiry; Executive Summary*. London: The Stationery Office.
- Gutteridge, R. & Dobbins, K. (2010). Service user and carer involvement in learning and teaching: A faculty of health staff perspective. *Nurse Education Today*, 30(6), 509-514.
- Happell, B.; Moxham, L. & Platania-Phung, C. (2011). The impact of mental health nursing education on undergraduate nursing students' attitudes to consumer participation. *Issues in Mental Health Nursing*, 32, 108–113.

Heslop, P.; Blair, P.; Fleming, P.; Hoghton, M.; Marriott, A. & Russ, L. (2013) *Confidential Inquiry into Premature Deaths of People with Learning Disabilities*. Bristol: Norah Fry Research Centre, University of Bristol.

Hoghton, M., Turner, S. & Hall, I. (2012) *Improving the Health and Wellbeing of People with Learning Disabilities: An Evidence-Based Commissioning Guide for Clinical Commissioning Groups (CCGs)*. London: Improving Health and Lives Learning Disability Observatory; Royal College General Practitioners; Royal College of Psychiatrist. Available at: https://www.improvinghealthandlives.org.uk/uploads/doc/vid_10118_IHaL%20NHS%20Trust%20Reasonable%20Adjustments%20survey%202010.pdf

Human Rights Act 1998. c 42. London: The Stationery Office.

Iacono, T.; Bigby, C.; Unsworth, C.; Douglas, J. & Fitzpatrick, P. (2014) A systematic review of hospital experiences of people with intellectual disability. *BMC Health Services Research*. 14:505.

Irvine, J.; Molyneux, J. & Gillman, M. (2014) 'Providing a Link with the Real World': Learning from the Student Experience of Service User and Carer Involvement in Social Work Education. *Social Work Education*, 34(2), 138-150.

Kirkpatrick, D.L. & Kirkpatrick J.L. (2006). *Evaluating training programs* (3rd ed.). San Francisco: CA. Berrett-Koehler Publishers, Inc.

Krahn, G.L.; Hammond, L. & Turner A. (2006) A cascade of disparities: health and health care access for people with intellectual disabilities. *Ment Retard Dev Disabil Res Rev*, 12, 70–82.

Lifelong Learning Network (2011). *Working Together – Service User and Carer Engagement in Health and Social Care: A Toolkit for Education*. Research and Development. Lifelong Learning Network, in association with the University of Wolverhampton, Staffordshire University, Keele University, and The Open University. Available at: <http://www.serviceuserandcarertoolkit.co.uk>

LeDeR. (2018). *The Learning Disabilities Mortality Review (LeDeR) Programme - Annual Report December 2017*. Bristol: Norah Fry Research Centre, University of Bristol.

McCormack, B. & McCance, T. (2010) *Person-centred Nursing: Theory, models and methods*. Oxford: Blackwell Publishing.

McGarry, J. & Thom, N. (2004) How users and carers view their involvement in nurse education. *Nursing Times*, 100, 36–39.

McKeown, M.; Malihi-Shoja, L.; Hogarth, R.; Jones, F.; Holt, K.; Sullivan, P.; Lunt, J.; Vella, J.; Hough, G.; Rawcliffe, L.; Mather, M. & CIT. (2012) The value of involvement from the perspective of service users and carers engaged in practitioner education: not just a cash nexus. *Nurse Education Today* 32, 178–184.

Mencap. (2007) *Death by indifference*. London: Mencap.

Mencap (2018) *Treat me well Campaign*. Available at: <https://www.mencap.org.uk/get-involved/campaign-mencap/current-campaigns/treat-me-well>

Mental Capacity Act, 2005 c9. London: The Stationery Office.

Mental Health Act, 2007 c12. London: The Stationery Office.

Michael, J. (2008) Healthcare for all: report of the independent inquiry into access to healthcare for people with learning disabilities. *Tizard Learning Disability Review*, 13(4), 28-34, <https://doi.org/10.1108/13595474200800036>

Minogue, V., Holt, B., Karban, K., Gelsthorpe, S., Firth, S. & Ramsey, T. (2009) Service user and carer involvement in mental health education, training and research — a literature review. *Mental Health and Learning Disabilities Research and Practice*, 6(2), 211-227.

NMC. (2010). *Standards for pre-registration nursing education*. London: NMC.

NMC. (2018). *Standards of Education Standards framework for nursing and midwifery education*. London: NMC.

Ottwell, R.; Demain, S.; Ellis-Hill, C.; Greengeyer, C. & Kileff, J. (2006). An expert patient led approach to learning and teaching: the case of physiotherapy. *Medical Teacher* 28(4), 120–126.

Reio, T. G., Rocco, T. S., Smith, D. H. & Chang, E. (2017). A Critique of Kirkpatrick's Evaluation Model. *New Horizons in Adult Education and Human Resource Development*, 29: 35-53.

- Rhodes, C. (2012) User involvement in health and social care education: a concept analysis. *Nurse Education Today*, 32, 185–189.
- Rhodes, C. (2013) Service user involvement in pre-registration children's nursing education: the impact and influence on practice: a case study on the student perspective. *Issues in Comprehensive Pediatric Nursing*, 36, 291–308.
- Rhodes, C. & Nyawata, I. (2011). *Service user and carer involvement in student nurse selection: key stakeholder perspectives*. *Nurse Education Today*, 31, 439–443.
- Rouse, D. (2011). Employing Kirkpatrick's Evaluation Framework to Determine the Effectiveness of Health Information Management Courses and Programs. *Perspectives in Health Information Management*, 8(Spring), 1c.
- Rush, B. (2008). Mental health service user involvement in nurse education: a catalyst for transformative learning. *Journal of Mental Health*, 17 (5), 531-542.
- RCN. (2013). *Meeting the health needs of people with learning disabilities*. *RCN guidance for nursing staff*. London: Royal College of Nursing.
- Rush, B. & Barker, J. H. (2006). Involving mental health service users in nurse education through enquiry-based learning. *Nurse Education in Practice*, 6, 254-260.
- Scammell, J.; Heaslip, V. & Crowley, E. (2016). Service user involvement in preregistration general nurse education: a systematic review. *J Clin Nurs*, 25: 53-69.
- Scottish Government. (2012) *Strengthening the Commitment: the report of the UK Modernising Learning Disabilities Nursing Review*. Edinburgh: Scottish Government.
- Social Services and Well-being (Wales) Act 2014 anaw 4*. London: The Stationery Office.
- Tew, J., C. Gell, et al. (2004). *Learning from Experience: Involving service users and carers in mental health education and training*. Nottingham: Mental Health in Higher Education.
- Torrance, C.; Mansell, I. & Wilson, C. (2012). Learning objects? Nurse educators' views on using patients for student learning: ethics and consent. *Education for Health*. 25, 92–97.
- Tuffrey-Wijne, I.; Giatras, N.; Goulding, L.; Abraham, E.; Fenwick, L.; Edwards, C. & Hollins, S. (2013). Identifying the factors affecting the implementation of strategies to promote a safer environment for patients with learning disabilities in NHS hospitals: a mixed-methods study. *Health Services and Delivery Research*, 1.13, Available from: <https://www.ncbi.nlm.nih.gov/books/NBK259489/> doi: 10.3310/hsdr01130
- Turner, M.; Sheldon, F.; Coles, C.; Mountford, B.; Hillier, R.; Radway, P. & Wee, P. (2000). Listening to and learning from the family carer's story: an innovative approach in interprofessional education. *Journal of Interprofessional Care* 14, 387–395.
- UN Convention on the Rights of Persons with Disabilities, 2008. Available at: <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/convention-on-the-rights-of-persons-with-disabilities-2.html>
- Welsh Government. (2016). *Follow-on Strategic Framework for Welsh Language Services in Health, Social Services and Social Care 2016 – 2019*, 30. Caerdydd: Welsh Government.
- World Health Organization (WHO) (1991). *Community Involvement in Health Care Development. Report of a WHO Study Group. Technical Report Series no. 809*. Geneva: WHO.
- Well-being of Future Generations (Wales) Act 2015 anaw 2*. London: The Stationery Office.
- Yardley, S. & Dornan, T. (2012), Kirkpatrick's levels and education 'evidence'. *Medical Education*, 46: 97-106.

Appendix 1

Identify, quantify and monetise set up costs V1, 13.04.18

NAME: Ruth Wyn Williams

Set up costs			
Direct	Identify	Quantify	Monetise
1.	1 x Lecturer Grade 8	<p>Annually salary £48,677 Hourly rate £32.30 The University calculate on-costs (NI/Pension/Levy) as a further 28.75% in addition to the pay.</p> <p>6 contact visits = 2 hours over 10 months</p>	<p>2 hours = £64.60 + 28.75% (£18.57) on-costs Total per visit £83.17 Total for 6 contact visits= £499.02</p>
2.	Travel to meet members of Mencap Môn at their Hub.	Bangor to Llangefni 18 miles X 6 = 108miles	108 miles @ 40p per mile = £43.20
Indirect	Identify	Quantify	Monetise
1.	1 x drama facilitator	There is no charge to the HEI as the Drama Facilitator attends the Mencap Môn Hub (the members meeting facility) thus no additional cost to the project.	No additional cost
2.	Members of Mencap Môn (plus family & carers)	No additional cost to the HEI as members meet regularly at their facility 'The Hub'. There is no charger to the HEI for attending The Hub.	No additional cost
			Total costs: £542.22

Appendix 2

Identify, quantify and monetise running costs V1, 13.04.18

NAME: Ruth Wyn Williams

Running costs			
Direct	Identify	Quantify	Monetise
1.	1 x Lecturer Grade 8	<p>Annually salary £48,677 Hourly rate £32.30 The University calculate on-costs (NI/Pension/Levy) as a further 28.75% in addition to the pay.</p> <p>2x teaching days annually (6 hours x 2) 2x preparation days annually (6 hours x 2) (The teaching and preparation days does not meet additionally criteria. That is, there is no additional cost to the HEI as the teaching and preparation days are expected within the job description of the lecturer.</p> <p>4 contact visits = 2 hours with members of Mencap Môn at the Hub</p>	<p>£0 No additional cost due to role not being above and beyond expected role.</p> <p>£258.40 + 28.75% (£74.29) = £332.69</p>
2.	<p>1 x Lecturer Grade 8</p> <p>An appropriately qualified person with the skills and knowledge in learning disability is required to support the members of Mencap Môn when attending the University. This enables the members to participate fully in the teaching and for the Lecturer that's facilitating the workshop to focus on the teaching and learning experience of the nursing cohort.</p>	<p>Annually salary £48,677 Hourly rate £32.30 The University calculate on-costs (NI/Pension/Levy) as a further 28.75% in addition to the pay.</p> <p>2x teaching half days annually (3 hours x 2)</p>	<p>£193.80 + 28.75% (£55.71) = £249.52</p>
3.	1 x large teaching room & 1x small teaching room with IT equipment	Does not meet additional criterion, rooms and equipment already provided by the University for the student nursing cohort	£0
4.	Stipend	£200 x 2 annually	£400

5.	Travel to the Mencap Môn Hub	Bangor to Llangefni 18 miles X 6 = 108miles	108miles @ 40p per mile = £43.20
Indirect	Identify	Quantify	Monetise
1.	1 x drama facilitator	Does not meet additional criterion—already provided/paid by Mencap Môn. Thus there is no charge to the HEI as the Drama Facilitator facilitates drama sessions for the members of Mencap Môn and teaching at the University is considered part of the drama facilitator’s work. Thus, no additional cost to the project.	No additional cost
2.	Travel cost for carers / support		No additional cost
3.	Mencap Môn members time		No additional cost
4.	Refreshments	25 x tea/coffee & Biscuits Tea Bags x 40= £2:00 Coffee = £4:00 Sugar = £1:00 Milk = £1:50 Biscuits = £2:00	Purchased personally by lecturer: e.g. Total= £10:50 – no cost to University
			Total: £1025.41

Appendix 3

Benefits: Nurse education: valuing the input of people with a learning disability to the BN (Hons) programme V1 05.06.18

Identify Benefits (from PtO)	State Assumptions: what is your attribution story?	Evidence Local or proxy?
<p>Individuals with learning disability and their family/carers - Members of Mencap Môn</p> <p>Valued role - Experts by experience Genuine partnership.</p>	<p>Enjoyment – making a difference Helping students learn Empowerment Voice heard</p>	<p>Video clips with service user feedback. Continued engagement in sessions</p>
<p>Patients with learning disability People with learning disability accessing health care can expect better health outcomes.</p>	<p>The evidence is clear about poor health outcomes for people with learning disability.</p> <p>The experience of working in partnership with people with a learning disability will impact on the students nurses knowledge, practice and skill of using the principle of ‘reasonable adjustment’.</p> <p>Person-centred care involves nurses working in accordance with a person’s values and preferences where possible, engaging in shared decision-making and relating to the service user as an individual (McCormack & McCance, 2010).</p>	<p>The Healthcare for All report also highlights the need for equal treatment and says that insufficient attention is given by healthcare staff to making reasonable adjustments (Michael, 2008).</p> <p>The Confidential Inquiry into Premature Deaths of People with Learning Disabilities (CIPOLD) Final Report (Heslop et al., 2013) found that, on average, men with learning disabilities die 13 years younger than the general male population and women with learning disabilities die 20 years younger than the general population. Many of these deaths are considered avoidable and/or premature.</p> <p><i>LeDeR update 2018</i> Most common individual causes of death: Pneumonia 16% Sepsis 11% Aspiration pneumonia 9% 64% of people with LD died in hospital, compared with 47% in the general population (n=1,244).</p> <p><i>Health needs Assessment report – people with learning disability in Scotland 2017.</i></p>

		<p>Different pattern of health disease experienced by people with learning disabilities when compared to the general population</p> <p>Case study example of reasonable adjustment: Requested example from local health liaison team.</p>
<p>Adult nursing students Skills and knowledge to apply the principle of 'reasonable adjustment' (a duty under the Equality Act) to nursing practice. Practice communication skills</p>	<p>There appears to be limited evidence of the longer term impact on future practice – e.g. within social work practice - Julie Irvine, Jeanie Molyneux & Maureen Gillman (2014) 'Providing a Link with the Real World': Learning from the Student Experience of Service User and Carer Involvement in Social Work Education, <i>Social Work Education</i>, 34:2, 138-150, DOI: 10.1080/02615479.2014.957178</p> <p>The effect of various learning strategies on nursing practice is challenging to measure through educational research (Morgan and Jones 2009). This is because it can be complex to directly relate the effects of specific educational strategies on practice since these are not delivered in isolation of other learning approaches and nursing students' life or practice experiences. Thus, linking longer term changes in attitude and behaviour is challenging.</p>	<p>Evidence to support via feedback session/evaluation – student pledges/ thank you notes to service users.</p> <p><i>(last teaching session 14.11.17; emailed participants 23.05.18 re evaluation – no response to date).</i></p> <p>Clinical portfolio outcome –student reflection</p> <p>A large number of studies have emphasised the need for healthcare students to have education and training around communication skills in relation to caring for people with learning disabilities. Some of these studies found that accessing effective healthcare was made more problematic due to poor communication between people with learning disabilities and health professionals (Alborz et al, 2005; Gates, 2011; Gibbs et al, 2008; McClimens et al, 2013; Mencap, 2007).</p> <p>Service user involvement in healthcare education is associated with several benefits for students, including: increased empathy, development of communication skills, increased confidence in promoting the rights of service users, and enhanced understanding of person-centred approaches to care (Cooper and Spencer-Dawe 2006, Rush 2008, Stickley et al 2009, Towle et al 2010, McCusker et al 2012).</p> <p>Service users with learning disabilities in Gates' (2011) study said that communication between people with</p>

		<p>learning disabilities and health professionals needed to be improved, as did carers of people with learning disabilities in McClimens et al's case study on the treatment of clients with learning disabilities in the NHS (2013).</p> <p>Sowney and Barr (2007) found that there was a lack of knowledge amongst accident and emergency nurses relating to ways of communicating with people with learning disabilities. The authors suggested that this needed to be addressed in both the clinical and educational arenas.</p>
<p>Staff Role model in practicing the principle of 'reasonable adjustment'. Normalising contribution of service users in nurse education. Relationship with service users and family</p>	<p>Strong commitment to developing genuine partnerships.</p> <p>Staff remain 'connected' to individuals with LD and their families.</p> <p>The involvement of service users in social work programmes is seen as providing a balanced education to potential practitioners and to modelling good practice for the future, especially when service user involvement is established from the beginning of the programme (Baldwin & Sadd, 2006 Baldwin, M., & Sadd, J. (2006).</p> <p>A break down what are seen as traditional power balances and develop real participation.</p> <p>Planning service-user participation provides an important opportunity to embed service-user involvement in teaching and learning.</p>	<p>Feedback from service users.</p> <p>Reflective account – NMC revalidation.</p> <p>SNTA finalist for partnership Award</p> <p>Conference presentation</p>
<p>Organisation</p>	<p>Embedding in culture of organisation.</p>	<p>Patient-centred policy.</p>

<p>Meeting and delivering on NMC requirements Standards of Education, requirements of validating new curriculum to commence 2020 PPI policy agenda Avoidance of a negative -</p>	<p>Barriers to such involvement such as organisational, process and cultural issues in universities have been considered. These included access, amount of paperwork, payment systems, training and support for service users and carers (Branfield et al., 2007; Branfield, F., Beresford, P., & Levin, E., 2007).</p> <p>A lack of support for this approach by education providers, as well as bureaucracy and prejudice, can result in service user involvement being tokenistic rather than a genuine partnership and change in power dynamics (Basset et al., 2006, McKeown et al., 2010, Bennetts et al., 2011).</p> <p>Repper & Breeze (2004, 2007) comment that consumer involvement seems to be based on the assumption that it will lead to practice that is more aligned to consumers expectations. However they found little evidence that studies were examining this, focusing, as they did, mainly on process rather than outcome, measuring the impact of user involvement is complicated by the lack of a clear understanding of the concept of user involvement practically and ideologically in the current welfare framework (Cowden & Singh, 2007).</p> <p>Logistical challenges, such as recruitment, payment and availability for timetabled sessions, can be a barrier to collaboration with service users in education (Basset et al., 2006, McKeown et al., 2010).</p>	<p>Requiring Universities to involve a service user as a panel member during the approval process for pre-registration nursing programmes – NMC</p> <p>Possible potential for research / evaluation project</p>
--	---	---

Interim Report Jan 1st 2018-July 1st 2018

This interim report has been compiled to show the number of referrals to Acute Liaison Nurses in the 3 District General Hospitals across the Betsi Cadwaladr University Health Board in North Wales. These are the number of people with a Learning Disability who are accessing acute health services who are known to Learning Disability services in North Wales and also those who are accessing the health services from outside North Wales.

The report will show the number of admissions, whether they were planned or unplanned and the average length of stay for the total admissions in each hospital, for the timeframe January 1st 2018 to July 1st 2018. The report will also show a comparison in the average length of stay for the same time period in the previous year. This interim report will feed into the comprehensive end of year report in January 2019 and will be compared with data from the 2 participating health boards in South Wales.

January 2018- July 2018 statistics:

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

January 2017- July 2017 statistics:

Statistics	Wrexham	Ysbyty Glan Clwyd	Ysbyty Gwynedd
No of referrals	113	78	31
No of non-LD referrals	7	1	0
No of hospital days	387	289	185
Average length of stay	7 days	4.5 days	6 days

Noticeably there is not a great deal of difference between the 2 years, this is in all probability due to Acute Liaison Nurses being established in BCUHB since 2010 and a better comparison on length of stays, would have been from earlier years unfortunately this evidence is not available.

The percentage of 30 day readmissions are as follows:

Wrexham	Ysbyty Glan Clwyd	Ysbyty Gwynedd
11 %	3%	4%

The total population of people with a Learning Disability known on Learning Disability GP registers for 2017-2018 is 2918.

Kim Scandariato Interim Locality Matron July 31st 2018

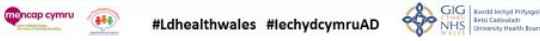
Appendix 5

Implementing reasonable adjustments: an example of good practice.

Claire Johnson, Registered Adult Nurse, Arrivals Lounge, Wrexham Maelor Hospital

The Value of a Learning Disability Health Champion

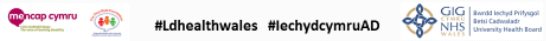
Claire Johnson
Registered Adult Nurse
Arrivals Lounge
Wrexham Maelor Hospital



#Ldhealthwales #IechydymruAD

How it all begin:

- It started 8 years ago when I joined the arrivals team.
- Arrivals lounge is a same day surgical unit admissions unit.
- It is open Monday to Friday and admits up to 40 patients a day for same day surgery. We cover all 11 theatres for Wrexham Maelor Hospital and all of the surgical specialities within the hospital.
- Patients have a pre op assessment up to 6 weeks prior to surgery- this is the point where our colleagues in pre op notify us of any patients with additional needs or complexities.



#Ldhealthwales #IechydymruAD

Arrivals Waiting Lounge



#Ldhealthwales #IechydymruAD

My drive to change practice.

- Improve on the patient experience & their individualised care.
- Engaging with a wonderful team of colleagues to enable them to see the unit & patient care differently for our patients with Learning Disabilities.
- Our NMC Code of Conduct- to prioritise people, to practice effectively and preserve safety.



#Ldhealthwales #IechydymruAD


My personal experience



#Ldhealthwales #IechydymruAD

Started by making reasonable adjustments.

- Allowing patients to arrive one hour prior to operation.
- Visiting the unit before day of surgery.
- Allowing them to go to theatre in their own nightwear/sportswear.
- Discussing their care needs in advance.
- Any sensory issues/concerns-adjusting to meet these needs.
- Giving them their own side room, if appropriate.
- De-cluttering rooms of medical devices that are not needed.



#Ldhealthwales #IechydymruAD

Patient Story

- Lily (name changed for confidentiality) needed surgery for treatment her kidney stones.
- They were causing great pain, discomfort and recurrent urinary tract infections.
- Best interest meeting was held in advance as Lily did not have capacity to consent and fully understand the risks/benefits of surgery.
- Lily had a diagnosis of a learning disability and complex needs.



Patient Story

- A multi disciplinary Best interest meeting was chaired and organised by our brilliant Learning disability Nurse, Rose.
- Lily had complex medical history. Also following a hip replacement the previous year. Had limited mobility and post operatively needed an ITU stay as she developed respiratory difficulty post op.
- Both parents were present throughout the meeting and now in their 70's. They talked lovingly and passionately about their 51 year old daughter. Who had limited communication through speech. But would let you know her feelings about you through eye gestures and body language.



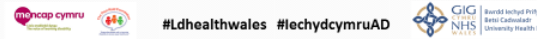
Patient Story

- It was all agreed that it was in Lily's best interest to have the surgery as a day case procedure.
- My colleagues in pre op shared their information and assessment on Lily, it was my turn now to plan and tailor her care.



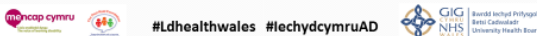
What I felt was valuable information.

- Lily was now in a residential care setting, but her parents visited everyday with Strawberries.
- She loved music, particularly Val Doonigan.
- She enjoyed watching Rowan Atkinson as Mr Bean over and over.
- But her favourite love was for a teddy and a doll which she has had from birth.
- Mum lovingly discussed how teddy had seen better days, how he been given several new sets of eyes and stuffed and re sewn on numerous occasions.



What did I do!

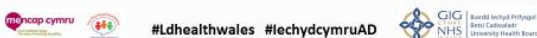
- I worked closely with Lily's parents and residential carers to tailor her care and the environment.
- Admission time was shortened to only an hour before procedure to allow enough time to be safely prepared for theatre. But not long enough to get anxious at waiting.
- All the care plan and admission document was filled in over the phone with parents and residential home prior to admission.



- Main focus on the day was engagement and interaction with her favourite past times.
- Mr Bean and Val Doonican had been downloaded onto our unit kindle.
- I safely prepared Lily for theatre with the team and theatre staff in a relaxed manner as not to cause further stress.



Teddy's own theatre gown



- Her checklist was done once on the ward by a theatre nurse alongside myself, to limit the wait at the theatre door.
- Mum came with Lily to theatre to talk and support Lily until she was under the anaesthetic.
- Both parents then waited on arrivals with refreshments until theatre recovery called for them.
- My colleagues on the post op day case ward had all the information to continue tailored care and discharge Lily & Teddy safely.



Arrivals Team



#Ldhealthwales #lechydymruAD



Sawdd Iechyd Prifysgol
Betsi Cadwaladr
University Health Board

Arrivals Team



#Ldhealthwales #lechydymruAD



Sawdd Iechyd Prifysgol
Betsi Cadwaladr
University Health Board

To summarise the values I believe of being a Learning Disability Health Champion.

- Gives patient centred care, at its best.
- Reassure's patient's, family members and carers that they matter.
- Great job satisfaction. I came into nursing to make a difference and feel this care does.
- By slight tweaks you can change a persons care from good/average to excellent.



#Ldhealthwales #lechydymruAD



Sawdd Iechyd Prifysgol
Betsi Cadwaladr
University Health Board