HEI's that deliver nurse education.

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. 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. p5).

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 f

To instil language and cultural competence in healthcare practitioners.

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'.

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.

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

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)

Adult nursing students:

The second level of evaluation in

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).

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

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:

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'

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.

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.

Heslop, P.; Blair, P.; Fleming, P.; Hoghton, M.; Marriott, A. & Russ, L. (2013)
. Bristol: Norah Fry Research Centre, University of Bristol.
Hoghton, M., Turner, S. & Hall, I. (2012)
.
London: Improving Health and Lives Learning Disability Observatory; Royal College General Practitioners; Royal College of Psychiatrist. Available at:

. 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. 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.
34(2), 138-150.
Kirkpatrick, D.L. & Kirkpatrick J.L. (2006). (3rded.). 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. , 12, 70–82.
Lifelong Learning Network (2011).
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).
. Bristol: Norah Fry Research Centre, University of Bristol.
McCormack, B. & McCance, T. (2010) Oxford: Blackwell Publishing.
McGarry, J. & Thom, N. (2004) How users and carers view their involvement in nurse education.
, 100, 36–39.
McKeown, M.;

	Identify	Quantify	Monetise
1.	1 x Lecturer Grade 8	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. 6 contact visits = 2 hours over 10 months	2 hours = £64.60 + 28.75% (£18.57) on-costs Total per visit £83.17 Total for 6 contact visits= £499.02
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
	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

	Identify	Quantify	Monetise
1.	1 x Lecturer Grade 8	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. 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. 4 contact visits = 2 hours with members of Mencap Môn at the Hub	 £0 No additional cost due to role not being above and beyond expected role. £258.40 + 28.75% (£74.29) = £332.69

5.	Travel to the Mencap Môn Hub	Bangor to Llangefni 18 miles X 6 = 108miles	108miles @ 40p per mile = £43.20
	Identify		

Members of Mencap Môn Valued role - Experts by experience Genuine partnership.	Enjoyment – making a difference Helping students learn Empowerment Voice heard	Video clips with service user feedback. Continued engagement in sessions

		Different pattern of health disease experienced by people with learning disabilities when compared to the general population Case study example of reasonable adjustment: Requested example from local health liaison team.

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

Meeting and delivering on NMC requirements
Standards of Education, requirements of validating new curriculum to commence 2020
PPI policy agenda
Avoidance of a negative -

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).

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).

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).

Logistical challenges, such as recruitment, payment and availability for timetabled se7 232.er7 18Tf1 0 0 1 3

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Appendix 5

Implementing reasonable adjustments: an example of good practice.

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