Council of Deans
of Health

Learning Disabilities

Meeting Education Needs
of Nursing Students

The UK Learning and Intellectual Disability
Nursing Academic Network (LIDNAN) and the
UK Council of Deans of Health (CoDH)

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The Learning Disabilities - Meeting the Educational Needs of Nursing Students is a project led by the UK Learning and Disabilities Nursing Academic Network (LIDNAN) in partnership with the UK Council of Deans of Health (CoDH). The project was overseen by a working group:

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Foreword

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. People with learning disabilities and their families should be able to expect no less than any other group using health care services. However, we know from the Confidential Inquiry into premature deaths of people with learning disabilities, published in 2013, that 42 per cent of the deaths that the panel investigated and agreed upon were assessed as premature deaths, with repeated problems of delayed diagnosis, poor identification of needs and inappropriate care.

Universities and their role in initial health professional education are only one part of the jigsaw. It is sometimes assumed that every issue in health and social care can be solved by more input in pre-registration education, which is simply not the case. However, the foundations of a health professional's practice are laid at this first stage of education and there is therefore a crucial role for our members to understand how best to equip students to work with people with learning disabilities across all health settings, putting people with learning disabilities at the centre of their own care.

This report is authored by those who are experts in health education, primarily for other educators. In reviewing both the literature and current practice the report aims to suggest realistic ways in which universities can best exercise their responsibility to ensure that competence in care for people with learning disabilities is reflected across all its health courses. Although this report is focused on the fields of nursing, this is an issue for all health and social care professionals. Our hope is that this will be a first step in a wider debate about education across the professions and that through this we will know how best to equip students to work with and serve the interests of people with learning disabilities and their families.

Professor Dame Jessica Corner
Chair, Council of Deans of Health

Executive Summary

People with learning disabilities have worse health and die younger on average than people without learning disabilities. There is good evidence to suggest that far more needs to be done across health and social care to improve the treatment, care and support that people with learning disabilities receive.

There are concerns on the overall provision of LD nurses: demand for learning disability nursing is likely to grow yet the overall numbers of learning disabilities nurses have decreased over time and many are now approaching retirement. However, there are also concerns that many staff working in general health and social care settings have limited knowledge of how to work with people with learning disabilities and little access to training. As part of responding to this, *Strengthening the Commitment,* a review[1] of learning disabilities nursing across the UK in 2011-2012, has called for those who develop or deliver education to ensure that nurses in other fields of practice develop core knowledge and skills to work 'safely and appropriately' with people with learning disabilities across their careers, including their initial pre-registration education.

This report presents a project by the UK Learning and Intellectual Disability Nursing Academic Network (LIDNAN) and the UK Council of Deans of Health (CoDH) that has addressed the specific question of how to best promote LD competence in other fields of nursing pre-registration education. Deans and senior staff of higher education institutions that are members of CoDH were invited to take part in a survey to identify barriers to the delivery of learning disability-related education across all nursing programmes. In addition, the project undertook a literature and policy review and collated good practice examples, highlighting activity being undertaken by HE institutions in relation to learning disability nursing in pre-registration education.

The report's recommendations highlight a number of areas in which HE provision and the framework that govern it could be developed. These include:
- A standard competency framework should be developed to support consistent delivery of learning disability competence, based on the priority areas identified in the literature.
- People with learning disabilities, their families and carers should be involved in all aspects of curriculum design and delivery.
- The role of learning disability nurses and how they support people across a range of settings should feature as part of education delivery.
- That HEIs consider a range of activities, including clinical simulation, as a means of delivering learning disability education

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[1] Strengthening the Commitment – The Report of the UK Modernising Learning Disability Nursing Review, Scottish Government (2012), http://www.scotland.gov.uk/resource/0039/00391946.pdf

1.   Introduction

The Learning Disabilities – Meeting the Educational Needs of Nursing Students project was established to look at how the education of pre-registration nursing students in other fields of practice can best develop core knowledge and skills for working effectively with people with learning disabilities. It was instigated from recommendations arising from the *Strengthening the Commitment*[1] (StC) report, a UK wide review into the challenges and work needed to ensure that there are sufficient learning disability nurses to provide good quality nursing for people with learning disabilities. The project was led by the UK Learning and Disabilities Nursing Academic Network (LIDNAN), a network of universities (HEIs), other education providers and practitioners that emerged from the recommendations of *Strengthening the Commitment* and was undertaken in collaboration with the UK Council of Deans of Health (CoDH).

The project focused on the second part of recommendation 11 of *Strengthening the Commitment* (emphasis added):

*"Those who commission, develop or deliver education should ensure that all learning disabilities nursing education programmes reflect the key values, content and approaches recommended in this report. **They should also ensure that nurses in other fields of practice develop the core knowledge and skills necessary to work safely and appropriately with people with learning disabilities who are using general health services**."*

Previous reports (Gates 2012, RCN 2010) highlight some of the issues in educating and developing a learning disability nursing workforce. Whilst superficially, these appear to concern commissioning and delivery of learning disability nursing programmes, there are broader implications relating to the delivery of health care education for all health students to enable them to provide safe and effective care for people with learning disabilities. This report focuses on those implications and offers evidence based and pragmatic solutions for education commissioners, education providers, lecturers and students.

The report explores the implications for the implementation of recommendation 11 in the context of a sector profile where only 40 per cent (29) of the universities that provide adult nursing (71)[2] in the UK have been commissioned to deliver learning disability nursing programmes. Appendix 1 is a report from the "Thinking Space" event held by NHS Education for Scotland (NES) in July 2014. Some of the outcomes from "Thinking Space" are incorporated into the overall conclusions and recommendations.

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[2] NMC (2014) approved programmes, http://www.nmc-uk.org/Approved-Programmes/

1.1. Project aims

1. To explore, with HEIs current learning and teaching strategies and identify factors that either support or inhibit the delivery of quality education for learning disability health care need.
2. To distil from the emerging evidence base, core competencies that should be included in all nursing programmes to ensure that people with learning disabilities receive safe, competent and appropriate nursing care.
3. To identify strategies to support HEIs in delivering effective quality education for learning disability health care.
4. To begin to develop, through collaboration and the LIDNAN network, accessible resources that can be used in all HEIs involved in nursing programme delivery.
5. To consider the transferability of the outcomes of the project to other health care practitioner education and to make recommendations on future development work.

There are other areas for development arising from recommendation 11 that require work beyond this project, these are:

- How do those who deliver learning disability nursing curricula ensure that they evidence the recommendations of the StC report?
- For other groups of practitioners such as associate practitioners and other health care professionals – how do education providers ensure that learning disability health care core competencies are addressed in curricula?

1.2. Project plan

This review was conducted in three phases:

1. A review of the literature and policy was undertaken, providing the rationale and context for the project and to use this evidence to refine the core competencies.
2. All HEIs in the UK that offer pre-registration adult nursing courses were surveyed to highlight those things that support and facilitate the delivery of learning disability health care issues in all health programmes and to identify barriers to effective delivery, in doing so to highlight the contribution of lecturers and mentors who are learning disability nurses.
3. Collation and presentation of good practice examples in development and delivery, particularly focussing on where co-production is integrated into all levels of activity.

2. Literature and Policy Review I: Health outcomes for people with LD and the policy response

2.1. People with learning disabilities face inequalities in healthcare

There is good evidence that people with learning disabilities have worse health and die younger on average than their peers without learning disabilities (Emerson *et al*, 2012; Public Health England, 2014; Scottish Government, 2012). Mencap (1998) reported that 26 per cent of people with learning disabilities will require general hospital services as compared to 14 per cent of the general population (cited in Brown, 2005). Part of the reason for this may lie in people with learning disabilities being exposed more to the causes of ill health through factors such as social deprivation, poorer health behaviours and poorer understanding of the signs of illness (Public Health England, 2014) and they have different patterns of disease to the general population (Gibbs *et al*, 2008). They also experience problems in accessing and using appropriate and timely health services (Krahn *et al*, 2006; Michael, 2008; Scottish Government, 2012), even though their health problem may have nothing to do with their disability (Michael, 2008). These inequalities of access to health services may be caused by barriers within the services themselves such as 'diagnostic overshadowing', untrained, inexperienced or discriminatory staff or failure to make 'reasonable adjustments' (Emerson *et al*, 2012).

In 2006, the Disability Rights Commission (DRC) published an investigation into the physical health inequalities experienced by people with learning disabilities and/or mental health problems. The report suggested that people with learning disabilities experience 'diagnostic overshadowing', in which physical health problems are viewed by health professionals as part of the person's learning disability and hence are not investigated fully or treated appropriately (DRC, 2006). Since then, other reports have highlighted the danger of this phenomenon in relation to people with learning disabilities and the barriers to equal treatment that are caused by it (Mencap, 2007; Michael, 2008).

Diagnostic overshadowing may in part come about as a result of care given by health professionals who lack training and experience in caring for people with learning disabilities. The authors of *Death by Indifference*, Mencap's report into the untimely deaths of six people with learning disabilities (Mencap, 2007), believed there was a fundamental lack of understanding and respect for people with learning disabilities within the UK's National Health Service (NHS). They found that people with learning disabilities received poor care in NHS hospitals due to this lack of understanding and a paucity of training in learning disability for staff. A number of other studies have pointed to a lack of knowledge about learning disabilities amongst healthcare staff which can lead to a lack of confidence and poor attitudes towards people with learning disabilities (Allen, 2008; Bradbury-Jones *et al*, 2013; Brown, 2005; Gibson, 2009; Marsham, 2009; McMurray and Beebee, 2007; Sowney and Barr, 2006).

2.2. There are gaps in training and awareness of healthcare staff

The *Healthcare for All* inquiry (Michael, 2008) reported that health service staff in general healthcare had limited knowledge about learning disability and the health needs of people with learning disabilities were poorly understood. The report highlighted the limited nature of training on learning disability that was provided to undergraduate and postgraduate clinical staff and suggested that this absence of training led to ignorance and fear. Witnesses giving evidence to the inquiry said that education in learning disabilities for staff had *"serious shortcomings"* (Michael, 2008). Other authors have highlighted a lack of training for healthcare staff about learning disabilities (Gibson, 2007; Vinales, 2013) and this may cause a barrier to health services effectively meeting the needs of people with learning disabilities (Melville *et al*, 2006). Emerson *et al* (2012) suggest that there is limited knowledge and training amongst health professionals in relation to the 2005 Mental Capacity Act England and Wales; a point which Mencap also raise in their follow up report to *Death by Indifference* (Mencap, 2012).

The lack of knowledge and awareness of learning disabilities amongst healthcare staff has prompted a call for more education and training in this area (Backer *et al*, 2009; Cooper *et al*, 2014; Gates, 2011; Gillett, 2014; Sowney and Barr, 2006). In order for the shortfall in knowledge and experience to be addressed, *Healthcare for All* recommended that:

> *"Those with responsibility for the provision and regulation of undergraduate and postgraduate clinical training must ensure that curricula include mandatory training in learning disabilities. It should be competence-based and involve people with learning disabilities and their carers in providing training."* (Recommendation 1: Michael, 2008, p54)

The report also indicated that due to the high levels of ignorance that surround learning disability amongst health professionals *"there is a strong argument... in favour of including basic teaching about learning disabilities in all pre-registration courses and involving people with learning disabilities in providing it"* (Michael, 2008, p34).

2.3. Policy response

The 2006 Disability Rights Commission (DRC) report recommends that governments in England and Wales should *"spearhead"* action to ensure that medical and nursing training at all levels (including undergraduate) tackled diagnostic overshadowing and the unequal treatment of people with learning disabilities in the NHS (DRC, 2006).

The Department of Health (DH) responded to *Healthcare for All*'s recommendations in their 2009 strategy *Valuing People Now* (DH, 2009). In this strategy, they accepted Recommendation 1 and indicated that they were working to review and improve training in learning disability for healthcare staff and were encouraging the engagement of people with learning disabilities and their carers in the design and delivery of this training. They also indicated that they were working with professional regulatory bodies responsible for setting standards in healthcare education to

support improvements in training and incorporate training in learning disability into all training for healthcare professionals (DH, 2009).

Mencap's report, *Death by Indifference: 74 Deaths and Counting* (Mencap, 2012), also responded to Recommendation 1 from *Healthcare for All*. They welcomed the increase in provision of training on learning disability in some hospital settings since the publication of *Healthcare for All* but bemoaned the lack of progress in relation to the establishment of mandatory training of all health professionals in learning disabilities:

> *Training is still left to the discretion of the training bodies concerned and in our view, this is not acceptable."* (Mencap, 2012, p20)

However, in 2010, the Nursing and Midwifery Council (NMC) had set out their standards for pre-registration nursing education which stipulated that all nurses "*must be able to recognise and respond to the needs of all people who come into their care including... people with learning disabilities..."* (NMC, 2010, p17). The standards also required that *"Theory and practice learning outcomes must take account of essential physical and mental health needs of all people including... people with learning disabilities..."* (NMC, 2010, p80). The standards advised programme providers that they should find ways to enable students to have contact with all specified client groups, including those with learning disabilities.

The Royal College of Nursing (RCN) have also recommended that all health practitioners should have training about people with learning disabilities (RCN, 2013; RCN, 2014) to ensure that they have "*the knowledge, skills and values to provide person-centred care that is appropriate to the abilities and needs of the individual and their family"* (RCN, 2014, p14).

> *"The RCN and the Nursing and Midwifery Council (NMC) is fully supportive of the need for services to provide equity of access and outcome for people with learning disabilities and, as a result, all nurses need to have some knowledge about the nursing needs of children, adults and older people with learning disabilities and this is a requirement of all pre-registration nursing programmes."* (RCN, 2014, p14)

The public inquiry into the Mid Staffordshire NHS Foundation Trust (Francis, 2013) also recommended that nursing training (not just in relation to caring for people with learning disabilities) should ensure a consistent standard is achieved by all nursing students across the country and that this should be implemented through the establishment of national standards.

The report of the UK Modernising Learning Disabilities Nursing Review *Strengthening the Commitment* (Scottish Government, 2012), although mainly focused on the role of learning disability nurses, recognised the need for the whole health workforce to be prepared to deliver high quality healthcare to people with learning disabilities and suggested that education and training were the key to ensuring this.

"...the importance of all nursing students at undergraduate level developing a core knowledge and skills to work with people with learning disabilities, their families and carers cannot be ignored" (Scottish Government, 2012, p40).

3. Literature and Policy Review II: Essential Components of Learning Disability Education for Healthcare Students

Literature and policy guidance highlight a number of components that should be considered in relation to education for healthcare students in the area of learning disability. These are listed below (the order has no significance) and then each component is discussed individually.

- Communication
- Attitudes towards people with learning disabilities
- Capacity/consent
- Equality/reasonable adjustments
- Role of carers
- Role of learning disability nurses/teams
- Learning Disability and health issues
- Challenging behaviour
- Placement experience.

3.1. Improving communication

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). Service users with learning disabilities in Gates' (2011) study said that communication between people with 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). 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.

A survey to assess palliative care staff's training needs around learning disabilities found that communication was a major concern for 80 per cent of the nurses who participated (Tuffrey-Wigne *et al*, 2005). Bradbury-Jones *et al* (2013) indicated that training in communication skills for use with people with learning disabilities had been found to be helpful in some of the literature they had reviewed and Nazarjuk *et al* (2013) reported that students who had taken part in an educational experience that involved service users with learning disabilities had gained knowledge and insight into ways of communicating effectively. A number of studies recommend that students learn a specific form of augmentative and alternative communication (AAC) such as Makaton, which is used by more than 100,000 people in the UK (Gibson, 2007; McClimens *et al*, 2012; RCN, 2013; Vinales, 2013). Vinales (2013) suggests that all nurses should have a basic

understanding of the various forms of communication that might be used. In his study (which evaluated an initiative giving two hours of training in Makaton to second year children's nursing students), students valued the training but felt that more training sessions and more exposure to Makaton users would enable them to retain the learning better and improve their skills. They also felt it would have been better to have the training in their first year (Vinales, 2013).

3.2. Attitudes towards people with learning disabilities

Health staff who do not have training around learning disability can have poor attitudes towards people with learning disabilities. Lewis and Stenfert-Kroese (2010) found that general nursing staff in four UK hospital trusts had less positive attitudes towards patients with learning disabilities than patients with physical disabilities and they were more likely to report that their skills and training were insufficient for caring for people with learning disabilities. *Death by Indifference* reports that health professionals are often ignorant of the difference between a professional's opinion of a patient's quality of life and the patient's opinion of their quality of life (Mencap, 2007). Mencap would like health professionals to have training that challenges these assumptions (Mencap, 2012). There is some evidence that health professionals' attitudes towards people with learning disabilities can be improved by education and training in learning disability (Backer *et al*, 2009; Nazarjuk *et al*, 2013; Read and Rushton, 2013). A number of the studies in Backer *et al*'s (2009) review found that people who had had education and training in learning disability had more positive attitudes towards people with learning disabilities. The students in Nazarjuk *et al*'s (2013) study also had improved attitudes towards people with learning disabilities after they had taken part in simulated practice education. Ten Klooster *et al* (2009) highlight the importance of fostering positive attitudes early on in nursing education.

3.3. Capacity and consent

There is a recognised paucity of knowledge amongst healthcare staff about the issues surrounding capacity and consent in relation to people with learning disabilities (Mencap, 2007; Merrifield, 2011).

> *"The Mental Capacity Act 2005 and its code of practice have been fully in force since 2007. But our cases strongly indicate that the principles the Act sets out are far from embedded in medical practice."* (Mencap, 2012, p17)

Sowney and Barr (2007) found that nurses lacked knowledge in relation to consent and people with learning disabilities' right to autonomy and information. Tuffrey-Wigne *et al* (2005) also found some issues around consent amongst palliative care staff in relation to caring for people with learning disabilities. A report into the health inequalities experienced by people with learning disabilities by the Learning Disabilities Observatory draws attention to the gaps in knowledge and training that exist amongst health staff in relation to the 2005 Mental Capacity Act (Emerson *et al*, 2012).

In the light of their findings, the confidential inquiry into premature deaths of people with learning disabilities (CIPOLD) recommended "*Mental Capacity Act training and regular updates to be mandatory for staff involved in the delivery of health or social care"* (Heslop *et al*, 2013, p117).

Mencap (2012) also recommend that all health professionals should be taught about their legal responsibilities under the Mental Capacity Act and how to put them into practice. Merrifield suggests that it is vital for healthcare staff to be familiar with the five principles[3] of the Mental Capacity Act as confusion often arises in this area (Merrifield, 2011).

3.4. Equality and reasonable adjustments

As well as calling for training in relation to the Mental Capacity Act, Mencap (2012) also recommend that all professionals should receive training around their obligations under the 2010 Equality Act and should be taught how to make reasonable adjustments, so that they can put their knowledge into practice when caring for people with learning disabilities. 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). The NMC's Standards for Pre-registration Nursing Education (2010) stipulate that nurses must be able to make reasonable adjustments in order to enable equal access to services. Cassidy (2012) emphasises the importance of the principles of dignity, respect and empowerment and suggests that they are essential aspects of value-based competence for students on pre-registration nursing programmes.

3.5. Role of carers

Carers play a key role when a person with learning disabilities accesses healthcare services by enabling communication, providing information, giving practical support and interpreting distress cues (Gibbs et al, 2008; Mencap, 2007). In Nazarjuk et al's (2013) study, engaging with carers helped the students to learn about the service users and develop a more positive attitude to their care. It is important that students are made aware of this role and learn to utilise this awareness in the practice setting.

3.6. Role of learning disability nurses/teams

Healthcare for All found that there was a lack of knowledge about the services and expertise which were available in learning disability teams which meant that they were not often accessed (Michael, 2008). However, Mencap highlight the professional requirement to ask for help and/or

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[3] Mental Capacity Act England and Wales (2005) Key Principles:
1. A person must be assumed to have capacity unless it is established otherwise
2. A person is not to be treated as unable to make a decision, unless all practicable steps to help him do so have been taken without success.
3. A person is not to be treated as unable to make a decision merely because an unwise decision is made.
4. An act done, or decision made, under this Act for or on behalf of a person who lacks capacity must be done, or made, in his best interests.
5. Before the act is done, or the decision is made, care must be taken to avoid restricting the person's rights and freedom of action.

Further details: http://www.legislation.gov.uk/ukpga/2005/9/contents

Scotland Adults with Incapacity Act (2000), available at:
http://www.legislation.gov.uk/asp/2000/4/contents

In Northern Ireland there is no specific capacity legislation but the Public Health Act (1967), available at: http://www.legislation.gov.uk/apni/1967/36 and Health and Personal Social Service – Northern Ireland - Order (1972), available at: http://www.legislation.gov.uk/nisi/1972/1265 make some provision.

refer on when faced with a new or difficult clinical situation (Mencap, 2007). Gibbs *et al* (2008) suggest that awareness of the support that learning disability teams can give needs to be raised and that learning disability liaison nurses can be helpful in the education of general healthcare staff. A study by Brown *et al* (2012) found that learning disability liaison nurses were involved in training of general healthcare staff and this included teaching on communication, capacity and consent.

3.7. Learning disability and health issues

As discussed previously, there is a lack of knowledge surrounding learning disability and the health issues that people with learning disabilities face. There is also ignorance amongst health professionals about types of learning disability and how to respond to the needs presented by people with different types of disability (Barriball and Clark, 2005; Gibson, 2007; Sowney and Barr, 2006). Sowney and Barr (2006) suggest that nurses need to be taught specifically about the health problems and conditions that people with learning disabilities experience. Mencap (2007) recommend that health professionals need to be *"more suspicious that the patient may have a serious illness and be more proactive in intervening and assessing the needs of a person with a learning disability"* (p20). Students also need to be aware of the possibility of diagnostic overshadowing (Gibson, 2007).

Page and Cash (2011) found that there is a lack of knowledge concerning how to perform life support for people with profound and multiple learning disabilities (PMLD) and they recommend that basic life support training be given to health professionals which is specifically directed towards this group of people.

3.8. Challenging behaviour

Student feedback from Barriball and Clark's (2005) research indicated that training on how to deal with challenging behaviour should be part of education relating to learning disability. Gibson (2007) also advocates training about ways of responding to challenging behaviour as part of learning disability education for students.

3.9. Placement experience

There is evidence that nurses who have a practice placement with people with learning disabilities in their pre-registration programme are more likely to feel confident in caring for this group of people (Sowney and Barr, 2006). Elder (2008) recommends that this placement should have some element of social services care so that nurses and midwives have some experience of the challenges and issues presented by people with additional support needs.

4. Literature and Policy Review III: Methodologies that HEIs can adopt in relation to Learning Disability education

There are a number of examples in the literature of methodologies that HEIs might adopt to assist in fulfilling the requirement for all undergraduate healthcare students to have education in learning disability. These methodologies are listed below and then discussed separately (again, the order is not significant).

- Involvement of service users and carers
- Use of scenarios/drama/live simulations
- Use of virtual learning environments/e-learning
- Use of learning disability nurses
- Practice placements
- Use of learning packages
- Interprofessional education.

4.1. Involvement of service users and carers

Death by Indifference (Mencap, 2007) recommends that health staff should receive training which involves people who have learning disabilities, as does the *Strengthening the Commitment* report:

> *"People with learning disabilities, their families and carers could be more involved in nurse education for all fields of nursing. Other nurses still need more knowledge and skills in working with people with learning disabilities."* (Scottish Government, 2012, p17)

Atkinson and Williams (2011) point out that if the NHS is to be patient led, there must be patient involvement in nurse education. In addition, Nazarjuk *et al* (2013) report that service user involvement in health education is advocated by the NMC and also by the General Medical Council (GMC) and they suggest that it is on the increase. Other authors have also advocated the involvement of people with learning disabilities and their carers in health education programmes as it can challenge attitudes, increase understanding of communication issues, improve students' confidence and deepen their insight into people with learning disabilities' lived experiences (Atkinson and Williams, 2011; Backer *et al*, 2009; Beadle *et al*, 2012; Bollard *et al*, 2012; DRC, 2006; McGarry and Aubeeluck, 2013; Read and Rushton, 2013; Thacker *et al*, 2007).

> *"Talking with people who have learning disabilities...and involving them in training or audit can bring real results."* (DRC, 2006, p103)

There have been a number of studies describing health educational interventions which involved people with learning disabilities. In some of these, people with learning disabilities took part in role playing and patient simulation activities (Barriball and Clark, 2005; Fursland, 2004; Gibson, 2009; McGarry and Aubeeluck, 2013; Nazarjuk *et al*, 2013; Thacker *et al*, 2007) and in others they acted as co-facilitators with teaching and/or professional staff (Atkinson and Williams, 2011;

Bollard *et al*, 2012; Gibson, 2007; Heidinger, 2006; Marsham, 2009; McClimens *et al*, 2012; McMurray and Beebee, 2007; Melville *et al*, 2006; Read and Rushton, 2013). A few studies have also involved people with learning disabilities in making educational films (Beadle *et al*, 2012; Gibson, 2009).

Authors generally acknowledged a positive impact of involving people with learning disabilities in health education, citing the value to students of being able to spend time with people with learning disabilities (Cassidy, 2012), changes in practice as a result of training that involved people with learning disabilities (Melville *et al*, 2006), bringing people with learning disabilities' experiences to life (Beadle *et al*, 2012; Read and Rushton, 2013) and increasing students' empathy and confidence (Atkinson and Williams, 2011; McGarry and Aubeeluck, 2013; Thacker *et al*, 2007).

Some authors point out that involving service users in education is not without its challenges. The impact on the service users themselves needs to be considered, as do issues of consent (Beadle *et al*, 2012). Bollard *et al* (2012) emphasise that time is needed for adequate preparation and suggest that effective user involvement is not a series of one-off activities but should be seen as a process. McGarry and Aubeeluck (2013) also recommend that educators ensure adequate preparation and support as the approach can be challenging.

4.2. Use of scenarios/drama/live simulations

A number of studies report on the use of drama and live simulations to educate students about learning disabilities. Some of these initiatives involved service users and carers in simulating patients (Barriball and Clark, 2005; Fursland, 2004; Gibson, 2009; McGarry and Aubeeluck, 2013; Nazarjuk *et al*, 2013; Thacker *et al*, 2007) whilst others used lecturing staff, learning disability nurses, actors or other students to portray people with learning disabilities (Gillett, 2014; McClimens and Scott, 2007; O'Boyle-Duggan *et al*, 2012).

The use of drama and live simulation in health education about learning disability can have an impact in relation to developing students' communication skills (Barriball and Clark, 2005; Fursland, 2004; Gibson, 2009; Gillett, 2014), increasing students' confidence (O'Boyle-Duggan *et al*, 2012), enabling students to experience situations that may arise in practice and provide feedback in a safe environment (Gillett, 2014; McClimens and Scott, 2007, Nazarjuk *et al*, 2013), enabling students to think critically about their practice (McGarry and Aubeeluck, 2013) and empowering students to challenge their preconceived beliefs and assumptions (O'Boyle-Duggan *et al*, 2012).

4.3. Use of virtual learning environments/e-learning

Some studies describe the use of e-learning and virtual environments in learning disability education. Boyd *et al* (2008) report on an education programme which developed an interactive virtual patient scenario using a CD-ROM to teach healthcare students about learning disabilities. The majority of students who used it reported increased knowledge and an increased comfort with the scenarios described. McClimens *et al* (2012) report on a virtual patient simulator that

was developed for a joint course for learning disability nursing and social work students. The use of patient simulators was enhanced by an online 'back story' so that a virtual patient/client was created. The project was specifically designed to educate health and social care professionals about meeting the care needs of people with profound and multiple learning disabilities (PMLDs). Birmingham City University has developed a virtual learning environment called Shareville which incorporates a simulated hospital and a simulated home for people with learning disabilities.[4] In the virtual hospital, students are exposed to patients who have learning disabilities. Issues such as attitudes towards people with learning disabilities, consent, communication difficulties, challenging behaviour and diagnostic overshadowing are covered through a variety of learning activities.

4.4. Use of learning disability nurses

The Department of Health's *Valuing People* report suggested that specialist learning disability services have a role to play in educating staff in general healthcare services about supporting people with learning disabilities to have their health needs met (DH, 2001 cited in McMurray and Beebee, 2007). Other authors have also highlighted the role that learning disability nurses can play in educating healthcare staff about learning disabilities by ensuring appropriate learning takes place through the provision of educational opportunities for general staff (Jukes, 2011) and developing their confidence and skills (Allen, 2008). Marsham (2009) suggests that one way to ensure that nursing students engage in issues relating to caring for people with learning disabilities is through the use of guest facilitators who are specialist learning disability nurses. Learning disability liaison nurses can also be involved in educational activities with pre-registration nursing students and may be able to offer practice placements to give students a wider learning experience (Brown *et al*, 2012; Jukes, 2011).

4.5. Practice placements

Practice placements are one way of ensuring that students gain experience of working with people with learning disabilities. Barriball and Clark (2005) report on a two week 'insight placement' for nursing students which was undertaken in social service, private and voluntary sector settings. The authors suggested that having real placement rather than a virtual placement was a strength of the programme. The quality of the placement was seen of paramount importance, though, as poor placements can lead to negative attitudes (Fitzsimmons and Barr, 1997 cited in Barriball and Clark, 2005). Hence, monitoring of the placements was seen as essential. Gibson (2007), however, suggests that a two week 'insight placement' is not long enough to build a rapport with people with learning disabilities.

Bernal (2004) says that placements help to 'normalise' people with learning disabilities for students, help students to improve their communication skills and assist them in forming meaningful relationships with people with learning disabilities. Bernal's study, however, found

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[4] http://shareville.bcu.ac.uk/index.php

that students did not feel that one day had been enough preparation for their placements (Bernal, 2004).

One author suggested that it can be difficult to provide enough practice placements in learning disability settings for students not doing learning disability nursing (Gibson, 2009). At this author's HEI, there were too many students and too few suitable placements available for all students to have an adequate clinical experience. This problem may be alleviated, however, by giving students an 'experiential placement' where they would go into clients' homes or workplaces. It would reduce the burden on clinical areas and extend the scope of student learning. In this scenario, students would learn about learning disabilities through the use of a social model of disability (McClimens *et al*, 2012).

4.6. Use of learning packages

The use of learning packages may be one way to address the need to teach healthcare students about caring for people with learning disabilities. In 2004, NHS Education for Scotland produced a learning package called *Getting it Right Together* which was designed for teaching nursing students about learning disabilities (Gibson, 2007). It comprised a CD-ROM and other learning materials which made up 15 hours' worth of learning disability specific material. Heidinger (2006) reported on a programme which used the package but Gibson (2009) suggested that the extent to which the package has been used by HEIs is unclear. In his 2007 paper, Gibson described the 15-hour programme as *"meagre"* (Gibson, 2007).

4.7. Inter-professional education

Barriball and Clark's (2005) study used teaching staff from different branches of nursing on their learning disability education programme for nursing students. The authors suggest that this has to be the case if the requirements of pre-registration education around learning disability are to be realised. In order to increase teaching staff's confidence and skills, a learning disability forum was established (Barriball and Clark, 2005). Another study which reported on inter-professional education around learning disabilities involved a workshop for midwifery and learning disability students on contraception (Gibbs and Colclough, 2010). The workshop was led jointly by a midwifery lecturer and a learning disability nursing lecturer. Students who attended felt that they were able to transfer their skills and knowledge to their work with their respective client groups and had also gained an insight into the other healthcare speciality (Gibbs and Colclough, 2010). Glasper (2011) highlighted the need for future champions of learning disability nursing to look beyond the boundaries of their own profession and develop ways of spreading their knowledge to other fields of nursing.

5.   Key themes emerging from the literature and policy review

The literature presents a range of factors to be considered when planning education for nursing students. The review speaks for itself in terms of the recommendations that arise from it and these are reflected in the overall conclusion and recommendation section. Overarching themes include:

1. It is clear from the literature and policy that HEIs and others who provide education for nurses must address learning disability competencies.
2. There is no prescriptive framework to enable this to happen.
3. Involvement of people with learning disabilities and their carers in the process of curriculum design and delivery is supported strongly in the literature.
4. The content and scope of that education and the priorities that need to be addressed to support people's health needs to become clear.
5. There is a range of educational strategies that can be effectively employed to deliver education on learning disabilities.

6. Survey of Higher Education Institutions

6.1. Survey design

In collaboration with the Council of Deans of Health, an initial survey was piloted in September 2013, reviewing the responses and questions led to some refinement. The pilot asked a number of questions about different professional groups[5]. It was decided at that point that focusing on wider professional group was too ambitious for the project and the number of questions was subsequently reduced to focus on pre-registration nursing. As the remaining questions were the same, analysis and discussion is based on aggregated responses across both the pilot and subsequent recirculation of the survey (Appendix 1 is a copy of the survey questions). The response rate was relatively low. However the project group felt that the quality of feedback in the response created enough validity in terms of the aims of the project to warrant inclusion as part of this report.

The survey was issued using the Bristol Online Survey and promoted through CoDH and the learning disability nursing networks. In total there were 17 responses which equates to a 24 per cent return. Of the 17 respondents, 13 are providers of the learning disability nursing field of practice. All 17 have adult nursing, with 15 providing mental health and 16 children's nursing. 13 HEIs who responded deliver all fields of practice.

13 of the 17 HEIs submitted contact details for best practice examples; these have been followed up and evidence is presented in section 7.

6.2. Mapping of learning disability competencies across health care programmes

All participants highlighted the importance of working with people with learning disabilities and their families to develop and deliver education and training. 7 respondents described how they involve people with learning disabilities and family carers in the educational process. This includes sessions being delivered jointly with people, the development of user and carer teams, curriculum development and involvement in quality assurance activity. *"In social work, the 2 family carers we recruited to support the LD nursing programme are now members of their service user and carer group ensuring the course contains working with people with learning disabilities and their families."*

Using existing competency frameworks to guide development of the educational experience was raised by several participants. Four respondents discussed how they use both the specific learning disability nursing competencies and the generic competencies including the essential skills clusters to guide curriculum development. Emphasis was placed on the development of competencies in practice learning. One respondent was clear about the importance to the nationally agreed framework for learning disabilities devised by NHS Education for Scotland

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[5] Occupational therapy, osteopathy, dentistry, medicine and clinical psychology

(NES 2013) and how these influence educational competencies across the board when delivering the learning disability experience. One respondent described how they have mapped their experience to the *Strengthening the Commitment* objectives.

Communication emerges as a very strong theme for all respondents and how generic and specific communication skills can be developed. One respondent highlighted a process whereby students views on learning disabilities are challenged and this moves on to consider how communication can be developed to support people with learning disabilities in a range of settings.

The final topic to emerge is the importance of exploring learning disability competencies in an inter-professional way. Three respondents discussed the importance of shared understanding of need across professions and one went on to describe how a simulated team approach is used in a practical way to promote positive practice.

Examples given of LD competencies in the nursing curriculum

- *Most programmes have always had service user involvement. Following the Michael Report the Faculty invested in a scheme in partnership with local LD organisations to ensure all pre-registration courses have input on the needs of people with a learning disability and their families. This consists at minimum of one lecture and one hour of input from service users, either as individuals or with others.*
- *Learning disabled trainers from "My Life My Choice" input into programmes.*
- *In nursing the development of competencies is integrated throughout the 3 year programme for each of the other 3 fields. It is led by learning disability nurse lecturers. Content includes: what is a learning disability, causation, inclusion, health needs, communication, Death by Indifference, complex needs, challenging behaviour, working with families, advocacy.*
- *We have a four-week insight placement for students in all fields in a learning disabilities area. Students also get an insight lecture from the learning disabilities senior lecturer and these lecturers also support students during their insight placements by visiting them. We are currently looking at further involvement by the LD lecturers in the pre-registration curriculum.*
- *We have hosted Service user and LD student conferences which other AHPs can attend.*
- *The Faculty has an established programme of inter-professional education. All students within the faculty complete two modules each year. This allows LD students to share their knowledge, experience and understanding of LD with other professional groups.*
- *We have an electronic virtual learning package available and also are developing a series of sessions jointly involving people with a learning disability, parents of people with a learning disability and learning disability nursing lecturers.*

In the examples above and throughout the evidence submitted, the need to work with people with learning disabilities in all aspects of development and delivery of education and training was cited as essential to delivering high quality experiences for students across the fields of practice.

Students having the opportunity to work and learn together was cited by a number of the respondents, examples of where the fields of nursing are undertaking activities and experiences together in activities such as clinical simulation were presented.

From the evidence in the survey communication emerges as a key factor in ensuring safe and effective nursing practice across all the fields of nursing when exploring learning disability issues and refining the competencies associated with the needs of people.

The inclusion of a 4 week practice placement is described by one provider as a means of ensuring that issues for learning disabilities are addressed. Others discussed how placement learning can be used to explore further the learning disability health needs component of the programmes.

6.3. Barriers to delivery of learning disability specific education

'Time' was highlighted as an issue by 9 of the respondents. When looking at the responses there are two key issues that emerge. The first is that all of the universities highlight that the learning disability teaching teams are considerably smaller than other fields of practice. Although the learning disability cohorts are similarly smaller than other fields the time allocated to teaching is the same, making it proportionate to other fields. The consequence of this is felt in terms of the amount of time and resource available to deliver across all the fields of practice. *"A very small team delivering the same amount of sessions and breadth of content as the larger branches. Plus we must not lose sight of the fact that all student nurses need learning disability awareness education"*

The second issue described in terms of time does not relate to staff resource, it concerns the fact that pre-registration curricula across all fields of practice are extremely busy and full. The consequence of this is the level of priority that is given to learning disability issues. One person stated "*It feels at times that students' needs are not fully addressed or taught, the curriculum is overloaded, there is no space to do justice to the subject*".

Related to the matters of time and resource, all of the respondents raised concern over a lack of expertise linked to the small number of learning disability nursing lecturers. A key question asked in the response was "what happens in HEIs where there are no learning disability nursing programmes and no lecturers in learning disability?"

The next point highlighted is the breadth of practice undertaken by learning disability nurses and the range of settings that all nurses work where they will come into contact with people with learning disabilities. This leads to the question of which subject areas should be covered and given the time and resource constraints highlighted one respondent sums this up as *"Trying to 'fit in' relevant content applicable to all fields"*

The promotion of the role of learning disability nurses and raising awareness of its importance to all fields of practice is the next topic to emerge. This is described in terms of the contribution that

learning disability nurses make, how they can support other nurses and practitioners and in ensuring that people with learning disabilities are signposted to the right services. The barriers highlighted here come from a perceived lack of understanding, once again compounded by limited resources, time and expertise.

Three respondents raised the issue of practice learning and the inability to provide insight opportunities for other fields of practice. This is perceived as a key way that students gain understanding of the needs of people with learning disabilities and the service provision for them. The last matter raised as a barrier is perhaps one of the most important and that is the value placed on learning disabilities by other fields of practice, programme leaders and managers in HEIs. *"Ensuring all staff see the relevance of including learning disability in the curriculum. Staff motivation to bring about positive change. Service user / carer involvement Having suitably qualified staff (learning disability) from a range of professions"*

6.4. Supporting delivery of learning disability health care education

This question elicited a number of responses and raised a range of issues specific to the aims of the project but also some wider topics that inform some of the debate related to the objectives of StC.

Factors related to the delivery of learning disability nursing education

There was a call from one respondent to launch a national awareness raising campaign about the role of the learning disabilities nurse, supporting recruitment and highlighting the range of opportunities afforded through a career in learning disability nursing.

There was some discussion about practice learning and being creative in the range offered to learning disability nursing students. In line with this the need to ensure that there are sufficient well motivated mentors out in practice.

One respondent suggested that there could be a more flexible approach to learning disabilities education affording a step off point for students who do not want to take the full degree and for them to be skilled practitioners in their own right.

The values base for learning disability nursing is cited as an example of how the profession has developed to define itself; this response urged that we continue this development and suggested that other fields of practice could benefit from a similar process.

The scope of learning disability practice was raised and the need to ensure that learning disability students can work in a range of settings and across the lifespan was mentioned.

Delivery of learning disability competencies to other fields of nursing

From four participants there was a clear call for the role of the NMC to be instrumental in ensuring that learning disabilities is addressed across curricula. One person highlighted that whilst the

essential skills clusters and other proficiencies ensure that students address the needs of a range of people, there is no clear learning disability competence and that the proficiency was too wide and not really expressed as a competence. This relates to some of the other submissions calling for a standardised set of competencies that are part of all nursing programmes.

The next subject concerns how the skills gap in some HEIs can be addressed. One respondent cites the fact that they have a regional network where universities come together, including those who do not have learning disability nursing, to share practice and develop joint work.

In keeping with that theme it was suggested that there should be some mechanisms for skilled clinical practitioners who work in areas where the HEI does not have learning disability nursing to be part of the pre-qualifying delivery team, enhancing their own development an inputting much needed specialist skills. It was also suggested that there should be some flexibility in the geography for placements allowing practitioners in areas where there is no learning disability nursing to be mentors.

Methods of delivery were addressed by some respondents and once again there was clear support for the development of inter-professional learning. Blended and distance learning were cited as methods used in Scotland to overcome the issue of distance and rural geography where there are only 2 providers of learning disability nursing.

The future of LIDNAN was supported by participants in that it is seen as a means to share and develop practice. One participant did highlight the issue of sustainability beyond the StC steering group's projected lifespan.

The content that should be addressed in all health care programmes

The final section presented here does not relate specifically to one question but emerged as a theme across all of the questions:

1. The values base of practice/ attitudes to people with learning disabilities
2. Communication
3. Mental capacity legislation and learning disabilities
4. What does it mean to make reasonable adjustments for people with learning disabilities
5. Health needs and people with learning disabilities
6. Being person centred
7. The importance of annual health checks
8. How to use a health action plan / patient passport
9. Dealing with people who challenge
10. The role of the learning disability nurse and how they can support practice

6.5. Key themes emerging from the survey

From the survey there are some clear themes that emerge; these appear to be consistent with the findings from the literature and policy review.

1. The need to have educational provision with co-production at its heart, where people with learning disabilities, families and carers contribute fully to the development, delivery and evaluation of nursing programme curricula.
2. The need for the development of a standard competency framework – expressed in a manner that is clear in terms of expectation, working as a guide to support quality educational delivery and which is achievable in an already crowded curriculum.
3. The prioritisation of content and being clear about subject areas is supported by the survey.
4. The need for the development of support systems for all HEIs and in particular those who do not have learning disability nursing to facilitate the development and delivery of education emerges as a strong theme.
5. In a similar vein, sharing resources and developing flexible delivery options would help to support all HEIs where resource is scarce.

6.6. Draft competency framework

Based on the key findings from the literature and information from the survey of universities, the project group has drawn up a draft competency framework to support universities in their work in this area. This is presented below for further discussion.

The purpose of the draft framework is to address the main areas that the literature review suggests contribute to current weaknesses in the experience of care of people with learning disabilities and their families. The framework captures these as a statement of competency, outlining the main knowledge, theory and skills components and then linking these with teaching and assessment strategies.

Draft competency framework

Competency statement	Knowledge and theoretical components	Skills	Attitudinal and values component	Suggested learning and teaching strategies	Suggested assessment strategies
Understands how capacity legislation supports people to make decisions	Capacity legislation, concept of best interests, communication including augmented methods, easy read and alternative formats. The formal roles enshrined in legislation. Record keeping	Listening and responding skills, care planning and record keeping. Referral to appropriate services	An ability to recognise that people can make some decisions rather than assuming that people cannot make their own decisions. Determination to get the best treatment and care for people	Practice learning outcomes. Lectures, learning packages. Simulation	Practice based assessment. Short answer
Makes reasonable adjustments that are relevant to the individual needs of people with learning disabilities	Positive behavioural support. Communication methods (as above) activities of daily living.	Feeding people, administering medication, providing personal care, Communication. Supporting mobility, Working with challenging behaviour. Care planning	Understanding that reasonable adjustments are a broad range of interventions including providing direct interventions for activities of daily living and working with people who may challenge.	Simulation Practice learning	Practice based assessment and reflective account
Understands how additional health needs in people with learning disabilities can impact on care delivery	Health action plans, annual health checks and health passports. The Improving health and lives work. Diagnostic overshadowing. Understanding the health conditions that do affect people with learning disabilities. Medicines management	Care planning, assessment skills, communication. Medicines management	Making professional judgements based on evidence – looking beyond the learning disability	Case studies, simulation on line learning and resources	Case studies

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Appreciates the role that family and other carers play in supporting people with learning disabilities and uses that knowledge to augment care delivery	Research on carers and their roles. Carers policies, the role of support groups. The legal status of family members	Negotiation skills, communication, care planning	Treating family members as co-workers in the care delivery process	Carers and families involvement in curriculum design and delivery of learning and teaching	Practice based competency and reflective account
Includes learning disability nurses / teams, routinely in education delivery	Awareness of the role of the learning disability nurse	Collaborative working Multi-disciplinary team working	Cooperation, collaboration, sharing best practice and developing a team spirit	Simulated practice. Input from learning disability teams into teaching and learning	Practice based competency in practice assessment document

7. Good Practice Examples

Alongside the literature review and the survey, we asked for examples of practice that illustrate the activity that is currently being undertaken in HEIs and through other means of promoting learning disability issues to health care workers. There were 13 examples submitted by HEIs and 4 further examples from other organisations.

From discussions with people who have submitted examples, there appears to be a sense that we need to develop shared resources to support all HEIs and in particular to ensure HEIs where there is no learning disability nursing programme can access contemporary and evidence-based resources to support curriculum learning and teaching activity.

Some of the articles mentioned below in the good practice examples have already been cited as part of the literature review; however there are links to these in the section as well.

In presenting the examples it is clear that the themes that have emerged though the literature review and the survey are demonstrated in current educational practice. All examples describe how people with learning disabilities and their carers have been involved in the process. Some HEIs have begun to develop competency frameworks to support delivery. The content of delivery is consistent with what the literature and survey highlight as priority areas and the educational methodologies used for delivery also reflect themes in the literature and survey.

The good practice examples are presented in tabular format below:

Examples from UK Universities and other organisations

Organisation	LD Nursing?	Activity
HEIs		
Birmingham City University	Yes	1. The first example describes a model of teaching based on live simulation. Actors play people with learning disabilities; set within clinical simulation settings that represent the practice environment of the student practitioner. In-scenario feedback and reflection are key to the activity. Marie has published this work. 2. The second presents the "Shareville" learning environment where students explore issues from health care needs to consent and capacity in a virtual environment representing a range of practice settings. Again this work is published.
University of Brighton	No	Nursing students (All fields) attend an induction session on learning Disabilities. The session involves causes and concepts, and looking at care principles drawn from key legislation (Valuing people now, continuing the commitment, six lives). Students have opportunities in practice to work alongside people with learning Disabilities between 5-25 days in a range of areas (Residential Homes Day services).
Canterbury Christ Church	No	1. A small team with two learning disability lecturers and one adult lecturer have developed clinical simulation activities. The session starts with theoretical input and then a group of people with learning disabilities come into the clinical skills unit and act as patients with the group – The team have published this work 2. For ODP students a simulated hospital admission is made using posters for information and for paramedics a range of community environments are simulated.
University of Chester	Yes	All students from fields other than learning disabilities undertake a compulsory learning activity using a Stillwell package and supported by a learning disabilities lecturer. The package takes a holistic approach and discusses key issues such as bullying and harassment, reflecting on the impact that these have on individuals.
Derby University	No	Students have competencies specified in their documentation for practice learning that focus on learning disability issues; they also undertake a simulated practice experience that has learning disability as part of

		that.
Edgehill University	Yes	Service users work with all students from health disciplines to deliver workshops and sessions on issues affecting people with learning disabilities.
University of Hull	Yes	During the induction period small groups of students have 'surgeries' with service users where there first experience of meeting *patients* as students include people with learning disabilities. This is followed up during the programme with lectures and workshops. A range of input is given in all courses and there is a level 4 optional module – lives worth living for non-professionally qualified staff.
University of Northumbria	Yes	Northumbria have implemented a full learning and teaching strategy based on implementation of Michael's recommendation 1(2009) it has three phases – starting with a workbook , followed by clinical simulation with people with learning disabilities and then a reflective practice session. This work has been published.
Oxford Brookes University	No	The Faculty remains committed to learning disability education despite no longer delivering the field, working closely with My Life, My Choice self-advocacy group workshops are delivered following theoretical sessions addressing key issues such as consent and capacity.
Other organisations		
RCN		The RCN has a webpage where there are a lot of resources to support nurses in understanding learning disability issues. They also have the learning disability DVD which can be requested for use. Two forum chairs – orthopaedic and pain/ palliative care have developed specific easy read material and there have been RCN fringe events at congress with more planned for the future.
Positive Choices		Inspired by the 2014 Positive Choices conference, a group of adult student nurses organised a conference in May 2014 which attracted over 200 students. Sourcing speakers and resources the conference evaluated extremely well and should become an established part of the academic year.
Tameside and Glossop NHS Trust		Acute liaison nurses regularly run in house workshops for students on placement at the acute hospital. They regularly receive phone calls about specific patients who have undertaken the workshop and feedback received suggest the workshops appear to have impact on practice.

8.   Conclusions and Recommendations

8.1. Conclusions

Consistent themes have emerged from the literature, survey and good practice examples. The evidence from all three sources confirms the need to address the first recommendation of *Healthcare for All* (2008) that "*Those with responsibility for the provision and regulation of undergraduate and postgraduate clinical training must ensure that curricula include mandatory training in learning disabilities. It should be competence-based and involve people with learning disabilities and their carers in providing training.*" (Recommendation 1: Michael, 2008, p54)

For nursing education this recommendation is very clear about the need to include a compulsory element of learning disabilities. However, achieving this has some inherent challenges. There are some overarching factors that need to be considered. These are firstly, the relationship between the ability to deliver quality education in HEIs where there is no learning disability field and the resources to deliver. The next factor concerns 'curriculum space' and the priority given to learning disability education. Implementing the recommendations in this report will support HEIs in finding the time to deliver learning disability education as it is proposed to develop realistic competencies that are supported by availability of resources.

The next theme to emerge concerns the need to develop a consistent approach, based on priorities that will have the greatest impact. From the literature and policy it is clear that there is no existing competency framework and the survey supports the notion of developing some standardised competencies. The priority topic areas that need to be addressed in educational delivery have been detailed within the report and these lend themselves to the development of a competency framework (recommendation 2).

Including people with learning disabilities and their carers in the development, validation and implementation of curricula is supported by all of the evidence. Achieving this requires HEIs to have clear policies and practices on service user inclusion. This is already integral in NMC validation so ensuring it includes people with learning disabilities is an extension of this and could form part of the dialogue through CoDH and NMC (Recommendation 1).

Priority areas have been consistent in the evidence, these are:
1. The values base of practice / attitudes to people with learning disabilities
2. Communication
3. Mental capacity legislation, consent and learning disabilities
4. What does it mean to make reasonable adjustments for people with learning disabilities?
5. Health needs and people with learning disabilities
6. Being person centred
7. The role of carers
8. The importance of annual health checks
9. How to use a health action plan / patient passport
10. Dealing with people who challenge

11. The role of the learning disability nurse and how they can support practice

Recommendation 3 reflects the need to ensure that learning disability education includes these areas.

The promotion of awareness of learning disability nursing, the role that learning disability nurses have and how this can be integrated into HEIs is also a key theme. The practice example from Tameside and Glossop NHS Trust demonstrates the impact that practitioners can have on nursing education. Whilst not every area has an HEI delivering learning disability nursing, all areas have learning disability nurses working in practice. Finding a means of engaging local practitioners in the development and delivery of learning disability education would support the recommendations in this report. Making such links could be undertaken in a variety of ways, support could come from education commissioning managers who work with local health care organisations at Nurse Director level. Through this mechanism links could be made, where they do not currently exist, between HEIs and local teams of learning disability nurses. Related to this is raising the profile of learning disabilities with managers, programme leaders and lecturers in HEIs. This forms part of recommendation 8, which is concerned with how HEIs can be supported to develop and deliver appropriate learning.

How education is effectively delivered has also emerged from the evidence in this report. There are a range of methodologies suggested in the literature, these are supported through the survey and appear in the good practice section. One issue to be considered is the provision of practice placements for all fields of practice. There is clear evidence that these do support learning and understanding, however the practicalities of providing so many placements and ensuring these are not to the detriment of service users makes this an area of complication. This report does not therefore recommend that all nursing students have placements in learning disability. However, HEIs should be encouraged to consider how they can contextualise the learning in the delivery of the learning disability element of the curriculum to the student nurses own practice. To this end a there is a recommendation that a practice learning outcome specifically addressing a learning disability competence is included in all nursing students practice assessment process and documentation. Continuing with methods of educational delivery, the report demonstrates how a range of methods can be used to support delivery, in particular clinical simulation using people with learning disabilities as patients. It would seem that a sensible recommendation is that HEIs consider a range of activities including clinical simulation as a means of delivering learning disability education.

The final theme is how to support HEIs in their endeavour to deliver learning disability education. It is recommended that this project moves to a second stage that includes the development of open access resources, led by LIDNAN, that not only support HEIs in delivering learning disability education but also raises the profile of learning disability in nursing across the board and within HEIs.

Finally it is proposed to develop a second phase to the project that picks up the areas highlighted in the introduction - other health professionals, associate practitioners and also how HEIs with learning disability pre-registration programmes evidence the outcomes of StC.

8.2. Recommendations

1. The implications of this report are disseminated at a policy level through CoDH, the NMC and education commissioners, highlighting the mandatory element within the *Healthcare for All* recommendation.

2. A standardised suggested competency framework (presented in draft on page 27-28) is developed and tested as a future element of this project.

3. The competency framework reflects the subject priority areas highlighted in this report.

4. People with learning disabilities and their carers are involved in all aspects of curriculum design and delivery.

5. All universities who deliver nurse education have a link lecturer for learning disabilities. This recommendation needs to be supported by education commissioners.

6. The role of learning disability nurses and how they support people across a range of settings should feature as part of the educational delivery. Involving local practitioners in HEIs is part of this recommendation and it is suggested that where such links are weak or do not exist, engagement is brokered through the educational commissioning process.

7. A specific learning disability competence is included in every nursing student's practice assessment and documentation.

8. HEIs consider a range of activities including clinical simulation as a means of delivering learning disability education.

9. A bank of open access resources is developed through LIDNAN to support HEIs in developing and delivering learning disability education and raise the profile of learning disabilities across the health education sector.

10. The project extends into a second phase to consider how organisations address the learning disability needs in other health curricula and how the recommendations of StC are evidenced by HEIs.

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Appendix 1: Thinking Space Workshop - report

Thinking Space
16th July 2014

Background

As part of 2014 – 2015 work plan NHS Education for Scotland identified that they would explore how part of recommendation 11 from *Strengthening the Commitment* (Scottish Government 2012) could be implemented. Recommendation 11 states that:

> *"Those who commission, develop or deliver education should ensure that all learning disabilities nursing education programmes reflect the key values, content and approaches recommended in this report. They should also ensure that nurses in other fields of practice develop the core knowledge and skills necessary to work safely and appropriately with people with learning disabilities who are using general health services."* - Recommendation 11 -
> *Strengthening the Commitment – The Report of the Review of Learning Disability Nursing* (StC) (Scottish Government 2012)

In Scotland it is the latter part of this recommendation around the knowledge and skills of NON learning disability fields of nursing that requires strengthening in all HEIs.

An email survey was undertaken across all the HEIs in Scotland that offer undergraduate nursing education. There was a very poor response rate (22per cent) perhaps suggesting that this is not a priority across the universities. It became apparent from the respondents and anecdotally that what is offered in relation to learning disabilities in each university differs widely both in content and quality.

NHS Education for Scotland (NES) decided to hold a Thinking Space event to which all of the following where invited:

1. Lecturers with responsibility for Learning Disability in the undergraduate programmes.
2. Liaison Nurses.
3. Students from learning disability and also students from the other fields of nursing.
4. Nurses from other fields of nursing.

Al these groups had representatives at the event.

Thinking Space Event

The thinking space event was held on 16.07.14 at NES headquarters in Edinburgh. The programme for the event can be seen at Appendix 1.

The event went very well and began with an exploration of two ways of increasing the input on learning disability in NON learning disability undergraduate programmes. They were:

1. Learning Disability bites

2. Hosting a conference on Learning Disability presented by the LD Action Aware students from the University of Bradford

Subsequent to this there were discussions in a version of world cafe where all the participants were able at some point in the morning to contribute to the questions.

The questions that were addressed were:

1. What should be included in non LD undergraduate nursing programmes?
2. Who should be involved?
3. How should this be delivered?
4. How do we ensure consistency?
5. How do we measure quality?

The results from the table top discussions can be seen at appendix 2.

The way forward

The content of the discussion for each of the tables was analysed and the following has been identified.

1. What should be included in non LD undergraduate nursing programmes?

Key ideas from the day
1. Cluster relevant topics together
2. Develop or source relevant materials
3. Explore the use of the LD portal on the knowledge network
4. Create learning disability bites in key areas

2. Who should be involved?

Key ideas from the day
1. A range of stakeholders need to be involved within each HEI
2. Link to the data base of people with learning disabilities and family carers which is being developed

3. How should this be delivered?

Key ideas from the day
1. Explore the creation of an interactive resource on "An ordinary Life".
2. Explore the development of pod casts – could be linked to learning disability bites.
3. Explore with University of Bradford the possibility of having a conference in Scotland.

4. Explore the creation of a community of practice for
    i)   Non LD lecturers
    ii)   Non LD nurses

4. How do we ensure consistency?

Key ideas from the day
1. A named lead in each HEI.
2. Make learning disability a priority for NES quality assurance.
3. Lobby NMC regarding content in non LD programmes.

5. How do we measure quality?

Key ideas from the day
1. Identify the types and quality of evidence required to meet the NMC outcomes.

At the end of the event participants brainstormed what they thought were the key messages from the day and these were:

- Importance of teaching everyone to start with seeing person as a valued individuals
- Value in learning from spending time with people with learning disabilities
- Students to have access to learning disability nurses
- Focus on communication and different ways of communicating
- Importance of the knowledge, skills and values of mentors
- Importance of the knowledge, skills and values of academic staff (HEI and FE)
- Teaching and learning approaches (HEI and FE)
- National approach – signposting to quality assured educational resources
- Interactive – assessment, OSCE

The key ideas and messages from the day can be delivered by a variety of stakeholders. It was identified that it would be useful to identify who was responsible for progressing the ideas and messages.

Universities with nursing programmes in Scotland
1. Each HEI with a nursing programme will identify a lead person for Learning Disability.
2. Each HEI with a nursing programme will involve a range of stakeholders within the delivery of the non learning disability undergraduate nursing programmes.
3. Each HEI will contribute to the creation of a database by giving the details of the contributors to the programmes to NHS Education for Scotland.
4. Explore the types and quality of evidence to meet the NMC's Learning Disability Outcomes ensuring that there is consistency across the HEIs.

NHS Education for Scotland
1. Create clusters from the content identified and map these to the outcomes identified for non-Learning Disability fields of nursing.
2. Explore the use of the LD portal.
3. Commission the creation of Learning Disability bites and or podcasts.
4. Hold the first meeting for the learning disability academic leads.

5. Make Learning Disability a priority for NES performance management in 2015.
6. Lobby the NMC regarding the quality and consistency of the content on Learning Disability in NON learning Disability fields.

Appendix 2: Thinking Space Workshop – table top discussions

1. **What should be included in non LD undergraduate nursing programmes?**

- Weave through the programmes
- Lose the fear!
- Core competencies
- Holistic care
- Alternative field experiences two to three weeks (Twice)
- What is harm (ASAP and Child Protection)
- Values and Attitudes (Three times)
- Multiple morbidity
- Acknowledge difference positively
- Start positive
- Diagnostic overshadowing
- Most common health problems – long term conditions
- Service user involvement
- Talking to the families for information – the importance of this
- Human rights
- Passports
- Makaton
- BSL
- Communication aids
- LD module added to clinical skills
- Interactive skills sessions
- What is a learning disability
- Autism awareness
- Services that exist for people with a learning disability
- Health equalities
- Accessible links
- Similarities and differences
- Meet people with LD
- Link LD to skills base
- Customer care
- Making reasonable adjustments and practical examples
- Raising awareness
- Input from LD nurses
- Adults with Incapacity – Consent
- Included in HCHP routes too
- Caused death
- Citizenship

2. Who should be involved?

- University of Bradford
- SCLD
- Health Improvement
- Social media (@ldactionaware)
- NES
- Complaints staff
- Academic leads
- Service leads
- Third sector
- Non LD practitioners
- Social services
- Medical staff
- NMC
- Advocates
- SALTs
- Dieticians
- Student nurses (twice)
- Adult returners
- LD practitioners - LD liaison nurses – AHPs – Community nurses
- Volunteers
- Universal services and targeted services
- Schools
- Funding bodies
- Government, UK and devolved
- Service users
- Health and social work integration
- Carers
- HEI / FE
- Advocacy
- Community engagement
- Publicity - PR
- Acknowledge different levels of involvement
- Nurse leaders
- PEFs
- School leavers
- Everyone
- GCU

3. How should this be delivered?

- Balance of educational experiential learning – holistic approaches (MH, Physical Health, multiple morbidities etc etc)
- Start with ordinary life / positive attitudes and values – seeing people with learning disabilities as valued citizens with human rights before moving towards health issues
- Practical learners – students of all fields accessing people with learning disabilities – that is university and practical experience
- Professionals to provide their experiences in delivering care. Health visitors both for the child and parents with learning disability. District nurses. Learning disability nurses
- Health passports
- Safely
- Honestly
- Ethnographic approaches
- By "experts"
- Active learning
- People with learning disability deliver direct input across all fields e.g. acute hospital experience, community experience
- Placement experiences for all- fields – joint approach
- Family carers input across all fields
- Paid carers and Independent Sector input
- Realistic
- Lived experiences
- Interactive workshops
- Seminars
- Discussions
- Pod casts of people's experiences
- On line resources – interactive
- Value based human rights approach
- Not just health – voluntary orgs, social care, education etc

4. How do we ensure consistency?

- Lead for learning disabilities in each university
- Shared outcomes
- Pre reg performance management
- Linked to national model
- Senior nurse group
- Linking with HEI and FE
- Shared forums
- Baseline measurements
- Scoping
- Thread running through pre reg and post reg
- Sharing good practice

- More learnpro?
- Needs to be ambitious but manageable and achievable
- Experiential learning
- Simulation
- Minimum dataset agreed across HEIs but Locally responsive, flexible, with an opportunity for growth
- Nationally agreed framework
- People with learning disability monitoring outcomes (shared sign off with mentors)

5. How do we measure quality?

- What is the baseline – What are we measuring?
- Input of LD and non LD nursing
- 360° audit and evidence – not just the mentor's opinion / judgement
- Feedback from parents / service users (Three times)
- Person centred outcomes for students and mentors
- Staff ratios increased in line with the complexity of the patients
- Not just the minimum – build in quality indicators
- Add LD specific OSCE
- Research
- Outcomes of care / health improvements/ education
- Access to associate mentor in LD
- Monitor levels of complaints
- Students have more time / confidence
- Nurses never have enough time – still need to provide care
- Change competences to Learning outcomes

↗ **UK LEARNING AND INTELLECTUAL DISABILITY NURSING ACADEMIC NETWORK (LIDNAN)**

LIDNAN provides a network of professionals interested in the education of learning disability nurses. The Network has been developed as a result of Strengthening the Commitment (2012) and intends to support the implementation of the educational recommendations within this report.

↗ **COUNCIL OF DEANS OF HEALTH**

The Council of Deans of Health is the representative voice of the 85 UK university health faculties providing education and research for nursing, midwifery and the allied health professions. Our members are experts in educating future and current health professionals, both in the UK and overseas. Members also carry out internationally-recognised research that benefits patients, developing new ideas that help solve some of health and social care's most pressing problems.

↗ **www.councilofdeans.org.uk**