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Improving the health of people with a learning disabilities: a public health nursing approach final literature review report

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# Improving the Health of People with a Learning Disabilities – A Public Health Nursing Approach Final Literature Review Report

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# **Executive summary**

## **Purpose**

The purpose of the mixed methods systematic review of literature was to summarise the best evidence available in order to inform the development of a robust suite of evidence based high impact areas, which relate to key areas that will support prevention, and local delivery of support for people with LD. The review also sought to summarise evidence available on the role and impact of LD nurses in meeting the public health needs of people with LD.

#### Methods

The Joanna Briggs Institute's (JBI) systematic review protocols were used to appraise studies. The PRISMA process was used to select the literature for review. Empirical (quantitative, qualitative, mixed methods) studies, synthesised evidence (literature reviews) and opinion papers, (n=36) were included in the review. A mixed methods approach to the review and synthesis was used due to the heterogeneous nature of the evidence. Quantitative data was converted into themes and presented with qualitative data through meta-aggregation using a narrative approach. JBI tools were used to pool findings and rate them for quality. Meta-synthesis was used to produce the synthesised findings.

## **Findings**

We retrieved 93 papers. Of these we excluded 26 papers after initial appraisal. We appraised 67 papers and excluded 31 after appraisal. Emerging themes include; surveillance, public health intelligence, policy / strategy development, policy / strategy implementation, health improvement, health promotion, health education, health improvement, assessing effectiveness, enhancing effectiveness, co-ordination, strategic leadership, professional leadership, clear / visible / accessible leadership, and scholarship.

#### Conclusions

Although there is some evidence to support the emerging themes, the literatures are limited in robustness and scope. Perhaps not surprisingly, this review leaves a number of questions unanswered. LD nurses, employers and commissioners of public health services need to have an agreed dialogical definition of public health.

Important lessons can be learnt in order to further develop and clarify the contribution of LD nurses to meeting the public health needs of people with learning disabilities. Urgent research is undertaken to further clarify current LD nurses' public health contributions to community and population public health including wider determinants of health, positive mental health and wellbeing, health protection including the uptake of immunisations and reduction of antimicrobial resistance. Rates of pre-mature mortality are still significantly high for people with learning disabilities and it is our considered view that specific work is undertaken to highlight the positive contributions LD nurses can contribute to the reduction in some of highest areas of prevalence premature mortality.

#### Introduction

Public Health England (PHE) commissioned the University of West London to undertake a systematic literature review on how the role of the learning disability (LD) nurse contributes to the role of public health and prevention across the lifespan. The overall objective of this review was to summarise evidence on how the role of the learning disability nurse contributes to the role of public health and prevention across the life span of people with LD. Specifically, the review seeks to answer the following questions;

- 1. Is there literature which explored the preventative roles of learning disabilities nurses?
- 2. Are there any themes emerging from these literatures that illustrate the positive factors affecting the involvement of learning disabilities nurses in leadership, public health, health promotion, high impact clinical interventions, and life course?

There is a lack of clarity on how the public health roles of LD nurses are to be carried out in practice. Due to the dearth of robust empirical studies clarifying a public health role for LD nurses is difficult. It is no surprise that the role has evolved differently across England or that primary care and social care providers may have conflicting views on LD nurses' public health role. Lack of public health role clarity for LD nurses, confusing and ambiguous expectations among healthcare professionals are likely to result in reduced quality of public health and healthcare experiences for people with learning disabilities. Clarity of public role expectations for LD nurses will be beneficial because it will improve communication, flexibility and responsiveness at every level of public health policy implementation for people with LD.

This report summarises the outcomes of the literature search, literature appraisal, literature selection process, data extraction and thematic synthesis. A literature review report will be available in the next few months.

#### **Purpose**

The purpose of the mixed methods systematic review of literature was to summarise the best evidence available in order to inform the development of a robust suite of evidence based high impact areas, which relate to key areas that will support prevention, and local delivery of support for people with LD. The review also sought to summarise evidence available on the role and impact of LD nurses in meeting the public health needs of people with LD.

## Review questions

This literature review sought to answer the following questions;

- 1. Is there literature which explored the preventative roles of LD nurses?
- 2. Are there any themes emerging from these literatures that illustrate the positive factors affecting the involvement of LD nurses in leadership, public health, high impact clinical interventions, and life course?

## **Background and context**

In the recent past a series of public health policy initiatives have been adopted in England including, Choosing Health (DH, 2004) Delivering Choosing Health (DH, 2005); Our health Our care Our say (DH, 2006a); Health challenge England (DH, 2006b); Tackling Health Inequalities (DH, 2007); Healthy Lives Healthy People (DH, 2010); The Forward View into Action: Planning for 2015/6 (NHS England, 2014), Change4Life: Let's Get Sugar Smart (DH, 2015), and more recently, Childhood Obesity - A Plan for Action (HM Government, 2016).

The renegotiation of the UK-wide General Practice (GP) contract in 2004 introduced enhanced services (optional – specialized services) which culminated in the introduction of Annual Health Checks for people with LD in 2006 through the Quality Outcomes Framework (QOF). Arguably these policies have in some way sought to address the public health needs of people with LD.

The avoidable disparity between the health, and the health needs of people with learning disabilities as compared to that of the general population has been acknowledged over many years (Kerr, 2004; Straetmans, *et al.*, 2007; Hatton and Emerson, 2015; Emerson, et. al., 2015; Kavanagh, *et al.*, 2017). These disparities result from poor access to health services, limited options in lifestyle, and poor living standards, but could be improved through appropriate interventions.

People with learning disabilities are known to have much greater health needs than those of comparable age groups who do not have learning disabilities (Backer, Chapman and Mitchell, 2009; Savage and Emerson, 2016; Emerson, et al., 2016a; Emerson, et al., 2016b; Robertson, et. al., 2017). For example, they experience higher rates of mental disorders as compared to the general population and that these health problems are commonly, and widely undiagnosed, misdiagnosed, and untreated (Llewellyn, Vaughan and Emerson, 2015; Emerson and Brigham, 2015). In addition, they experience higher rates of visual impairments, higher rates of epilepsy, hypertension and hypothyroidism, obesity. People with learning disabilities are more likely to die from preventable causes (Mencap 2007; Pawar and Akuffo 2008; Heslop, et al., 2013; Heslop, et al., 2014; McCallion and McCarron, 2014; Emerson, et. al., 2014. Robertson, et al., 2015; Bakker-van Gijssel, et al., 2017). The life expectancy of people with learning disabilities has increased with that of the general population in recent years. However, overall life expectancy still remains lower, and mortality rates remain significantly higher than those of the general population (Heslop, et al., 2013; Heslop, et al., 2014; Robertson, et al., 2015; Bakker-van Gijssel, et al., 2017). What is perhaps important in the context of public health is an understanding of the risk factors in order to prevent premature deaths, and the role LD nurses can play to minimize the potential consequences of those risks.

International studies have demonstrated widespread concerns about the inequalities in health for people with learning disabilities (WHO, 2003; Melville, *et al.*, 2006; Kavanagh *et al.*, 2016), and poor access to healthcare (Brown, *et al.*, 2010). These

disparities in health, and poorer health outcomes for people with learning disabilities have been attributed to service users, health organisations, and health service systems. Communication difficulties and limited understanding of the diagnostic, and treatment issues for people with learning disabilities, and mainstream healthcare professionals' limited augmentative communication skills further limits the diagnosis and treatment of people with learning disabilities appropriately (Blair, 2013). People with learning disabilities have complex health needs, and comorbidity is common. Life-style related comorbidity as a significant contributory factor to disparities in health for people with learning disabilities. Cognitive impairments limit people with learning disabilities' ability to access public health initiatives.

People with learning disabilities experience unequal access to health services (DRC, 2006). They experience inadequate diagnosis of treatable conditions (Mencap, 2007; DH, 2007; Heslop, *et al.*, 2013; Heslop, *et al.*, 2014; Robertson, *et al.*, 2015). A significant proportion of health inequalities experienced by people with learning disabilities are linked to poor quality healthcare provision (Michael, 2008; Mencap, 2012; Parliamentary Health Ombudsman and Social Services Ombudsman, 2009), and therefore preventable. In recent years, UK government health policy has focused on improving people with learning disabilities' access to mainstream services. However, the continuing disparities in health experienced by people with learning disabilities suggest that policies alone are not enough.

Barriers to accessing health services by people with learning disabilities contribute to health inequalities. The lack of role clarity of the professionals working with people with learning disabilities has been consistently identified as one of the most common barriers (Mafuba, 2009, 2013; Mafuba and Gates, 2015; Mafuba, Gates and Cozens, 2016). Primary healthcare services have an important role in meeting the public health needs of people with LD but there is a lack of evidence as to the roles LD nurses play in meeting these needs.

Poor uptake of public health initiatives, reduced access to health screening, and health promotion services amongst the population of people with learning disabilities is a longstanding issue (Allerton and Emerson, 2012; Robertson, et. al., 2014). There is a need for effective health advocacy from relevant health professionals. Studies have shown that people with learning disabilities are likely to be passive participants in their health and healthcare, and that they are dependent on others for their health and healthcare outcomes (Campbell and Martin, 2009). Delivering effective public health initiatives for people with learning disabilities is challenging (Thomas and Kerr, 2011). McIlfatrick, Taggart, and Truesdale-Kennedy (2011) have observed that the provision of public health services for people with learning disabilities is opportunistic, despite evidence that point to a need for targeted activities (Chauhan, et al., 2010; Robertson, et. al., 2014). Preventative interventions such as health screening are effective in identifying the health needs of people with learning disabilities (Emerson, Copeland and Glover, 2011; Robertson, et. al., 2014).

To effectively meet the public health needs of people with learning disabilities it is important to clarify the roles of LD nurses. It is also important to establish the evidence base for the most effective approaches to delivering public health services to people with learning disabilities. LD nurses' public health roles need to be clarified and located within the wider public health framework.

## Dialogical definition of 'public health'

Public Health England exists to protect and improve the nation's health and wellbeing, and reduce health inequalities. However, it has not been possible to locate PHE's dialogical definition of 'public health'. This is important because the concept of public health is a contentious one (Dawson and Verweij, 2007) and there is no agreed definition of what 'public health' may mean (Baggott, 2011). Given this ambiguity it is important to explore literature to develop a working definition.

## According to Winslow,

'Public health is the science and the art of preventing disease, prolonging life and promoting physical health and efficiency through organised community efforts for the sanitation of the environment, the control of community infections, the education of the individual in principles of personal hygiene, the organisation of medical and nursing service for the early diagnosis and preventative treatment of disease, and the development of social machinery which will ensure to every individual in the community a standard of living adequate for the maintenance of health' (Winslow, 1920, p.23).

This approach to public health highlights the importance of public health roles, including those of LD nurses.

The Acheson Report has described public health as,

"....the science and art of preventing disease, prolonging life and promoting health through organised efforts of society" (Acheson, 1988, p.27).

Another notable influence on the meaning of public health is the Faculty of Public Health (FPH). The FPH is the standard setting body for professionals, and specialists in public health in the UK. The FPH organises public health practice into 3 domains (health improvement, health protection, and improving services). In addition to the 3 domains, the FPH identifies 9 key areas of public health practice;

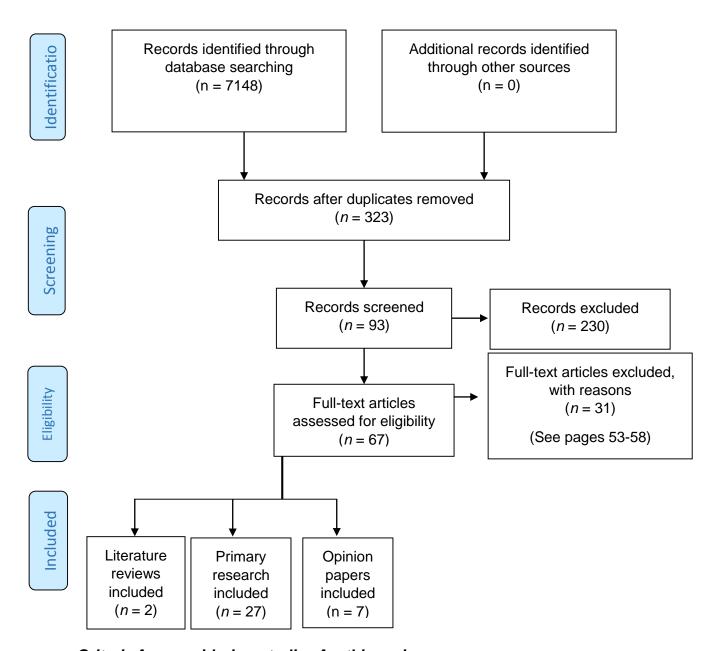
- 1. Surveillance and assessment of the population's health and wellbeing.
- 2. Assessing the evidence of effectiveness of health and healthcare interventions, programmes and services.
- 3. Policy and strategy development and implementation.
- 4. Strategic leadership and collaboration for health.
- 5. Health improvement.
- 6. Health protection.
- 7. Health and social service quality.
- 8. Public health intelligence.
- 9. Academic public health.

The key areas influenced our theme nomenclature during the thematic synthesis process.

## **Methods**

The Joanna Briggs Institute's (JBI) systematic review protocols were used to appraise studies. The Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) process was used to select the literature for review (see figure 1). Empirical (quantitative, qualitative, mixed methods) studies, synthesised evidence (literature reviews) and opinion papers, (n = 36) were included in the review. A mixed methods approach to the review and synthesis was used due to the heterogeneous nature of the evidence. Quantitative data was converted into themes and presented with qualitative data through meta-aggregation using a narrative approach. JBI tools were used to pool findings and rate them for quality. Meta-synthesis was used to produce the synthesised findings. Thematic synthesis was used to generate analytical themes (Thomas and Harden, 2007).

Figure 1: Literature appraisal and selection flow diagram.



# Criteria for considering studies for this review

#### Types of studies

In particular qualitative, quantitative, and multiple method papers based on empirical work, were reviewed. In the absence of empirical studies the review included; editorials, commentaries, practical and theoretical papers; indeed all published papers in the public domain.

## Types of phenomena of interest

This component of the review considered Nursing and Midwifery Council (NMC) registered LD nurses' preventative nursing roles.

## Search strategy for identification of studies

Search terms

*Group A:* learning disability / intellectual disability / mental retardation / mental handicap / developmental disability / mental deficiency.

*Group B:* learning disability nurse, community learning disability nurse, role, public health, health promotion, public health policy, healthcare, views, perceptions, experience, user involvement, policy implementation, participation, and consultation.

## Literature search strategy

The search strategy aimed to locate both published and unpublished studies and papers. The search was limited to English language reports. A three-step search strategy was used. An initial limited search of MEDLINE and CINAHL was undertaken, followed by an analysis of the text words contained in the title and abstract, and of the index terms used to describe the articles. A second search using all identified keywords and index terms was then be undertaken. Thirdly, the reference list of all identified reports and articles was searched for additional studies.

The search strategy was limited to studies undertaken and published prior to commencement of the review [February 2018]. We did not set time parameter as we believed studies which explored the issue under review were very limited.

#### Electronic searches

We adopted the search strategy for Boolean logic in order to search in all databases. We searched the JBI Reports (Wiley Online Library); MEDLINE; EMBASE; PsycINFO; CINAHL (EBSCOhost); ScienceDirect; Google Scholar; Academic Search Elite; Index to Theses (UK and Ireland); ETHOS; Theses.com; and Dissertations Abstracts.

*Table 1* below provides details of how search terms were used, databases searched and the results obtained.

## Table 1: Search results

Search 1 15.02. 18 Results

## CINAHL, Medline, Academic Search Elite, PsychINFO

Domain 1: nurs\*

#### AND

Domain 2: "learning disabilit\*" OR "intellectual disabilit\*" OR "mental retardation\* OR "mental handicap\*" OR "developmental disabilit\*" OR "mental deficienc\*"

#### AND

Domain 3: communit\* OR role\* OR "public health" OR "health promotion" OR "public health polic\*" OR healthcare OR "health care" OR view\* OR perception\* OR experience\* OR "user involvement\* OR "policy implementation" OR participation OR consultation

References: 7,260

Limited to English: 7148

Search 2 23.2.18 Results

## CINAHL, Medline, Academic Search Elite, PsychINFO

Domain 1: nurs\* [Title]

#### AND

Domain 2: "learning disabilit\*" OR "intellectual disabilit\*" OR "mental retardation\* OR "mental handicap\*" OR "developmental disabilit\*" OR "mental deficienc\*" [Title]

#### AND

Domain 3: communit\* OR role\* OR "public health" OR "health promotion" OR "public health polic\*" OR healthcare OR "health care" OR view\* OR "health prevention" OR "health protection" OR "health education" OR "life course" OR "clinical intervention\*" OR leadership

Domain 1 and Domain 2 limited to [Title] field: 683

1998-2018: 620 references 2008-2018 384 references

Limited to English: 323 References

## Searching other sources

We searched the reference and citation lists of the review papers for additional sources and adjust search terms where it is found to be necessary.

#### Types of studies

The review in particular included qualitative, quantitative, and multiple method studies published in peer-reviewed journals. However, because of the dearth of empirical studies that specifically addressed the objectives of the current review, opinion papers (published in peer reviewed journals and unpublished) were included.

Furthermore, because of the lack of appropriate studies, systematic literature reviews were also included.

## Types of participants

We included empirical studies with adult participants (aged 18 years or older) working with adults in learning/intellectual disabilities. Participants were primarily healthcare professionals. We included studies where relevant non-healthcare professionals were participants where we deemed the findings to be relevant to the aims of the review. We included opinion papers which had no participants but which addressed themes pertinent to the objectives of the review. We included systematic reviews that included studies which involved adult healthcare professionals and relevant others as participants, and which synthesised evidence pertinent to the current review.

#### Inclusion and exclusion criteria

Studies/papers were included if they were undertaken, and published before commencement of this review, and were originally published in English; any papers subsequently translated into English, following original publication, were also considered. Published (for example - peer reviewed journal articles), and unpublished studies (for example - theses) were considered for review if their focus related to preventative health in people with learning disabilities.

## Assessment of methodological quality

Papers selected for retrieval were assessed by two reviewers undertaking this systematic review for methodological validity, and relevance to the overall objective of this proposal prior to inclusion in the final review, using the standardized critical appraisal instruments from the Joanna Briggs Institute (see *appendices B-F*). Any disagreements that arose between the reviewers were resolved through discussion with the review panel.

#### Data extraction

JBI data extraction tools were used to extract quantitative and qualitative data. The reviewers undertook this independently. Data was extracted from papers included in the review using a modified Timmins and McCabe (2005) table. Any disagreements that arose between the reviewers were resolved through discussion with a review panel comprising members of the research team.

The reviewers independently carried out data extraction using a data extraction form table based on Timmins and McCabe (2005). In addition, the critical appraisal outcomes were incorporated into the table using the JBI *Critical Appraisal of Evidence of Effectiveness* (see appendix B), the JBI *Critical Appraisal Checklist for Qualitative Research* (see appendix C), the JBI *Critical Appraisal Checklist for Systematic and Research Syntheses Reviews* (see appendix D) and the JBI *Critical Appraisal Checklist for Text and Opinion Papers* (see appendix E). In addition JBI's *Levels of Evidence for Effectiveness* was used grade the evidence (see appendix F). We resolved any disagreement by discussing the matter with other team members. We

extracted the following data; authorship (author(s), year, country of origin), study objectives, methods (type of paper, study design, setting (where applicable) participants (where applicable), number of studies (where applicable), data collection methods (where applicable), data analysis methods (where applicable) and findings / conclusions.

## Data synthesis

We fully anticipated a paucity of work to have been undertaken in this area, and that data and material retrieved would be heterogeneous and disparate in nature. Therefore we employed the Joanna Briggs Institute (JBI) mixed methods approach to synthesis. A mixed methods approach to the review and synthesis was deemed more appropriate because of the heterogeneous nature of the evidence available. This was also important in order to maximise the synthesised findings. We are cognisant of the emergent nature of mixed methods reviews. The inclusion of diverse forms of evidence was considered important for broadening the evidence base to inform the review (Sandelowski *et al.* 2012). While we acknowledge the limitations of the credibility of mixed methods studies, systematic reviews and opinion papers which were included in this review, we are of the view that the careful inclusion of a wide range of literature into this review in the absence of robust randomised controlled trials for inclusion in the systematic review is important in strengthening the findings and conclusions.

## **Findings**

We retrieved 93 papers. Of these we excluded 26 papers after initial appraisal. We appraised 67 papers. In total 36 papers were included in this review of literature. 31 papers were excluded and we have provided detailed comments about our reasons for excluding these papers (see pages 53-58).

We were commissioned to undertake the literature review based on 5 themes of the contribution of LD nurses to public health; public health, health promotion, lifespan, complex interventions, and leadership. It was difficult to separate studies which investigated the public health and health promotion roles of LD nurses separately. Consequently we combined these two groups of studies into one.

Because of the wide range of papers included in the review, the findings and emerging themes are complex. It was impossible to categorise emerging themes using the four themes used to group the papers. This is because the emergent themes appeared across all the papers, except those in the leadership theme. We have categorised the findings from this systematic review into 16 themes which describe LD nurses' contribution to public health. These include; surveillance, public health intelligence, policy / strategy development, policy / strategy implementation, health improvement, health promotion, health education, health improvement, assessing effectiveness, enhancing effectiveness, co-ordination, strategic leadership, professional leadership, clear / visible / accessible leadership, and scholarship. Citations are presented chronologically from the most recent to the

oldest, and a standardised nomenclature is used for their reporting; name, year, scope of study, design, participants, scale/s of measurement, findings, and limitations. Where a citation falls into more than one theme then its subsequent use will only report on findings.

## Theme 1: Public health and health promotion

This section presents aspects from the studies used in this review of literature that are directly related to the significance of LD nurses in relation to their public health and health promotion roles in a wide range of clinical settings.

In the UK-wide, the study by Mafuba, Gates and Cozens (2016) explored how public health policy was reflected in community learning disability nurses' job descriptions and person's specifications. This study was part one of a 3-phase sequential multiple methods study. Other papers from this study are also included in this review. The study used documentary analysis method and Grounded Theory data analysis. The study analysed purposively sampled LD nurses' job descriptions and person specifications (n = 203) (band 5: n = 63; band 6: n = 87; band 7: n = 47; band 8: n = 876). The study identified a number of public health role descriptors for community learning disabilities nurses. Role descriptors for band 5 nurses were; implement (30%) (24), facilitate (19%) (15), contribute (16%) (13), promote (12%) (10), develop (9%) (7), liaise (9%) (7), plan (4%) (3), and reduce inequalities (1%) (1). Public health role descriptors for band 6 nurses were reported as; implement (27%) (12), facilitate (18%) (8), reduce inequalities (15%) (7), promote (13%) (6), enable (9%) (4), advise (7%) (3), contribute (7%) (3), and develop (4%) (2). Public health role descriptors for band 7 nurses were identified as; implement (34%) (17), reduce inequalities (16%) (8), promote (14%) (7), facilitate (12%) (6), enable (10%) (5), lead (8%) (4), contribute (4%) (2), and liaise (2%) (1). For band 8 nurses public health role descriptors were; enable (33%) (4), lead (25%) (3), evaluate (17%) (2), develop (17%) (2), and contribute (8%) (1).

A study undertaken in the UK by Marriott, *et al.* (2015) described the role of the screening liaison nurses for adults with learning disabilities. The paper describes the screening liaison nurse role and presents case examples of the work they do. The study identified working with the main screening programmes to put reasonable adjustments in place, development of easy to understand letters and information, training for mainstream screening staff regarding the needs of people with learning disabilities, and supporting women to manage cervical screening as some of the key roles of screening liaison nurses.

Lloyd and Coulson (2014) undertook a study in the UK that explored LD nurses' experiences of supporting women with learning disabilities to access cervical screening. The study involved 10 LD nurses and identified their roles in preparing women psychologically for screening, managing the challenges of supporting women with complex needs, and managing the challenges of supporting women with complex needs.

In his PhD thesis, Mafuba (2013) from the UK, has reported findings from a UK-wide 3-stage sequential multiple methods study which aimed to explore, describe and explain how community learning disability nurses experienced and perceived their public health roles. Stage 1 of the study explored how public health policy was reflected, and articulated in community learning disability nurses' job descriptions, and or person specifications (n = 205). In Stage 2 of the study the researcher used a grounded theory approach involving learning disability nurse consultants from across the UK (n = 17). Stage 3 was explanatory, and involved an on-line questionnaire survey of community learning disability nurses (n = 171). Papers published as a result of this study are included in the current review. The study identified LD nurses' public health roles as; academic, health education, health prevention, health promotion, health protection, health surveillance, healthcare access facilitation, healthcare delivery, leadership, and policy development and implementation.

In the UK, Mafuba and Gates (2015) reported on one stage of a 3-phase sequential multiple methods study that explored and explained the contribution of community learning disability nurses in the implementation of public health policies for people with learning disabilities using a 9-item online questionnaire survey (UK-wide) (n =171) (band 5: n = 19; band 6: n = 67; band 7: n = 59; band 8: n = 26). The study demonstrated that community learning disability nurses are involved in; health surveillance, health promotion, health facilitation, health prevention and protection, health education, and healthcare delivery. The study also reported on the public health involvement rates of community learning disabilities nurses; healthcare delivery (band 5: 66.7%; band 6: 73.7%; band 7: 62.0%; band 8: 83.3%; Overall: 71.3%), health education (band 5: 76.2%; band 6: 91.2%; band 7: 86.0%; band 8: 72.2%; Overall: 81.4%), health prevention and protection (band 5: 71.4%; band 6: 84.2%; band 7: 74.0%; band 8: 50.0%; Overall: 69.9%), facilitating access to health (band 5: 85.7%; band 6: 100.0%; band 7: 96.0%; band 8: 94.4%; Overall: 94.0%), health promotion (band 5: 95.2%; band 6: 100.0%; band 7: 88.0%; band 8: 88.9%; Overall: 93.0%), and health surveillance (band 5: 57.1%; band 6: 73.7%; band 7: 60.0%; band 8: 44.4%; Overall: 58.8%).

Brown, *et al.* (2012) undertook a study in the UK which examined the impact and outcomes of four learning disabilities liaison nurse (LDLN) services in south-east Scotland on the healthcare experiences of people with learning disabilities attending for general hospital care. The study involved 85 participants including; patients with learning disabilities (n = 5), carers (n = 16), primary care healthcare professionals (n = 39) and general hospital professionals (n = 19) and learning disability liaison nurses (n = 6). The study concluded that LDLN role impacted on three key areas (clinical patient care; education and practice development strategic organisational developments) and involved; information sharing relating to care needs, risk management, giving behavioural advice, providing communication advice, providing educational support, providing psychological support, undertaking pre-morbid

baseline assessments, developing eating and drinking guidelines, and making accessible information about national cancer screening programmes.

In the UK, Taggart, Truesdale-Kennedy and McIlfatrick (2011) undertook a study with 6 focus groups. Participants were community learning disabilities nurses (n = 29), as well as residential care staff. The study concluded that community learning disabilities nurses needed to develop a health promotion programme for women with learning disabilities focusing on; breast awareness, information on screening healthier lifestyles, supporting the women to self-examine and report any abnormalities, development of health education material, development of health promotional activities, and training for all professionals involved in supporting women with learning disabilities.

A literature review undertaken by Mafuba (2009) in the UK reviewed literature on community learning disability nurses' role in public health. The literature review included 9 studies. In the literature review the author concluded that LD nurses contributed to public health through; health facilitation, health promotion, and health education.

In the UK, Marshall, McConkey and Moore (2003) reported on a study which followed-up people aged 10 years and over (n=464) identified as overweight and obese following special health screening clinics run by community learning disabilities nurses. The study sought to determine the actions taken and evaluated the impact of health promotion classes on participants' weight loss. In the study the authors reported that the health screening identified; overweight or obesity, and higher levels of blood pressure. The study also reported that the health promotion classes led to a significant reduction in weight and body mass index scores. In addition the study concluded that health screening per se had limited impact on reducing obesity levels in people with learning disabilities and that focus needed to be on creating more active lifestyles.

Barr, et al. (1999) reported on a study undertaken in the UK which introduced health screening for people with learning disabilities involving community learning disabilities nurses in an area in Northern Ireland. 373 people with learning disabilities were screened for weight, blood pressure, urinalysis, breast cancer, testicular cancer, and received eye and hearing tests. The study concluded that the primary contribution of community learning disability nurses was raising the profile of the health needs of people with learning disabilities, and supporting people with learning disabilities to stay in better health.

## Theme 2: Lifespan

This section presents aspects from the studies used in this review of literature that are directly related to the significance of learning disabilities nurses in relation to their public health roles through the lifespan of people with learning disabilities in a wide range of clinical settings.

A recent study carried out by Cleary and Doody (2017) in Ireland explored nurses' experiences of caring for older people with learning disability and dementia using descriptive phenomenology. LD nurses (n = 9) and general nurses (n = 2) participated in the study. The study highlighted the importance of knowing the person, the need for greater knowledge of dementia, and the importance of individuals' health needs including end-of-life care as fundamental to how older people with learning disabilities were supported.

An opinion paper written in the UK by Delahunty (2017) described how nursing staff might use the Child and Adolescent Learning Disability Screening Questionnaire (CALDS-Q) to help identify children who should be formally be assessed for a learning disability. The paper concluded that school nurses can identify children with potential learning disability, act as a link between schools and other services, LD nurses can facilitate transition from nursery into school or transition into adult services, nurses who have regular contact with children and their families can monitor children's development, and that nurses can identify children who should be prioritised for further a learning disability assessment.

Northway, et al. (2017) in the UK published an article that describes an activity undertaken at a conference in Cardiff in 2016. This was not an opinion paper but the research was not methodological. Delegates were asked to identify the roles of LD nurses at different lifespan stages. There were more than 200 delegates (LD nurses, students, people with learning disabilities and their families, nurses from other fields, and other professionals). Participant responses identified new and emerging roles relevant to public health across a range of settings as; provision of family support and parenting, provision of positive behavioural support, safeguarding of children and adults, health liaison roles and reasonable adjustments, health promotion and education (medication monitoring, promotion of health checks and screening, personal and sexual relationships, nutrition and dysphagia management), facilitating transition from child to adult services and other life stages, supporting the communication of people with learning disabilities, provision of advice about available services, provision of awareness raising and education, involvement in pre-natal screening, providing support in relation to diagnosis, undertaking developmental assessments, working in schools, providing advice and support to schools, mental health promotion and support, promotion of resilience, and assessment of dementia.

In Ireland, Nelson and Carey (2016) published an opinion article which highlighted the importance of the role of learning disabilities nurses in assessing mobility, as part of the holistic assessment of older adults with learning disabilities. The paper identified LD nurses' roles that are relevant to public health that include promotion of the health and well-being of people with learning disabilities. The paper also identified assessment of mobility decline in older people with learning disabilities and supporting maintenance of optimal health as important contributions by LD nurses.

In the Netherlands, Wagemans, *et al.* (2015) reported on a study that included LD nurses (n = 10) and social workers (n = 1) as participants. The aim of this study was to clarify the process of making end-of-life decisions for people with learning disabilities from the nurse's perspective and concluded that nurses needed to be the centre of communication because they have a complete picture of the patient.

A PhD thesis by Arrey (2014) reported on a study undertaken in the UK which sought to gain an in-depth phenomenological understanding of how LD nurses and palliative care professionals identified and responded to the distress of people with communication difficulties and learning disabilities in palliative care settings. 13 participants (LD nurses, n = 8 and palliative care professionals, n = 5) participated in the study. The study observed that LD nurses played a key role in responding to the needs of people with learning disabilities and communication problems in palliative care settings by building relationships, providing insight into factors that determine how people with learning disabilities and communication difficulties in palliative care settings communicate distress, sharing professional knowledge, and providing training and engaging in collaborative working.

In Ireland, Doody, Markey and Doody (2013) reported on a study that explored the experiences of registered LD nurses (n = 7) caring for older people with learning disabilities using a phenomenological approach. The study identified some themes of relevance to the public health roles of LD nurses including; the importance of knowing the person well, engagement in proactive planning, and involvement in preparing other nursing specialisms to care holistically for people with learning disabilities.

In a PhD study undertaken in the UK, Ng (2011) explored the perceived knowledge and skills of LD nurses in the context of how they assessed, recognised and discovered patients' illnesses and how they provided end of life care to terminally ill people with profound learning disabilities in residential care homes. The Grounded Theory study involved LD nurses as participants (n = 36). Themes that emerge from the study which are relevant to the public health roles learning disabilities relevant to public include; knowing the patient well, being in a position to make referrals to GPs, establishing physical health baselines, and the longitudinal presence of the nurse in the provision of health services to people with learning disabilities.

Marshall and Foster (2002) reported on a study undertaken in the UK. The focus group study explored the most appropriate healthcare role for delivering health care in a special need school for children with a broad range of severe learning disabilities. The study involved 4 in-depth focus group interviews (8-10 interviewees per group) (teachers, classroom assistants, parents, occupational therapists, physiotherapists, speech and language therapists, social workers, and community learning disability nurses). The roles community learning disabilities nurses identified in the study include; liaison between professionals and significant others such as parents and relatives, facilitation of effective inter-professional, interdisciplinary and interpersonal

communication concerning the healthcare needs of the children, provision of hygiene advice, provision of dietary advice, and continence promotion.

## Theme 3: Complex interventions

This section presents aspects from the studies used in this review of literature that are directly related to the significance of learning disabilities nurses in relation to their public health roles involving complex interventions across the lifespan and in a wide range of clinical settings.

A study undertaken in Ireland by Doody, Slevin and Taggart (2017) explored the contribution of clinical nurse specialists in learning disabilities nursing using focus groups. Participants were learning disability clinical nurse specialists (n = 31). The study identified some of the roles of learning disability clinical nurse specialists that are relevant to public health as; undertaking assessments, carrying out evaluations, monitoring progress, advocating for people with learning disabilities, being the first point of contact, providing support for families of people with learning disabilities, design information booklets or packages, providing informal and formal advice, undertaking research, and providing formal / informal education.

In an opinion paper written in the UK Adams and Shah (2016) examined the reasons why medication was prescribed, best practice, the side effects and the issues that are involved with the withdrawal of psychotropic medicines, in particular antipsychotics, in people with learning disabilities. In the paper the authors identified the roles of learning disabilities nurses that are relevant to public health. The authors argued that LD nurses play important roles such as; reviewing and assisting with the withdrawal of antipsychotic medication, reducing prescribing of antipsychotic medicines for people with learning disabilities, maintaining and enhancing the general physical health and well-being of people with learning disabilities, advising people with learning disabilities and their carers about constipation, monitoring how well a medication is working, improving communication between healthcare professionals in primary and secondary care, and improving health outcomes for people with learning disabilities.

In the USA, a study by Auberry and Cullen (2016) sought to determine whether nurses working in the field of learning disabilities experienced increased confidence when they implemented the American Association of Neuroscience Nurses (AANN) Seizure Algorithm (evidence-based seizure algorithm for nurses working in the field of learning disabilities) during telephone triage. Participant nurses were LD nurses from Indiana Developmental Disabilities Nurses Association (n = 15) who provided nursing care to individuals with learning disabilities and epilepsy living in community-based settings. Of significance to the current literature review is the authors' findings that using the AANN Seizure Algorithm increased self-confidence for many of the nurses in guiding care decisions during telephone triage. The study also reported that the treatment effect was statistically significant 3.169 (p < 0.01). The authors

concluded that LD nurses played important roles in providing seizure guidance to people with learning disabilities living in the community.

MacArthur, *et al.* (2015) undertook a mixed methods study in the UK which examined the role of learning disabilities liaison nurses in facilitating reasonable and achievable adjustments to support access to general hospital services for people with learning disabilities. In the study 6 liaison nurses collected quantitative data from 323 referrals, and interviews and focus groups were held with 85 participants (adults with learning disabilities (n = 5), carers (n = 16), primary care staff (n = 39), general hospital (n = 19) and learning disability liaison nurses (n = 6). The study identified roles of learning disabilities liaison nurses that are important to public health including; facilitation of reasonable and achievable adjustments, identifying patient need, information sharing relating to care needs, provision of behavioural advice, provision of communication advice, provision of client psychological support, provision of carer educational support, undertaking pre-morbid baseline assessment, provision of eating and drinking guidelines, and provision of diagnostic advice.

In the UK, in an opinion paper Morton-Nance (2015) explored the evolving role of learning disabilities nurses and their unique contribution and examined the nature of specialist nursing in practice in acute care settings. Among other things the paper highlights the some of the roles of learning disabilities which contribute to public health as; undertaking pre-admission screening and clinical assessment, advocating for people with learning disabilities and advising hospital staff on all reasonable adjustments needed, assisting with capacity/risk assessments, advising on and providing plans of care for complex admissions and discharges, educating people with learning disabilities, family members and carers, raising awareness of learning disabilities and autism, serving as a contact person for community teams, internal hospital teams, admissions and discharge teams, people with learning disabilities and external sources to enhance health outcomes, and offering advice on treatment options.

An opinion paper written in Ireland by Sheerin (2012) broadly identified public healthoriented roles in relation to; assessment of need, undertaking health surveillance and health promotion activities, enablement and empowerment, and addressing health inequalities from a nursing perspective.

In her study undertaken in the UK, Marsham (2012) explored therapeutic roles of community learning disabilities nurses. In the study semi-structured interviews based on Critical Incident Technique were used to collect data from practicing community learning disabilities nurses (n = 7) with more than 2 years' experience of managing a caseload of adults with learning disabilities. Community learning disabilities nurses' perceptions of their therapeutic role had elements of preventative health. Management of long-term conditions, prevention of relapse and recovery, facilitation of self-management, development of coping skills, reduction of challenging behaviour, increased healthcare access, assessing the person's understanding of

their needs, and maximising support networks through liaison work were perceived as preventative roles.

In a literature review undertaken in Australia, Taua, Hepworth and Neville (2012) synthesized researches that investigated the role of nurses caring for people with a dual disability of learning disability and mental illness. Although it is unclear if any of the studies included in the review had LD nurses as participants some of the roles identified are relevant to the public health practice of learning disabilities nurses. Among other roles, the review identified assessment, advocacy/health promotion (including working with family), facilitating communication and safety/risk management which could be argued to have relevance to the public health practice of learning disabilities nurses.

A study undertaken in the UK by Jenkins (2012 explored the contribution of registered nurses in meeting the health needs of older people with learning disabilities using case studies developed around older people with learning disabilities (n = 6; age range – 45 - 75+). The study highlighted the contribution of nurses to the identification of undiagnosed health problems such as mental health problems, constipation, hearing and visual problems.

In Ireland, McKeon (2009) reported on a study which sought to provide a baseline of clinical nursing skills used in learning disabilities nursing. The study used a questionnaire survey based on the nursing skills list from The Royal Marsden Hospital Manual of Clinical Nursing Procedures (Mallett and Dougherty, 2000). 18 from a residential setting and 8 from a community living setting. The study identified nursing roles that are relevant to public health as; violence prevention, and assessment.

Llewellyn and Northway (2007) reported on a study that was undertaken in the UK which investigated the advocacy role of LD nurses (n = 18) in Wales using focus groups. Participants were registered learning disabilities nurses who were working in small residential settings. The study concluded that there was a need for LD nurses to advocate for service users in their areas of practice.

In a study undertaken in the UK, Barr (2005) provided an overview of the changes in the caseload and working practices of community nurses (n = 40) for people with learning disabilities over an 11-year period in Northern Ireland. The findings from this study include; increased involvement in health monitoring casework, increased working with people with learning disabilities who develop mental health problems, increased working with older people with learning disabilities and older carers, increased number of LD nurses working with people with epilepsy, and increased number of LD nurses working with children.

Slevin and Sines (2005) explored the role of LD nurses (n = 22) in their day-to-day work with people who challenge in the UK. The study identified roles that are relevant to meeting the public health needs of people with learning disabilities and these

include; promoting amelioration of detrimental effects of challenging behaviour, undertaking initial assessment, prevention, educating staff in residential homes or in schools, and monitoring and evaluation of the outcomes of interventions.

## Theme 4: Leadership

This section presents aspects from the studies used in this review of literature that are directly related to the significance of LD nurses in relation to their leadership roles in a wide range of clinical settings.

An opinion paper authored by Gray (2015) in the UK describes the Scottish learning disabilities senior nurse group's position paper on leadership. The main aim of the paper is to ensure that the contribution of learning disabilities nursing is recognised across the NHS and that it continues to be led effectively, including through succession planning as senior staff retire. The paper identifies key elements to successful leadership in learning disability nursing practice which are relevant to the delivery of public health services for people with learning disabilities as; making leadership visible, ensuring access to leaders, having a national pathway of influence, having a system of identifying new leaders, and establishing governance structures that allow reporting at board levels and nationally.

A study undertaken in the UK by Cheseldine, Brown and Wilkie (2010) discussed the use of Goal Attainment Scaling (GAS) within secondments as a means of identifying learning needs and developing practice in the area of Child and Adolescent Mental Health Service (CAMHS) for children and young people with learning disabilities. The study involved community learning disabilities nurses (n = 5) who were on secondment over a period of 3 years. The goals they set in their secondments were evaluated using Goal Attainment Scaling. The study concluded that secondment can be an effective method of facilitating staff development.

In a study undertaken in Ireland Galvin and Timmins (2010) explored registered LD nurses' (n = 8) experience managerial support. The study highlighted the importance of; the professional role of the clinical nurse manager, the leadership role of the clinical nurse manager, provision of personal supports, the positive effects of clinical nurse manager support, obtaining holistic viewpoint of the nurses' role, upholding professional standards and practices, expertise in practice, leading and facilitation of learning in practice, and availability of leaders.

Sines and McNally (2007) explored perceptions of clinical supervision among community-based residential LD nurses (n = 35) in south-east England in the UK. Among others the study findings included; a need for greater clarity in the roles of supervisor and supervisee, a need for clearer separation of managerial and developmental imperatives, a need for a range of options for type of supervision and choice of supervisor, importance of supervision for staff working in isolated community-based services, clinical supervision had positive impact on personal needs and professional practice by (providing advice, improving knowledge,

improving skills, providing general support, helping to reflect on practice, enabling supervisee to be more person centred, assisting to think independently, enabling respondents to be more effective decision makers, helping to manage stress, improving self-confidence, and helping to develop career).

#### Discussion

Whereas this systematic review has failed to locate any papers that have specifically addressed the contribution of LD nurses to public health, health promotion, lifespan, complex interventions, and leadership numerous papers have been identified, based on empirical studies, reviews of literature and opinion papers that have sought to explore a range of roles that directly or indirectly impact on the public health roles of LD nurses. These have been organised into themes that include; surveillance, public health intelligence, policy / strategy development and implementation, health improvement, health promotion, health education, enhancing effectiveness, strategic leadership, professional leadership, clear, visible and accessible leadership, and scholarship. What is clear from this review is the wide range of activities which the public health roles of LD nurses entail. For example, Northway, et. al., (2017) have reported that in order to effectively promote the health and wellbeing of people with learning disabilities, LD nurses need to engage in a wide range of roles and they need to assimilate emergent roles. They identified new and emerging roles across a range of settings and these include; family support and parenting, positive behavioural support, safeguarding of children and adults, health liaison roles and reasonable adjustments, health promotion and education, transition from child to adult services and other life stages, supporting the communication of people with learning disabilities, providing advice about available services, awareness raising and education, involvement in pre-natal screening, providing support in relation to diagnosis, developmental assessment, working in schools, and providing advice and support to schools, mental health promotion and support, promotion of resilience, assessment of dementia, promoting employment, and supporting individuals to remain in their home.

#### Surveillance

Community learning disabilities nurses who participated in Mafuba's study (Mafuba, 2013) reported that demographic ignorance was one of the most common limiting factors on LD nurses' ability to implement public health initiatives for people with learning disabilities. In the same study, in a UK-wide survey of community LD nurses (n = 171), health surveillance was the least common reported public health activity with only 58.8% of participants reporting some involvement. The RCN has argued that all nurses need to engage actively in 'upstream' public health which focuses on surveillance and prevention (RCN, 2012). They have argued that knowing and understanding the health needs of their local population underpin the public health work of all nurses. The importance of the role of LD nurses in surveillance is evidenced by its appearance in 17 papers (47.2%) of the papers in the current review. Perhaps it is important for LD nurses to develop an understanding that the continuous, systematic collection, analysis and interpretation of health-related data is

essential for the effective planning, implementation, and evaluation of their public health practice. An important aspect of surveillance is the information sharing relating to the health needs of people with learning disabilities. In undertaking their roles LD nurses screen and assess the health needs of people with learning disabilities. It is therefore important for them to combine health screening with health promotion, because health screening by itself has limited impact on reducing the health needs of people with learning disabilities.

What emerges from the current literature under review is the complexity and changing needs of people with learning disabilities. This means that ongoing assessment of needs is essential to maintaining and promoting the health and wellbeing of people with learning disabilities. The importance for LD nurses in engaging in interprofessional working in ongoing assessment of needs cannot be over-emphasised. Knowing the person well seems to be important in understanding the needs of people with learning disabilities. What also emerges from the studies is that LD nurses need to be able to assess for a wide range of needs including; mental health problems, the needs of older people with learning disabilities, needs of people with epilepsy, and the health needs of children with learning disabilities.

#### Health facilitation / Health liaison

Working collaboratively requires effective health facilitation and health liaison. To promote the health and wellbeing of people with learning disabilities effectively, LD nurses need to work collaboratively to improve access to mainstream services (Marriott, et. al., 2015). Working collaboratively can be complex and varied. For example, the role may involve working with main screening programmes to put reasonable adjustments in place, developing easy to understand materials and information, providing training for mainstream screening staff regarding the needs of people with learning disabilities, or supporting people with learning disabilities to attend screening appointments. This requires LD nurses to have a complex repertoire of knowledge and skills.

For LD nurses to engage effectively in implementing the complex public health interventions needed, they do not only require skills to assess presenting needs, but they need to be able to undertake pre-morbid baseline assessments in order to identify public health needs. Undertaking pre-morbid baseline assessments is important in facilitating access to appropriate services and providing appropriate advice. Effective and comprehensive assessment need to lead to appropriate interventions or signposting. For example, LD nurses working with school children can identify children with potential learning disabilities who can then be prioritised for further assessment. Referring and prioritising people for further assessment is important in dealing with undetected health problems such as mental health problems, constipation, hearing and visual problems, and strokes.

In order to effectively promote the health and wellbeing of people with learning disabilities, LD nurses need to engage in a wide range of roles and they need to

assimilate emergent roles (Northway, *et. al.*, 2017). These roles need to extent from the community to acute care settings and *vice versa* through advocacy, facilitation of reasonable adjustments, health facilitation, health liaison and raising awareness.

It is also evident that needs assessment need to result in the development of preventative interventions. Of note is the need for the public health roles of the LD nurses to focus on enablement, for example when working with people with dual diagnosis or lifestyle related conditions. It could be argued that health inequalities need to be addressed through empowerment and enablement. Therefore, LD nurses need to engage in improving the health and wellbeing of individuals and communities of people with learning disabilities through enabling and supporting people to develop self-management skills.

## Public health intelligence

Another important contribution to public health by LD nurses is raising the profile of the health needs of people with learning disabilities. This requires LD nurses not only to undertake comprehensive needs assessments at the individual level, but at the population level as well. The implications of this are that in order for LD nurses to have a positive impact on meeting the public health needs of people with learning disabilities, their roles need to make contributions to public health intelligence for people with learning disabilities. Public health knowledge and intelligence is essential in providing information which is essential for identifying issues that have negative impacts on people with learning disabilities' health, and for planning to address these needs.

#### Policy / strategy development and implementation

Papers in this review have highlighted the lack of co-ordination or consistency in the implementation of public health policies or strategies for people with learning disabilities. It is clear from recent reports that there are significant deficits in public health policy implementation for people with learning disabilities in mainstream services (Michael, 2008; Mencap, 2012). There is no clear framework for LD nurses' public health roles. This has resulted in confusion over how learning disabilities nurses should be involved in public health policy implementation for people with learning disabilities. This is likely to result in poor translation of public health policies into practice for people with learning disabilities. It could also be argued that this lack of clarity for the responsibility for implementing public health policies for people with learning disabilities contributes to the ineffectiveness and poor outcomes of these policies. LD nurses at all levels are in a unique position to make important contributions in implementing public health policies for people with learning disabilities through engaging in health surveillance, health promotion, health facilitation, health prevention and protection, health education, and healthcare delivery (Mafuba, Gates and Cozens, 2016).

For LD nurses to have a positive impact on meeting the public health needs of people with learning disabilities, their roles need to encompass the whole policy process. In

order to improve the effectiveness of public health policy implementation for people with learning disabilities, LD nurses need to focus on their visibility in public health policy agenda setting, development, implementation and evaluation. This requires LD nurses to occupy leadership roles in public health services.

## Health promotion and health education

The health promotion and health education roles of LD nurses were highlighted in 18 (50%) of the studies under review. It is however important to point out that how LD nurses promote health and prevent disease, disability and premature death through education-based voluntary behaviour change activities varies significantly. For example, this can involve developing eating and drinking guidelines, providing advice, making accessible information about national screening programmes, or running health promotion classes for people who are overweight or obese. As noted earlier, to be effective LD nurses need to combine health screening with health promotion. This is important because health promotion and health education activities need to be based on the assessed needs of individuals.

People with learning disabilities can benefit from health promotion and health education activities. In their study Marshall, McConkey and Moore, (2003) demonstrated that health promotion classes for people with learning disabilities led to a significant reduction in weight and body mass index scores. It is important that in implementing public health strategies for people with learning disabilities, LD nurses need to support people to create more active lifestyles. In addition, it is also evident that there is a need for LD nurses to engage in developing or adapting health promotion programmes for people with learning disabilities. Engagement with public health need to be all encompassing to include promoting the health and wellbeing of children, adults, parents, and older adults with learning disabilities.

Another important aspect of public health for people with learning disabilities is the need to engage all stakeholders at individual and population levels. People with learning disabilities need support with maintaining optimal health and engaging all stakeholders is invaluable. What is clear from the studies in this review is the complexity of the health promotion and health education LD nurses need to engage in. For example; providing family support and parenting, providing positive behavioural support, supporting transition from child to adult services and other life stages, providing mental health promotion and support, providing seizure guidance to this people with learning disabilities living in the community, raising awareness of learning disabilities and autism, educating staff in residential homes, or in schools, and advising people with learning disabilities and their carers about constipation. Mafuba (2013), and Mafuba and Gates (2015) have reported the concept of a 'jack of all trades' and 'role diversity' and their relationship to a lack of public health role clarity of LD nurses who often work in professional isolation. It could be argued that this complex health promotion and health education practice environment may contribute to lack of engagement with public health activities.

## Improving health

For people with learning disabilities, health improvement is essential in improving their health and wellbeing or that of their communities. LD nurses can contribute to this through enabling and supporting healthy lifestyle choices and also addressing determinants of health. Maintaining people with learning disabilities in better health is an important public health role of LD nurses and they need to engage in health improvement by supporting people to develop self-management skills. These roles may focus on management of long term conditions, developing of coping skills, and maximising support networks for people with learning disabilities in the community.

## Enhancing effectiveness

The Royal College of Nursing (RCN, 2016, p.29) have concluded that many aspects of the public health roles of nurses are hidden. They have also argued that nurses need to articulate these roles to commissioners and managers. Perhaps of more significance is their recommendation for nurses need to

'be "skilled-up" to work with commissioners so meaningful key performance indicators, service level agreements and local incentive targets (such as CQUINs (Commissioning for Quality and Innovation)) are set which reflect public health nursing'.

Monitoring the effectiveness of treatments is essential to the promotion of the health and wellbeing of people with learning disabilities. Adams and Shah (2016) have concluded that LD nurses have an important role in; reducing prescribing of medicines for people with learning disabilities, monitoring how well a medication is working, and improving communication between healthcare professionals which is essential to improving public health outcomes for people with learning disabilities. This is particularly of significance where there are complex and multi-disciplinary interventions complex. In such situations co-ordinated monitoring progress becomes invaluable. LD nurses play a significant role in enhancing the effectiveness of public health interventions. To enhance effectiveness, LD nurses need to work collaboratively to improve access to mainstream services. Literature included in this review highlighted a number of different ways LD nurses can contribute to the effectiveness of services for people with learning disabilities. For example, working with main stream services to put reasonable adjustments in place, developing easy to understand letters and information, and training mainstream staff regarding the needs of people with learning disabilities. This is important because many professionals work directly with people with learning disabilities and they can contribute to meeting their public health needs. It is therefore important to understand that in order to deliver effective health promotion, LD nurses need to support other health and healthcare professionals who work directly with people with learning disabilities across the lifespan.

Effective public health interventions by LD nurses will need to engage all stakeholders at individual and population levels. What is clear from the studies under review is the need for liaison between professionals and significant others such as parents and

relatives, facilitation of effective inter-professional, interdisciplinary and interpersonal communication concerning the complex health and healthcare needs of people with learning disabilities. LDnurses need to appreciate that in most cases they will be the healthcare professional with a complete picture of the person, as well as being at the centre of communication (Wagemans, et. al., 2015. This is essential because effective communication underpins effective promotion of health and wellbeing of people with learning disabilities. In

To engage effectively in complex interventions, LD nurses are in many cases the first point of contact and therefore need to advocate effectively for the people they support, as well as supporting their families and carers. The advocacy role of LD nurses is therefore important in the effectiveness of public health services delivery to people with learning disabilities.

Delahunty (2017) has suggested that LD nurses working as school nurses have a role in promoting the health and wellbeing of children with learning disabilities by acting as a link between schools and other services. They argued that this role is essential in enhancing the effectiveness of transition from schools into adult services. LD nurses are often in more regular contact with people they support and therefore better placed to facilitate links between services.

## Leadership

Leadership is essential for successful implementation of public health policies for people with learning disabilities. Mafuba (2013) observed a 'leadership vacuum' in learning disability practice that was likely to negatively impact on how LD nurses enacted their public health roles. There needs to be a realisation among LD nurses, employers and commissioners of services of a lack of representation of LD nurses at senior management level. The implication of this is that the public health needs of people with learning disabilities are overshadowed by other priorities. The lack of public health leadership is worrying given the difficulties and the complexities of multiprofessional, and inter-organisational public health environments in which LD nurses are expected to undertake their public health roles. The lack of leadership may mean that employers of LD nurses become unclear about the contributions LD nurses could make in meeting the public health needs of people with learning disabilities.

No studies in the current review specifically investigated the public health leadership needs in learning disabilities nursing practice. Effective delivery of public health to people with learning disabilities require visible and accessible professional and strategic nurse leaders. Clinical, professional, and strategic nurse leaders who can lead and facilitate learning in public health practice are essential. Leaders with a holistic understanding of the LD nurses' public health roles are important to effective delivery of public health to people with learning disabilities. Such leaders are needed to maintain professional standards of practice, and provide supervision and support. Also, clear, visible, progressive and accessible leadership is essential to sustainable public health services for people with learning disabilities.

Sines and McNally (2007) have argued that this is important in improving essential knowledge and skills. It is clear from the literature that appropriate and clear leadership is important in the provision of support, reflection on practice, and enabling LD nurses to be effective clinicians.

We concur with Gray (2015) who has argued for a clear strategic 'national pathway of influence'. However, it is important to point out that there are no clear national learning disabilities nursing leadership structures. The need to identify new leaders with a 'voice' at national level is therefore of paramount importance. In the absence of national structures there is need for consideration of secondments in order to develop experienced leaders. Secondment can be an effective method of developing learning disabilities public health nurse professional and strategic leaders.

## Scholarship

Given the well documented complexity, poorer health, higher rates of co-morbidity, inequalities in health, poor access to health services and higher rates of premature mortality experienced by people with learning disabilities, the limited scholarly activity in this area is concerning. The consequence of this is the dearth of studies that investigated the contribution of LD nurses to public health. There is also a lack of studies that evaluated the impact of LD nurses' public health roles on the health and healthcare outcomes of people with learning disabilities.

#### **Conclusion and recommendations**

We have undertaken a systematic review of literature, which has been conducted in a robust and transparent manner. We have identified a number of themes that we believe help make sense of the data we have extracted from the studies we have reviewed. Although there is some evidence to support the emerging themes, the literatures are limited in robustness and scope. Also, other than one sequential multiple methods study that investigated the public health roles of community learning disabilities nurses we could not locate any studies which specifically investigated the involvement of LD nurses in leadership, health promotion, high impact clinical interventions, and life course. We have therefore attempted to discuss the relevance of the findings we have highlighted from the papers reviewed to meeting the public health needs of people with learning disabilities. Perhaps not surprisingly, this review leaves a number of questions unanswered. For example of critical importance is the need for an articulated agreement as to exactly what public health means, and to whom. LD nurses, employers and commissioners of public health services need to have an agreed dialogical definition of public health.

While we are conscious of the narrative nature of our review, we conclude that important lessons can be learnt in order to further develop and clarify the contribution of LD nurses to meeting the public health needs of people with learning disabilities. The public health practice of LD nurses need to be understood in the context of the complexity and changing needs of people with learning disabilities. This review has to some extent demonstrated that ongoing assessment of needs at individual and

population levels is essential to maintaining and promoting the health and wellbeing of people with learning disabilities. The review has also identified some evidence for the need for collaborative working by LD nurses through health facilitation and health liaison. Another important learning point from this review is the need for a clear framework for LD nurses' public health roles. We have also identified some evidence which demonstrate that LD nurses can contribute to better outcomes for people with learning disabilities through supporting healthy lifestyle choices and also through addressing the wider determinants of health. We also conclude that LD nurses need to be in positions where they are involved in monitoring of the effectiveness of interventions for people with learning disabilities. We also highlight the need to address the 'leadership *vacuum*' in learning disabilities nursing practice that is likely to negatively impact on how LD nurses meet the public health needs of people with learning disabilities.

It is our conclusion that LD nurses need to engage in scholarly activity and contribute to the evidence base that demonstrate their positive contribution to meeting the public health needs of people with learning disabilities, and the positive impact to health outcomes for people with learning disabilities. In addition, given the well documented complexity, poorer health, higher rates of co-morbidity, inequalities in health, poor access to health services and higher rates of premature mortality experienced by people with learning disabilities, we recommend that urgent research is undertaken to further clarify current LD nurses public health contributions to community and population public health including wider determinants of health, positive mental health and wellbeing, health protection including the uptake of immunisations and reduction of antimicrobial resistance. Rates of pre-mature mortality are still significantly high for people with learning disabilities and it is our considered view that specific work is undertaken to highlight the positive contributions LD nurses can contribute to the reduction in some of highest areas of prevalence premature mortality.

Key: Opinion paper (grey literature) Synthesised evidence (literature review) Empirical (original) study

Table 1: Data table

## Theme 1: Public health and health promotion

Authors / Country	Critical Appraisal + JBI Level of Evidence	Aims / Purpose	Methods / Participants	Study Findings / Conclusions	Synthesised Conclusions	Category / Sub-theme
Barr, O., Gilgunn, J., Kane, T. and Moore, G. (1999) / UK	Aim(s) / Purpose – clear Source standing – Journal of Advanced Nursing. Relevance – clear JBI evidence level – 4b Decision – Include. However, the study is not explicit in role of community learning disability nurses in the actual screening itself.	Introduce health screening for people with learning disabilities in an area in Northern Ireland.	Health screening project (Screening for weight, blood pressure, urinanalysis, breast cancer, testicular cancer, eye test, hearing test). 373 people with learning disabilities.	The primary contribution of community learning disability nurses is raising the profile of the health needs of people with learning disabilities.     Maintaining people with learning disabilities in better health.	Learning disability nurses contribute to the needs assessment and health promotion.	Public health intelligence.  Health improvement.
Brown, M., MacArthur, J., McKechanie, A., Mack, S., Hayes, M. and Fletcher, J. (2012) / UK	Aim(s) / Purpose – clear Source standing – Journal of Learning Disability Research Relevance – clear JBI evidence level – 4b. Decision – Include. Although the study had 85 participants, only 6 were learning disability liaison nurses.	The aim of the study was to examine the impact and outcomes of four Learning Disability Liaison Nurse Services in south-east Scotland on the healthcare experiences of people with learning disabilities attending for general hospital care. The study sought to answer 3 questions; 1. What are the core elements and dimensions of the four different LDLN Services? 2. How do the different stakeholders view the LDLN Services and what are their criteria for evaluating the	Mixed-methods and thematic analysis 85 participants including; patients with learning disabilities (n = 5), carers (n = 16), primary care healthcare professionals (n = 39) and general hospital professionals (n = 19) and learning disability liaison nurses (n = 6).	<ol> <li>The LDLN role impacted on three key areas (clinical patient care; education and practice development strategic organisational developments).</li> <li>Information sharing relating to care needs.</li> <li>Risk management.</li> <li>Behavioural advice.</li> <li>Communication advice.</li> <li>Educational support.</li> <li>Psychological support.</li> <li>Pre-morbid baseline assessment.</li> <li>Eating and drinking guidelines.</li> <li>Provision of advice.</li> <li>Making accessible information about national cancer screening programmes.</li> </ol>	Key areas of public health practice of LDLNs are varied and include surveillance, health protection and health promotion.	Surveillance  Health promotion

Lloyd, J.L. and Coulson, N.S. (2014) / UK	Aim(s) / Purpose – clear Source standing – Journal of Learning Disabilities Relevance – clear JBI evidence level – 4.b Decision – Include.	outcomes of a care episode?  3. What elements of the LDLN Service are viewed as being particularly effective in supporting healthcare professionals, people with ID and their carers in general hospitals?  The present study explored learning disability nurses' experiences of supporting women with learning disabilities to access cervical screening in order to examine their role in promoting attendance and elucidate potential barriers and facilitators to uptake.	Semi-structured interviews and experiential thematic analysis. 10 learning disability nurses recruited from Derbyshire Healthcare NHS Foundation Trust.	The role of the learning disability nurse  1. Preparing women psychologically for screening: The value of the preparation intervention.  2. Managing the challenges of supporting women with complex needs: Balancing women's rights against the potential for distress.  3. Managing the challenges of supporting women with complex needs: The value of the learning disability nurse's expertise.	Learning disability nurses play a significant role in enhancing the effectiveness of public health interventions.	Enhancing effectiveness.
Mafuba, K. (2009) / UK	Aim(s) / Purpose – clear Source standing – Learning Disability Practice. Relevance – clear JBI evidence level – 4a. Decision – Include. Methodology for appraising, selecting studies and synthesizing evidence is unclear.	The aim of the study was to review the literature on community learning disability nurses' role in public health.	Literature review 9 studies	Learning disability nurse contribute to public health through;  1. health facilitation, 2. health promotion, and 3. health education.	LD nurses' involvement in health facilitation, health promotion and health education is important in improving access to screening services.	Policy implementation.

Mafuba, K. and Gates, B. (2015) / UK	Aim(s) / Purpose – clear Source standing – British Journal of Learning Disabilities. Relevance – clear JBI evidence level – 3e. Decision – Include The sampling method used in this study was focused on achieving representativeness rather than variability. This limits the generalisability of the findings beyond community learning disability nursing practice. In addition, although the sample size was sufficient for internal validity, a larger sample size would be required for wider external validity.	This paper reports on one stage of a 3-phase sequential multiple methods study that explored and explained the contribution of community learning disability nurses in the implementation of public health policies for people with learning disabilities.	A 9-item online questionnaire survey (UK-wide) (n = 171) (band 5: n = 19; band 6: n = 67; band 7: n = 59; band 8: n = 26). Non-proportional quota sampling. Participants – community learning disability nurses.	The study demonstrates that community learning disability nurses are involved in;  1. Health surveillance, 2. health promotion, 3. health facilitation, 4. health prevention and protection, 5. health education, and 6. healthcare delivery. Area of public health involvement response rates; 1. Healthcare delivery (band 5: 66.7%; band 6: 73.7%; band 7: 62.0%; band 8: 83.3%; Overall: 71.3%). 2. Health education (band 5: 76.2%; band 6: 91.2%; band 7: 86.0%; band 8: 72.2%; Overall: 81.4%). 3. Health prevention and protection 4. (band 5: 71.4%; band 6: 84.2%; band 7: 74.0%; band 8: 50.0%; Overall: 69.9%). 5. Facilitating access to health (band 5: 85.7%; band 6: 100.0%; band 7: 96.0%; band 8: 94.4%; Overall: 94.0%). 6. Health promotion (band 5: 95.2%; band 6: 100.0%; band 7: 88.0%; band 8: 88.9%; Overall: 93.0%). 7. Health surveillance (band 5: 57.1%; band 6: 73.7%; band 7: 60.0%; band 8: 44.4%; Overall:	LD nurses at all levels can make important contributions in meeting the public health needs of people with learning disabilities.	Policy implementation.
Mafuba, K., Gates, B. and Cozens, M. (2016) / UK	Aim(s) / Purpose – clear Source standing – Journal of Learning Disabilities Relevance – clear	The aim of this study was to explore how public health policy in the United Kingdom was reflected in community learning	Documentary analysis using Grounded Theory data analysis.		The involvement of LD nurses with public health is complex across at all levels.	Policy / strategy development.  Policy / strategy implementation.

	JBI evidence level – 4b.  Decision – Include. The study was extensive and examined job descriptions and person specifications of community learning disability nurses from across the UK. However, the findings of this study need to be understood and interpreted in the context of public health services for people with learning disabilities in the United Kingdom between 2008 and 2012 when the study was undertaken.	disability nurses' job descriptions and person's specifications. (This study was part one of a 3-phase sequential multiple methods study).	Purposive sampling(Glaser and Strauss, 1967). This study involved an exploratory documentary analysis of (n = 203) (band 5: n = 63; band 6: n = 87; band 7: n = 47; band 8: n = 6) learning disability nurses' job descriptions and person specifications.	5. Develop (9%) (7) 6. Liaise (9%) (7) 7. Plan (4%) (3) 8. Reduce inequalities (1%) (1)  Band 6 1. Implement (27%) (12) 2. Facilitate (18%) (8) 3. Reduce inequalities (15%) (7) 4. Promote (13%) (6) 5. Enable (9%) (4) 6. Advise (7%) (3) 7. Contribute (7%) (3) 8. Develop (4%) (2)  Band 7 1. Implement (34%) (17) 2. Reduce inequalities (16%) (8) 3. Promote (14%) (7) 4. Facilitate (12%) (6) 5. Enable (10%) (5) 6. Lead (8%) (4) 7. Contribute (4%) (2) 8. Liaise (2%) (1)  Band 8 1. Enable (33%) (4) 2. Lead (25%) (3) 3. Evaluate (17%) (2) 4. Develop (17%) (2) 5. Contribute (8%) (1)		Co-ordination.
Mafuba, K.	Aim(s) / Purpose –	The study sought to	This was a 3-phase	The study identified learning disability	For LD nurses to	Policy / strategy
(2013) / UK	clear <b>Source standing</b> –	answer one key guestion and 3	exploratory sequential multiple	nurses' public health roles as;  1. academic,	have a positive impact on meeting	implementation.
PhD Thesis	British Library Relevance – clear JBI evidence level – 3e. Decision – Include. This study was extensive and included 3 separate studies. The findings have been	subsidiary questions. Key question: What are the public health roles of the community learning disability nurse, and what are the moderators of how	methods study. Phase 1 was documentary, and involved collecting and analysing community learning disability nurses' job descriptions, and or	<ol> <li>academic,</li> <li>health education,</li> <li>health prevention,</li> <li>health promotion,</li> <li>health protection,</li> <li>health surveillance,</li> <li>healthcare access facilitation, healthcare delivery,</li> <li>leadership, and</li> </ol>	the public health needs of people with learning disabilities, their roles need to encompass the whole policy process.	Policy / strategy development.

Marriott, A.,	published in journal articles included in this review. Here we include the conclusions of the overall study. Detailed roles are identified in the published studies.  Aim(s) / Purpose —	they enact their public health roles? Subsidiary questions:  1. How is public health policy reflected in community learning disability nurses' job descriptions, and person specifications?  2. What is the community learning disability nurse' perception of the moderators of how they enact their public health roles?  3. What are the correlates of public health role moderators of how community learning disability nurses enact their public health roles in implementing public health policy for people with learning disabilities?  The purpose of this	person specifications ( <i>n</i> = 203). Phase 2 was descriptive, and used a Grounded Theory approach ( <i>n</i> = 17 learning disability nurse consultants). Phase 3 was explanatory, and involved an online questionnaire survey ( <i>n</i> = 171 community LD nurses).	9.	implémentation.	To promote the	Health
Turner, S., Ashby, S. and Rees, D. (2015) / UK	clear Source standing – Tizard Learning Disability Review Relevance – clear	paper is to describe the role of the screening liaison nurses for adults with learning disabilities	describes the screening liaison nurse role and presents 2 case	2.	screening programmes to put reasonable adjustments in place.	health and wellbeing of people with learning disabilities effectively, LD nurses need to work	facilitation / Health liaison.  Enhancing effectiveness.

	JBI evidence level – 4d.  Decision – Include. The project had identifiable impact. In 2011, the uptake of breast screening by eligible women in the general population was 75% (36% for women with learning disabilities). In 2013, general population (75%) and women with learning disabilities (77%).	employed by Peninsula Community Health. This paper reports on the national situation in regard to cancer screening for people with learning disabilities and explores the barriers which limit their participation in these screening programmes. It describes the screening liaison nurse role and presents case examples of the work they do.	examples of the work they do. A Primary Care Trust (PCT) employed two screening liaison nurses to improve the uptake of the cancer screening programmes by people with learning disabilities. The screening liaison nurses worked with the screening programmes and GPs to identify people with learning disabilities eligible for screening and ensure they have the appropriate information and support to participate.	3.	Training for mainstream screening staff regarding the needs of people with learning disabilities. Support women to manage cervical screening.	collaboratively to improve access to mainstream services.	
Marshall, D., McConkey, R. and Moore, G. (2003) / UK	Aim(s) / Purpose – clear Source standing – Journal of Advanced Nursing Relevance – clear JBI evidence level – 4c. Decision – Include. The findings of the study do not identify the public health roles of learning disability	The aim of the study was to follow-up people identified as overweight and obese following special health screening clinics and to determine the actions taken. The study also evaluated the impact of health promotion classes on	A clinic led by two learning disability nurses was held for all people aged 10 years and over (n = 464).	<ol> <li>2.</li> <li>3.</li> </ol>	The health screening identified; a. overweight or obesity. b. higher levels of blood pressure. The health promotion classes led to a significant reduction in weight and body mass index scores. Health screening per se has limited impact on reducing obesity levels in people with learning disabilities.	To be effective LD nurses need to combine health screening with health promotion.	Surveillance.  Health promotion.

	nurses but demonstrate impact of some of their roles.	participants' weight loss.		Need to create more active lifestyles.		
Taggart, L. Truesdale- Kennedy, M and McIlfatrick, S. (2011) / UK	Clear Source standing – Journal of Learning	The aim of this paper was to examine how community nurses and residential staff support women with learning disabilities to access breast screening services.	6 focus groups and thematic content analysis. Participants were community learning disability nurses ( <i>n</i> = 29) and residential care staff.	The study concluded that there is a need for developing a health promotion programme for women with learning disabilities focusing on;  1. breast awareness.  2. information on screening healthier lifestyles.  3. supporting the women to selfexamine and report any abnormalities.  4. development of health education material.  5. development of health promotional activities.  6. training for all.	LD nurses need to use comprehensive public health frameworks in order to meet the public health and healthcare needs of people with learning disabilities.	Surveillance.  Health promotion.  Health education.

Theme 2: Lifespan

Authors / Country	Critical Appraisal + JBI Level of Evidence	Aims / Purpose	Methods / Participants	Study Findings / Conclusions (Level 1)	Synthesised Findings / Conclusions (Level 2)	Category / Sub-theme (Level 3)
Arrey, S.K.	Aim(s) / Purpose –	This study sought to	Hermeneutic	The study concluded that learning	To deliver effective	Enhancing
(2014) / UK	clear	gain an in-depth	phenomenology	disability nurses play a key role in	health promotion, LD	effectiveness.
PhD Thesis	Source standing – British Library Relevance – clear JBI evidence level – 4b. Decision – Include. Although the main focus of this thesis	phenomenological understanding of how learning disability nurses and palliative care professionals identify and respond to the distress of people with	incorporating a constructivist perspective was used. Purposive sampling. Semi structured interviews. Thematic analysis.	responding to the needs of people with communication difficulties and learning disabilities in palliative care settings by;  1. Building relationships with communication difficulties and learning disabilities in palliative care settings.	nurses need to support other health and healthcare professionals who work directly with people with learning disabilities.	
	was on identifying and responding to distress of people with communication	communication difficulties and learning disabilities in	13 participants (learning disability nurses – ( $n = 8$ ) + 5	Providing insight into factors that determine how people with communication difficulties and learning disabilities in palliative		

	difficulties and learning disabilities in palliative care settings, some of their author's observations and conclusions are relevant to public health.	palliative care settings. The objectives were: To critically explore the lived experiences of learning disability nurses and palliative care professionals who care for distressed people with communication difficulties and learning disabilities in palliative care settings. To critically explore the perceptions of learning disability nurses and palliative care professionals about factors which determine how people with communication difficulties and learning disabilities express distress in palliative care settings.	palliative care professionals).	care settings communicate distress.  3. Sharing professional knowledge.  4. Training and collaborative working.	
Cleary, J. and Doody, O. (2017) / Ireland	Aim(s) / Purpose – clear Source standing – Journal of Clinical Nursing. Relevance – clear JBI evidence level – 4b. Decision – Include. Although the main focus of this study was on learning disability	To explore nurses' experiences of caring for older people with learning disability and dementia.	Descriptive phenomenology (Husserl). Semi-structured interviews. Colaizzi's framework for data analysis. Participants (n = 11) learning disability nurses (n	The study highlighted;  1. the importance of knowing the person,  2. the need for greater knowledge of dementia, and  3. the importance of individuals' health needs including end-of-life care.  Effective health promotion require comprehensive needs assessment at the individual population levels.	ents and

	nurses' experience of caring for people with		= 9) and general nurses (n = 2).			
	learning disability and dementia, some of the activities are related to					
Delahunty, L. (2017) / UK	public health.  Aim(s) / Purpose – clear  Source standing – Nursing Children and Young People.  Relevance – clear  JBI evidence level – 5c.  Decision – Include.  The author is a psychology research Assistant at the University of Edinburgh. The author argues that nurses would benefit from a greater ability to identify learning disabilities (including health visitors, school nurses, practice nurses, and nurses working in paediatric clinics). Although this paper does not include learning disability nurses, given anecdotal evidence of learning disability nurses working as school nurses, we decided to include it in the	This article describes learning disability, the kind of support children with learning disabilities need, and how nursing staff might use the Child and Adolescent Learning Disability Screening Questionnaire (CALDS-Q) to help identify children who should be formally assessed for learning disability.	Opinion paper.	<ol> <li>School nurses can identify children with potential learning disability.</li> <li>School nurses can act as a link between schools and other services.</li> <li>Learning disability nurses can facilitate transition from nursery into school or transition into adult services.</li> <li>Nurses who have regular contact with children and their families can monitor children's development.</li> <li>Nurses can identify children who should be prioritised for further learning disability assessment.</li> </ol>	LD nurses have a role in promoting the health and wellbeing of children with learning disabilities.	Surveillance.  Co-ordination.
	review.					

Doody, C., Markey, K. and Doody, O. (2013) / Ireland	Aim(s) / Purpose – clear Source standing – Journal of Clinical Nursing Relevance – clear JBI evidence level – 4b. Decision – Include. Although this paper focuses on the learning disability nurses' experience of caring for people with learning disability and dementia, there are themes of relevance to public health that emerge.	To explore the experiences of registered learning disability nurses caring for the older person with learning disability.	Heideggerigan phenomenology. Approach. Semistructured interviews. Thematic analysis (Burnard's framework). Purposive sample of learning disability nurses ( <i>n</i> = 7).	The study identified some themes of relevance to public health;  1. Knowing the person.  2. Proactive planning.  3. Greater emphasis on preparing other nursing specialisms to care holistically for people with learning disabilities.	Because of their knowledge of people with learning disabilities, LD nurses have a key role in facilitating access to services.	Health facilitation / Health liaison.
Marshall, D. and Foster, I. (2002) / UK	Aim(s) / Purpose – clear Source standing – British Journal of Nursing Relevance – clear JBI evidence level – 4b. Decision – Include. The methodology of this study is not clearly described. In particular it is not clear how many learning disability nurses were involved.	This study sought to explore what the most appropriate healthcare role was for delivering health care in a special school catering for children with a broad range of severe learning disabilities.	Pilot study focus group interviews. Four in-depth focus group interviews (8-10 interviewees per group). Stratified random sample (teachers, classroom assistants, parents, occupational therapists, physiotherapists, speech and language therapists, social workers, and community learning disability nurses).	<ol> <li>The role of the nurse was found to include;</li> <li>the need for liaison between professionals and significant others such as parents and relatives.</li> <li>facilitation of effective interprofessional, interdisciplinary and interpersonal communication concerning the healthcare needs of the children.</li> <li>providing hygiene advice.</li> <li>providing dietary advice.</li> <li>continence promotion.</li> </ol>	Effective public health interventions by LD nurses need to engage all stakeholders at individual and population levels.	Enhancing effectiveness.  Health promotion.

Nelson, S. and Carey, E. (2016) / Ireland	Aim(s) / Purpose – clear Source standing – Learning Disability Practice Relevance – clear JBI evidence level – 5c. Decision – The authors include a learning disability nursing student and a learning disability nurse tutor. We included this paper because it is well researched and supported by extensive references of significance.	This article highlights the importance of the role of RNIDs in assessing mobility, as part of the holistic assessment of older adults with learning disability, and describes a variety of resources practitioners can use.	Opinion paper.	The paper identified the relevant roles of the learning disability nurse as;  1. Promotion of the health and wellbeing of people with learning disabilities.  2. Assessment of mobility decline in older people with learning disabilities.  3. Supporting maintenance of optimal health.	Ongoing assessment of needs is essential to maintaining and promoting the health and wellbeing of people with learning disabilities.	Surveillance Health promotion.
Ng, J. S. W. (2011) / UK PhD Thesis	Aim(s) / Purpose – clear Source standing – British Library Relevance – clear JBI evidence level – 4b. Decision – Include. This study predominantly explored how learning disability nurses working in palliative care settings for people with learning disabilities perceived their own knowledge and how it influenced how they provided support.	The aim of the study was to explore the perceived knowledge and skills of learning disability nurses in the context of how they assess, recognise and discover patients' illnesses and how they provide end of life care needs to terminally ill people with profound learning disabilities in residential care homes.	Grounded theory. Thematic analysis. In-depth interviews. 36 learning disability nurses participated.	Relevant emerging themes are; 1. Knowing the patient well. 2. Referral to GP. 3. Establishing a baseline of the physical. 4. The longitudinal presence of the nurse.	Ongoing assessment of needs and interprofessional working are essential to maintaining and promoting the health and wellbeing of people with learning disabilities.	Surveillance.

K. (2017) / UK	Aim(s) / Purpose – clear Source standing – Learning Disability Practice Relevance – clear JBI evidence level – 5b. Decision – Include. We included this paper because it was written by an eminent professor of learning disability and learning disability nursing students. The paper identified a wide range of new and emerging public health roles of learning disability nurses.  Aim(s) / Purpose –	This article describes an activity undertaken at a conference in Cardiff in 2016.	This was not an opinion paper but the research was not methodological. Delegates were asked to identify the roles of learning disability nurses at different lifespan stages (200+ delegates (learning disability nurses, students, people with learning disabilities and their families, nurses from other fields, and other professionals). Thematic analysis was used.	Responses identified new and emerging roles across a range of settings;  1. Family support and parenting 2. Positive behavioural support 3. Safeguarding of children and adults.  4. Health liaison roles and reasonable adjustments.  5. Health promotion and education - medication monitoring, promotion of health checks and screening, personal and sexual relationships, nutrition and dysphagia management.  6. Transition from child to adult services and other life stages.  7. Supporting the communication of people with learning disabilities.  8. Providing advice about available services.  9. Awareness raising and education.  10. Involvement in pre-natal screening. Providing support in relation to diagnosis.  11. Developmental assessment  12. Working in schools, and providing advice and support to schools.  13. Mental health promotion and support  14. Promotion of resilience.  15. Assessment of dementia.  16. Promoting employment.  17. Supporting individuals to remain in their home.  In the study nurses were identified as;	In order to effectively promote the health and wellbeing of people with learning disabilities, LD nurses need to engage in a wide range of roles and they need to assimilate emergent roles.	Surveillance.  Enhancing effectiveness.  Health promotion.  Health education.
A.M.A., van Schrojenstein Lantman-de	clear Source standing –	was to clarify the process of making end-of-life decisions	Semi-structured interviews.	Being at the centre of communication.	communication is essential to effective promotion of health	effectiveness.

Valk, H.M.J., Proot, I.M., et al (2015) / Netherlands  Journal of Policy and Practice in Learning Disabilities Relevance – clear JBI evidence level – 4b. Decision – Include. Although this study was undertaken in the Netherlands and focussed on learning disability nurses' perceptions of how people with learning disabilities make end of life decisions, there are themes of relevance to the current review.	for people with learning disabilities from the nurse's perspective.	Participants (learning disability nurses – <i>n</i> = 10; social workers – <i>n</i> = 1).	2.	Having a complete picture of the patient.	and wellbeing of people with learning disabilities.	
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### Theme 3: Complex interventions

Authors / Country	Critical Appraisal + JBI Level of Evidence	Aims / Purpose	Methods / Participants	Study Findings / Conclusions	Synthesised Conclusion	Category / Theme
Adams, D. and Shah, C. (2016) / UK	Aim(s) / Purpose – clear Source standing – Learning Disability Practice. Relevance – clear JBI evidence level – 5b. Decision – Include. The two authors are experienced senior pharmacists. The article was subjected to double-blind review and was checked for plagiarism.	The article examines the reasons why medication is prescribed, best practice, the side effects and the issues that are involved with the withdrawal of psychotropic medicines, in particular antipsychotics, in people with learning disabilities.	Opinion paper.	<ol> <li>The learning disability nursing roles identified include;</li> <li>Reviewing and assisting with the withdrawal of antipsychotic medication.</li> <li>Reducing prescribing of antipsychotic medicines for people with learning disabilities.</li> <li>Maintaining and enhancing the general physical health and well-being of people with learning disabilities.</li> <li>Advising people with learning disabilities and their carers about constipation.</li> </ol>	Monitoring the effectiveness of treatments is essential to the promotion of the health and wellbeing of people with learning disabilities.	Assessing effectiveness.  Health education.

			<ul><li>5.</li><li>6.</li><li>7.</li></ul>	Monitoring how well a medication is working. Improving communication between healthcare professionals in primary and secondary care. Improving health outcomes for people with learning disabilities.		
Auberry, K. and Cullen, D. (2016) / USA  Source standin Journal of Learn Disabilities Relevance – clay JBI evidence lear 4b.  Decision – Inclu Although their focus of this structure was evaluating implementation pilot study to test confidence leven nurses prior to implementing the evidence-based algorithm, the involvement of I disability nurses screening for epwas relevant to current review.	sought to determine whether nurses working in the field of learning disability experience increased confidence when they implemented the American Association of Neuroscience Nurses (AANN) Seizure Algorithm during telephone triage.	This was a 3-month long implementation pilot study of an evidence-based seizure algorithm for nurses working in the field of learning disabilities. Participant nurses provided nursing care to individuals with learning disabilities and epilepsy living in community-based settings via telephone triage. The aim of the implementation pilot study was to test the confidence level of nurses prior to implementing the evidence-based algorithm and 3 months post implementation of the seizure algorithm.	2.	Using the AANN Seizure Algorithm increased self- confidence for many of the nurses in guiding care decisions during telephone triage. The treatment effect was statistically significant 3.169 (p < 0.01). Learning disability nurses provide seizure guidance to this people with learning disability living in the community.	LD nurses need to have knowledge and skills to identify the public health needs of people with learning disabilities.	Health education.

Barr, O. (2005) / UK	Aim(s) / Purpose – clear Source standing – Journal of Clinical Nursing Relevance – clear JBI evidence level – 4b. Decision – Include. The study did not specifically seek to identify community learning disability nurse's public health roles. Some of these roles were implicit in the findings and	To provide an overview of the changes in the caseload and working practices of community nurses for people with learning disabilities over an 11-year period in Northern Ireland.	Learning disability nurses from Indiana Developmental Disabilities Nurses Association volunteered to participate ( <i>n</i> = 15). Postal survey questionnaire. Community nurses in Northern Ireland ( <i>n</i> = 40). Response rate (81.63%).	The findings of this project show;  1. Increased involvement in health monitoring casework.  2. Increase in working with people with learning disabilities who develop mental health problems.  3. Increase in working with older people with learning disabilities and older carers.  4. Increase in learning disability nurses working with people with epilepsy.  5. Increase in learning disability nurses working with children.	Ongoing assessment of needs and interprofessional working are essential to maintaining and promoting the health and wellbeing of people with learning disabilities.	Surveillance.
Doody, O., Slevin, E. and Taggart, L. (2017) / Ireland	conclusions.  Aim(s) / Purpose — clear Source standing — Journal of Clinical Nursing Relevance — clear JBI evidence level — 4b. Decision — Include. The study is unclear as to the type of services the nurses worked in. The study specifically investigated the roles undertaken by the participants, and the	To explore the contribution of clinical nurse specialists in learning disability nursing in Ireland.	Exploratory qualitative approach using focus groups. Nonprobability purposeful sample. Focus group semistructured interviews (5 Focus groups. Participants – learning disability clinical nurse specialists ( <i>n</i> = 31). Burnard's (2011) data analysis framework.	The roles of nurses were identified as;  1. Assessment. 2. Evaluation. 3. Monitoring progress. 4. Advocating for client. 5. First point of contact of needs. 6. Support for family. 7. Design booklets or packages. 8. Informal and formal advice. 9. Research. 10. Education formal / informal.	To engage effectively in complex interventions, LD require assessment, evaluation and scholarship skills.	Surveillance.  Assessing effectiveness.  Enhancing effectiveness.  Scholarship.

	roles included public health roles.					
Jenkins, R. (2012) / UK	Aim(s) / Purpose – clear Source standing – British Journal of Nursing Relevance – clear JBI evidence level – 4d. Decision – Include. Although not explicit, the case studies imply that learning disability nurses working with older adults with learning disabilities play important public health roles.	This study sought to explore the implications for registered nurses in meeting the health needs of older people with learning disabilities.	Case study developed around older people with learning disabilities (n = 6; age range – 45 – 75+).	The study highlighted;  1. Undetected health problems - for example, difficulties diagnosing mental health problems, constipation, hearing and visual problems, and strokes.  2. Higher mental health needs.	To engage effectively in complex interventions, LD require a wide range of knowledge and assessment skills that are essential in identifying the complex public health needs of people with learning disabilities.	Surveillance.
Llewellyn, P. and Northway, R. (2007) / UK	Aim(s) / Purpose – clear Source standing – Journal of Research in Nursing Relevance – clear JBI evidence level – 4b. Decision – Include. The study investigated the advocacy role of learning disability nurses in all areas of	The aim of the study was to investigate the advocacy role of learning disability nurses in Wales.	Grounded theory. Focus groups of Registered learning disability nurses (n = 18) working in small residential settings.	Need for learning disability nurses to advocate for service users in their areas of practice.	The advocacy role of the LD nurse is important to the delivery of public health services to people with learning disabilities.	Enhancing effectiveness.

MacArthur, J., Brown, M., McKechanie, A., Mack, S., Hayes, M. and Fletcher, J. (2015) / UK	their practice, arguably including public health roles.  Aim(s) / Purpose – clear Source standing – Journal of Advanced Nursing Relevance – clear JBI evidence level – 4b. Decision – Include. Although this study focussed on roles in facilitating reasonable adjustments, some of the findings and conclusions are relevant to public health.	To examine the role of learning disability liaison nurses in facilitating reasonable and achievable adjustments to support access to general hospital services for people with learning disabilities.	Mixed methods. Quantitative data of all liaison nursing referrals over 18 months and qualitative data collected from stakeholders with experience of using the liaison services within the previous 3–6 months. Six liaison nurses collected quantitative data of 323 referrals. Interviews and focus groups were held with 85 participants (adults with learning disabilities ( <i>n</i> = 5), carers ( <i>n</i> = 16), primary care staff ( <i>n</i> = 39), general hospital ( <i>n</i> = 19) and learning disability liaison nurses ( <i>n</i> = 6).	Roles of learning disability liaison nurses;  1. Facilitating reasonable and achievable adjustments.  2. Identifying patient need.  3. Information sharing relating to care needs.  4. Behavioural advice.  5. Communication advice.  6. Client psychological support.  7. Carer educational support.  8. Pre-morbid baseline assessment.  9. Eating and drinking guidelines.  10. Diagnostic advice.	LD liaison nurses have an important public health role through needs assessment, facilitating access to appropriate services and providing advice.	Surveillance. Enhancing effectiveness. Health education.
Marsham, M. (2012) / UK	Aim(s) / Purpose – clear Source standing – British Journal of Learning Disabilities Relevance – clear JBI evidence level –	The aim of the study was to explore the therapeutic role from the perspective of community learning disability nurses.	Literature review. Descriptive phenomenology. Semi-structured interviews based on Critical Incident Technique.	Community learning disability nurses' perceptions of their therapeutic role include;  1. Long-term conditions management.  2. Relapse prevention and recovery.	Community LD nurses need to engage in health improvement to improve the health and wellbeing of individuals and communities through enabling by	Surveillance.  Health promotion.  Health improvement.

	4b.  Decision – Include. The findings of this study are presented using a very abstract approach. Some of the findings can be very clearly linked to public health.		Systematic content analysis. Practicing community learning disability nurses with more than 2 years' experience of managing an adult caseload ( <i>n</i> = 7).	<ol> <li>Facilitating self-management.</li> <li>Escalating treatment pathways.</li> <li>Developing coping skills.</li> <li>Reduce challenging behaviour.</li> <li>Increased healthcare access.</li> <li>Assessing the person's understanding of their needs.</li> <li>Maximising support networks involved liaison work.</li> </ol>	supporting people to develop self-management skills.	
McKeon, M. (2009) / Ireland	Aim(s) / Purpose – clear Source standing – Journal of Learning Disabilities Relevance – clear JBI evidence level – 4b. Decision – Include This study captures a baseline picture of the nursing skills used in learning disability nursing at a specific point in time. It illustrates that nursing in learning disabilities requires a wide range of clinical skills to be taught and adopted in nurse training where basic core nursing skills underpin the care of people with learning disabilities.	The aim of the study was to provide a baseline of clinical nursing skills used in learning disability nursing. The objectives were to determine the types and levels of clinical nursing skills used in learning disability nursing.	Questionnaire survey (questionnaire used a nursing skills list from The Royal Marsden Hospital Manual of Clinical Nursing Procedures (Mallett and Dougherty, 2000)). 26 questionnaires were completed, 18 from a residential setting and 8 from a community living setting.	The study identified nursing roles as;  1. Violence prevention.  2. Assessment.	LD liaison nurses have an important public health role in relation to people with challenging needs through needs assessment and development of preventative interventions.	Surveillance.  Health improvement.
Morton- Nance, S. (2015) / UK	Aim(s) / Purpose – clear Source standing – Relevance – clear	This article aims to explore the evolving role of the learning disability nurse and	Opinion paper.	The paper highlights the important roles of LD as;  1. Pre-admission screening and clinical assessment.	The public health roles of LD nurses need to extent to acute care settings through	Surveillance. Enhancing effectiveness.

	JBI evidence level – 5c.  Decision – Include. The author is a hospital learning disability liaison nurse specialist. The paper is well researched and has been subjected to double-blind review.	their unique contribution, specifically within the acute setting, and examines the nature of specialist nursing in practice.		<ol> <li>3.</li> <li>4.</li> <li>6.</li> <li>7.</li> </ol>	disabilities, family members and carers. Raises awareness of learning disabilities and autism.	advocacy, facilitation of reasonable adjustments, health facilitation, health liaison and raising awareness.	Health education.
Sheerin, F.K. (2012) / Ireland	Aim(s) / Purpose – Unclear Source standing – British Journal of Learning Disabilities Relevance – clear JBI evidence level – 5c. Decision – Include. The author is an experienced learning disability nurse based in the School of Nursing and Midwifery at Trinity College, Dublin. The aims of the paper are not clearly stated	Aim of the paper is not clearly stated.	Opinion paper / review of policy development and research evidence.		e paper broadly identified public alth-oriented roles in relation to; Assessment of need. Health surveillance and health promotion. Enablement and empowerment. Addressing health inequalities – nursing.	LD nurses have an important public health role through needs assessment and addressing health inequalities through empowerment and enablement.	Surveillance.  Health improvement.

Slevin, E. and Sines, D. (2005) / UK	and consequently it discusses a number of related issues. The article has been subjected to double blind peer review.  Aim(s) / Purpose – clear Source standing – Journal of Nursing Studies Relevance – clear JBI evidence level – 4b. Decision – Include. The study investigated roles of learning disability nurses when managing challenging behaviour. Some of the roles identifies have a public health focus.	This study aimed to explicate the role of learning disability nurses in their day-to-day work with people who challenge.	Grounded theory. Theoretical sampling (n = 22 learning disability nurses). In-depth face-to-face interviews.	Relevant roles were; 1. Promoting amelioration of detrimental effects of challenging behaviour. 2. Initial assessment. 3. Prevention. 4. Education - staff in residential homes, or in schools. 5. Monitoring and evaluation.	Needs assessment underlie the public health roles of LD nurses when working with people with challenging needs.	Surveillance.  Health improvement.  Enhancing effectiveness.
Taua, C., Hepworth, J. and Neville, C. (2012) / Australia	Aim(s) / Purpose – Clear. Source standing – International Journal of Mental Health Nursing Relevance – clear JBI evidence level – 4a. Decision – Include. The methodology used to undertake this literature review is unclear. However, some of the categories of the roles of nurses that were identified have a public health focus.	The aim of the literature review was to synthesize researches that investigated the role of the nurse caring for people with a dual disability of learning disability and mental illness.	Literature review. 2000 and 2010 resulted in a total of 21 articles that met the inclusion criteria	Seven key categories of the role of the nurse were identified including;  1. Assessment.  2. Advocacy/health promotion (including working with family).  3. Communication.  4. Safety/risk management.	The public health roles of the LD nurses when working with people with dual diagnosis include needs assessment and enablement.	Surveillance. Enhancing effectiveness.

Theme 4: Leadership

Authors / Country	Critical Appraisal + JBI Level of Evidence	Aims / Purpose	Methods / Participants	Study findings / conclusions	Synthesised conclusions	Category / Theme (Level 3)
Cheseldine, S., Brown, M. and Wilkie, F. (2010) / UK	Aim(s) / Purpose –  Source standing – Nurse Education Today Relevance – 4d. JBI evidence level –  Decision - Include. The study methodology lacked theoretical rigour and the focus was not specific to public health. The results of the study demonstrated that secondment is effective.	This paper aims to discuss the use of Goal Attainment Scaling (GAS) within secondments, as a means of identifying learning needs and developing practice in the area of Child and Adolescent Mental Health Service (CAMHS) for children and young people with learning disabilities.	Secondments were provided to a Child and Adolescent Mental Health Service (CAMHS) for children and young people with learning disabilities for 2 days a week for six months. This was taken up by community learning disability nurses ( <i>n</i> = 5) over a period of 3 years. The goals they set in their secondments were evaluated using Goal Attainment Scaling (GAS).	The study concluded that secondment can be an effective method of facilitating staff development.	Secondment can be an effective method of developing LD public health nurse professional and strategic leaders.	Strategic leadership.
Galvin, G. and Timmins, F. (2010) / Ireland	Aim(s) / Purpose – clear Source standing – Journal of Nursing Management Relevance – clear JBI evidence level – 4d. Decision – Include This is a small-scale study (n = 8) and the findings represent the viewpoints of a select number of RNIDs. The findings are specific to this	The study aimed to explore registered learning disabilities nurses experienced managerial support.	Heideggerian constructivist phenomenology. Unstructured interviews. Colazzi's (1978) data analysis. Purposive sampling ( <i>n</i> = 8 learning disability nurses).	<ol> <li>The study highlighted the importance of;</li> <li>The professional role of the clinical nurse manager.</li> <li>Leadership role of the clinical nurse manager.</li> <li>Personal supports.</li> <li>Positive effects of clinical nurse manager support.</li> <li>Obtaining holistic viewpoint of the nurses' role.</li> <li>Upholding professional standards and practices.</li> <li>Expertise in practice.</li> </ol>	Effective delivery of public health to people with LD require visible and accessible professional and strategic nurse leaders.	Professional leadership.  Strategic leadership.  Visible and accessible leadership.

	group of RNIDs and to this ID service and as such cannot be generalized to any other group of nurses or ID service.			<ul><li>8. Leads and facilitates learning in practice.</li><li>9. Availability of leaders.</li></ul>		
Gray, J. (2015) / UK	Aim(s) / Purpose – clear Source standing – Learning Disability Practice. Relevance – clear JBI evidence level – 5c. Decision – Include. The author is a consultant nurse in learning disabilities in Scotland. Their insight and experience make their contribution relevant and appropriate.	The article describes the Scottish learning disability senior nurse group's position paper on leadership. Its main aim is to ensure that the contribution of learning disability nursing is recognised across the NHS and that it continues to be led effectively, including through succession planning as senior staff retire.	Opinion paper.	The paper identifies key elements to successful leadership in learning disability nursing practice.  1. Making leadership visible.  2. Ensuring access to leaders.  3. National pathway of influence.  4. Identifying new leaders.  5. Establish governance structures that allow them to report, at board level and nationally, their progress in delivering.	Clear, visible, progressive and accessible leadership is essential to sustainable public health services for people with learning disabilities.	Clear, visible and accessible leadership.  Strategic leadership.
Sines, D. and McNally, S. (2007) / UK	Aim(s) / Purpose – clear Source standing – Journal of Learning Disabilities Relevance – clear JBI evidence level – 4b. Decision – Include. The use of a purposeful sample carries with it the	This study explored perceptions of clinical supervision among community-based residential learning disability nurses in south-east England ( <i>n</i> = 35).	A descriptive, exploratory study using a questionnaire.	<ol> <li>They study identified;</li> <li>A need for greater clarity in the roles of supervisor and supervisee</li> <li>A clearer separation of managerial and developmental imperatives.</li> <li>A need for a range of options for type of supervision and choice of supervisor.</li> </ol>	Clear, visible, progressive and accessible professional and managerial leadership is essential to sustainable public health services for people with learning disabilities.	Clear, visible and accessible leadership.

potential for bias in	4. Supervision was found
that	to be important for staff
those who come	working in isolated
forward may be	community-based
motivated by a	services.
hidden agenda or	5. Clinical supervision had
	positive impact on
represent	
people with a	personal needs and
particular view. In	professional practice by;
addition it is	a. providing advice,
significant to note	b. improving
that	knowledge,
the study sample	c. improving skills,
was restricted to	d. providing general
one professional	support,
group, located in	e. helping to reflect on
one	practice,
regional area in	f. enabling supervisee
England.	to be more person
	centred,
	g. assisting to think
	independently,
	h. enabling
	respondents to be
	more effective
	decision makers,
	i. helping to manage
	stress,
	j. improving self-
	confidence, and
	k. helping to develop
	career.

## Studies excluded after appraisal

Article	Comments
Bollard, M. (2002) 'Health promotion and learning disability', <i>Nursing standard (Royal College of Nursing (Great Britain):</i> 1987), 16(27), pp. 47-55. doi: 10.7748/ns.16.27.47.s57.	The article provides an overview of health promotion, its origins and relevance to nursing. It highlights the importance of a health promotion model for people with learning disabilities and the key role that communication plays in applying the model. The article is directed at nurses working in the acute hospital setting who will at some stage nurse people with learning disabilities, but who would not ordinarily encounter such people in their everyday practice. The article does not identify or discuss public health roles of learning disability nurses.
Castles, A., Bailey, C., Gates, B. and Sooben, R. (2014) 'Experiences of the implementation of a learning disability nursing liaison service within an acute hospital setting: a service evaluation', <i>British Journal of Learning Disabilities</i> , 42(4), pp. 272-281. doi: 10.1111/bld.12070.	The paper reports on a service evaluation undertaken on a learning disability liaison nursing service developed within a large acute hospital in Portsmouth. The purpose of the evaluation was to establish whether such a service proved beneficial to patients with learning disabilities and, if so, to identify ways of improving the service. In addition, the evaluation sought to establish whether service users of the service understood the liaison role and how it may be used to enhance future hospital experiences. Also, the evaluation sought to establish whether the liaison nursing role had increased confidence of hospital staff in meeting the needs of people with learning disabilities, and whether the service had helped to meet carer's needs. The article does not provide evidence that help to answer the question in the current review.
Crotty, G. and Doody, O. (2015) 'Therapeutic relationships in learning disability nursing practice', <i>Learning Disability Practice</i> , 18(7), pp. 25-29. doi: 10.7748/ldp.18.7.25.e1660.	The article reports on a study that examined the therapeutic relationship within learning disability nursing. It highlights the role of the nurse and the meaning of the therapeutic relationship by identifying its four building blocks of engagement, empathy, communication and trust. The article does not have relevance to learning disability nursing public health roles.
Dalena, S., Ball, A., Taylor, G., Turner, D. and Watts, J. (2015) 'Learning disability community nursing team', <i>British Journal of Nursing</i> , 24(20), pp. 1028-1029. doi: 10.12968/bjon.2015.24.20.1028.	The paper describes the Sutton Clinical Health team commissioned by the Sutton Clinical Commissioning Group (CCG) which is located within the London Borough of Sutton local authority since 2009. The article does not identify public health roles.

Gale, J. (2002) Building practice through managing change: a grounded theory study of learning disability nurses. (BL: DXN062782) ProQuest Dissertations Publishing. Available at: https://search.proquest.com/docview/301 605690. PhD Thesis.	The thesis investigates issues arising from the emergent theory through which learning disability nursing practice could be strengthened and developed. The study discusses the context in which learning disability nurses work generally and does not discuss their roles.
Genders, N. (2016) Making a difference? Understanding the working lives of learning disability nurses: 30 years of learning disability nursing in England. PhD Thesis, De Montfort University, UK.	The study explored the lived experience of the careers of learning disability nurses in England. The study does not identify what could be considered to be learning disability nursing public health roles.
Jenkins, R. (2009) 'Nurses' views about services for older people with learning disabilities', <i>Nursing older people</i> , 21(3), pp. 23.	The study explored nurses' views of the strengths and weaknesses of patterns of service provision for older people with learning disabilities in relation to three service models and parent / carer needs. The article does not identify what could be considered to be learning disability nursing public health roles.
Gray, J. and Watson, V. (2017) 'Evaluation of a learning disability liaison nurse service', <i>Learning Disability Practice</i> (2014+), 20(5), pp. 35. doi: 10.7748/ldp.2017.e1861.	The article reports on a service evaluation contributes to the evidence base for liaison nursing roles. It provides a longer-term view of patterns of referral and the characteristics of people with learning disabilities who have been supported by the liaison nurse. The evaluation does not identify what could be considered to be learning disability nursing public health roles.
Jenkins, R. (2012) 'The role of nurses in meeting the health care needs of older people with learning disabilities', <i>Journal of Learning Disabilities</i> , 16(2), pp. 85-95. doi: 10.1177/1744629512442032.	The paper summarises the aims and objectives of studies that are included in the review. The review does not provide any new synthesised evidence. It focuses on highlighting the lack of research in learning disability nursing roles for older people. The paper does not identify what could be considered to be learning disability nursing public health roles.
Jukes, M. (2002) 'Health facilitation in learning disability: a new specialist role', <i>British Journal of Nursing</i> , 11(10), pp. 694-698. doi: 10.12968/bjon.2002.11.10.694.	The article attempts to examine the important role of the health facilitator in learning disability and recommends that the specialist community learning disability nurse already has the appropriate skills and knowledge to carry out competently the role across the acute, primary and secondary care sectors. The paper does not identify what could be considered to be learning disability nursing public health roles.

Lewis, P., Gaffney, R.J. and Wilson, N.J. (2017) 'A narrative review of acute care nurses' experiences nursing patients with learning disability: underprepared, communication barriers and ambiguity about the role of caregivers', <i>Journal of Clinical Nursing</i> , 26(11-12), pp. 1473-1484. doi: 10.1111/jocn.13512.	The narrative review describes how nurses experience caring for people with learning disability in an acute care setting. The literature review does not identify what could be considered to be learning disability nursing public health roles.
Llewellyn, P.J. (2005) An investigation into the advocacy role of the learning disability nurse, University of Glamorgan, PhD Thesis.	The objectives of this thesis were to find out whether nurses advocated for their clients with learning disabilities. The study also explored any problems which nurses had with the advocacy role and considered their advocacy education and educational requirements in learning disability nursing practice. The thesis does not identify what could be considered to be learning disability nursing public health roles.
Lovell, A. (2017) 'Learning Disability Nursing in Secure Settings: working with complexity', <i>Journal of Psychiatric and Mental Health Nursing</i> , 24(1), pp. 1-3. doi: 10.1111/jpm.12364.	This study identified and discussed the personal attributes required by learning disability nurses to work effectively with people with an offending background in secure and community settings. The study does not identify what could be considered to be learning disability nursing public health roles.
Marsden, D. (2012) 'The role of technology in learning disability nursing: Daniel Marsden and colleagues report on how a group of students has used social networking media to form deeper bonds with clients and interact with members of their team', <i>Learning Disability Practice</i> , 15(3), pp. 28.	This article outlines possible professional development and consultation opportunities that could be available through technology, and suggests that cost savings can be made with little effect on the quality of outcomes. The opinion paper does not identify what could be considered to be learning disability nursing public health roles.
Marsh, L. and Sweeney, J. (2008) 'Nurses' knowledge of constipation in people with learning disabilities', <i>British Journal of Nursing</i> , 17(Sup2), pp. S16. doi: 10.12968/bjon.2008.17.Sup2.28718.	The article discusses a study that sought to examine registered nurses' knowledge of constipation using the 'Bowel Knowledge Survey' adapted from Richmond and Devlin (2003). The paper does not identify what could be considered to be learning disability nursing public health roles.
Martin, A., Connor-Fenelon, M.O. and Lyons, R. (2012) 'Non-verbal communication between Registered Nurses Learning Disability and people with an learning disability', <i>Journal of Learning Disabilities</i> , 16(2), pp. 97-108. doi: 10.1177/1744629512442033.	The article presents the findings of a qualitative study which explored the experiences of registered learning disability nurses of communicating with people with a learning disability who communicate non-verbally. The study does not identify what could be considered to be learning disability nursing public health roles.
Martin, G., Axon, V. and Baillie, S. (2004) 'A joint practice nurse/community learning	The authors report on a pilot health check model offered to patients with learning

disability nurse annual health check for disabilities registered with a large general primary care patients with learning practice. The pilot was conducted at the disabilities', Learning Disability surgery site. The article does not identify what Practice, 7(9), pp. 30. could be considered to be learning disability nursing public health roles. Mitchell, D. (2000) 'No claim to be called sick The thesis explores the development of nurses at all': an historical study of learning learning disability nursing between 1913 and disability nursing. (BL: DXN062779). . 1959. Its main objective was to explore the ProQuest Dissertations Publishing. Available question of why learning disability work is at: https://search.proguest.com/docview/301 situated in the nursing profession. The thesis 616049. PhD Thesis. does not identify what could be considered to be learning disability nursing public health roles. The article describes a framework for learning Moulster, G., Ames, S. and Griffiths, T. (2012a) 'A new framework for learning disability practice. It is intended to empower disability nursing: implementation', Learning nurses to update their practice, ensure good Disability Practice, 15(8), pp. 20. health outcomes and improve the care experience of people with learning disabilities, and their family, carers and friends. The paper does not identify what could be considered to be learning disability nursing public health roles. Moulster, G., Ames, S. and Griffiths, T. In this, the authors describe the piloting, (2012b) 'A new framework for learning implementation, auditing and evaluation of the disability nursing: implementation', Learning 'Moulster and Griffiths framework' for learning Disability Practice, 15(8), pp. 20. disability nursing practice. The study does not identify what could be considered to be learning disability nursing public health roles. Northway, R. (2017) 'Perspectives: The In this article Professor Ruth Norhway argues health of people with learning disabilities: that all nurses (whatever their field of practice) realising the future potential of all nurses have a potential role to play in improving the and nursing to reduce health health and well-being of people with learning disparities', Journal of Research in disabilities. The paper does not identify what Nursing, 22(8), pp. 637-640. doi: could be considered to be learning disability 10.1177/1744987117742041. nursing public health roles. Northway, R. (2001) 'Poverty as a practice In this article the author argues that poverty issue for learning disability nurses', British has a negative impact on mental and physical Journal of Nursing, 10(18), pp. 1186-1192. health. They further argue that this should tie doi: 10.12968/bjon.2001.10.18.9939. an area of concern for learning disability nurses. Furthermore, the authors points out poverty can impact the lives of their of people with learning disabilities and nurses should incorporate this understanding into their practice. Interventions which can be implemented at the level of individual clients, groups and society to tackle poverty and its effects are proposed. It is not clear what role learning disability nurses can play in this very important public health issue.

O'Connor, M. and Carey, E. (2017) 'The role of nurses in supporting people with learning disabilities to manage asthma', <i>Learning Disability Practice</i> , 20(1), pp. 24-29. doi: 10.7748/ldp.2017.e1778.  Parrish, A. and Styring, L. (2003) 'Nurses' role in the developments in learning disability care', <i>British Journal of Nursing</i> , 12(17), pp. 1043-1047.	This article gives an overview of asthma and how it is treated. The article also discusses learning disability nurses' role in supporting people with learning disabilities to manage their own condition. The study does not identify what could be considered to be learning disability nursing public health roles.  This opinion paper discusses the changes in attitude of society in the UK towards people with learning disabilities in the 20 years to 2003.
Ring, H., Gilbert, N., Hook, R., Platt, A., Smith, C., Irvine, F., Donaldson, C., Jones, E., Kelly, J., Mander, A., Murphy, C., Pennington, M., Pullen, A., Redley, M., Rowe, S. and Wason, J. (2016) 'Improving outcomes in adults with epilepsy and learning disability (EpAID) using a nurse-led intervention: study protocol for a cluster randomised controlled trial', <i>Trials</i> , 17(1), pp. 297. doi: 10.1186/s13063-016-1429-7.	This is a study protocol paper of a trial that investigates whether nurses with expertise in epilepsy and learning disabilities, working proactively to a clinically defined role, can improve clinical and quality of life outcomes in the management of epilepsy within this population, compared to treatment as usual.
Sheerin, F.K. (2008) 'Diagnoses and interventions pertinent to learning disability nursing', <i>International journal of nursing terminologies and classifications: the official journal of NANDA International,</i> 19(4), pp. 140-149. doi: 10.1111/j.1744-618X.2008.00102.x.	This literature review aims to identify the diagnoses and interventions that are employed by learning disability nurses in Ireland. The paper explores the relevant professional literature, drawing on a broad scope of sources. The review does not identify what could be considered to be learning disability nursing public health roles.
Smith, K. (2016) 'The support needs of learning disability nurse facilitators of sex offender treatment programmes: a discussion', <i>Journal of Learning Disabilities and Offending Behaviour</i> , 7(2), pp. 94-102. doi: 10.1108/JIDOB-09-2015-0035.	The paper discusses the facilitation of Sex Offender Treatment Programmes (SOTP) and the issues this raises in providing support for learning disability nurses. The paper does not identify what could be considered to be learning disability nursing public health roles.
Tagg, L. and Kenny, G. (2006) 'Family nursing and parents who have a learning disability', <i>Paediatric Nursing</i> , 18(2), pp. 14-18. doi: 10.7748/paed.18.2.14.s18.	The paper examines the issue of the rights of adults with learning disabilities and illustrates that when these rights are not upheld they increase vulnerability.
Taua, C., Neville, C. and Scott, T. (2017) 'Appreciating the work of nurses caring for adults with learning disability and mental health issues', <i>International Journal of Mental Health Nursing</i> , 26(6), pp. 629-638. doi: 10.1111/inm.12291.	The study explored best practice for nurses caring for people with learning disabilities and mental health issues in inpatient mental health settings. The study sought to understand the skills nurses utilize in caring for this client group. The specific aim was to understand how nurses managed complex processes of determining and delivering inpatient mental health care for people with learning disabilities and did not identify nursing roles.

van der Linde, J. and Casteleijn, D. (2016) 'A comparison of two assessments of levels of functioning in clients with learning disability between occupational therapists and nursing staff within a long-term mental healthcare facility in South Africa', *Curationis*, 39(1), pp. e10. doi: 10.4102/curationis.v39i1.1665.

This study collected information on the occupational performance and the adaptive functioning of the mental healthcare users with learning disabilities in order to determine the patient profile within the hospital. The study does not identify what could be considered to be learning disability nursing public health roles.

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Brown, M., MacArthur, J., McKechanie, A., Mack, S., Hayes, M. and Fletcher, J. (2012) 'Learning Disability Liaison Nursing Services in south-east Scotland: a mixed-methods impact and outcome study', *Journal of Learning Disability Research*, 56(12), pp. 1161-1174. doi: 10.1111/j.1365-2788.2011.01511.x.

Brown, M., MacArthur, J., McKechanie, A., Hayes, M. and Fletcher, J. (2010) Equality and access to general healthcare for people with learning disabilities: Reality or rhetoric? *Journal of Research in Nursing*, 15 (4), p.351-361.

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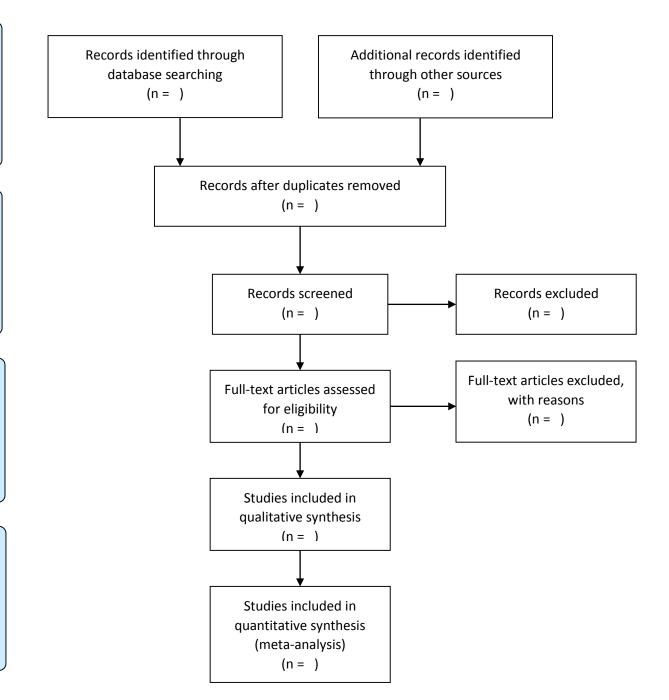
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# Appendix B: JBI Critical Appraisal of Evidence of Effectiveness

Reviewer			Date:			
Αι	·· uthor:		Year:	Record Number:		
1.	Was the assignmen	t to treatment grou No	ps truly random? Not clear	N/A		
2.	Were participants b Yes	linded to treatment No	allocations? Not clear	N/A		
3.	Was allocation to tre	eatment groups cor No	ncealed from the allo	ocator? N/A		
4.	Were the outcomes the analysis? Yes	of people of people	e who withdrew des Not clear	cribed and included in N/A		
5.	Was the assignmen	t to treatment grou No	ps truly random? Not clear	N/A		
6.	Were control and tre Yes	eatment groups cor No	nparable at entry? Not clear	N/A		
7.	Were groups treated Yes	d identically other the No	han for the named in Not clear	nterventions? N/A		
8.	Were outcomes me Yes	asured in the same No	e way for all groups? Not clear	N/A		
9.	Were outcomes me Yes	asured in a reliable No	way? Not clear	N/A		
10	). Was appropriate sta Yes	atistical analysis us No	ed? Not clear	N/A		
	Overall appraisal:					
	Include	Exclude	Seel	k further information		
	Comments (including	reasons for exclus	sion):			

## Appendix C: JBI Critical Appraisal Checklist for Qualitative Research

IXCVI	iewerDa	Date			
Auth	norYear	Record Number			
		Yes	No	Unclear	Not applicable
1.	Is there congruity between the stated philosophical perspective and the research methodology?				
2.	Is there congruity between the research methodology and the research question or objectives?				
3.	Is there congruity between the research methodology and the methods used to collect data?				
4.	Is there congruity between the research methodology and the representation and analysis of data?				
5.	Is there congruity between the research methodology and the interpretation of results?				
6.	Is there a statement locating the researcher culturally or theoretically?				
7.	Is the influence of the researcher on the research, and vice- versa, addressed?				
8.	Are participants, and their voices, adequately represented?				
9.	Is the research ethical according to current criteria or, for recent studies, and is there evidence of ethical approval by an appropriate body?				
10.	Do the conclusions drawn in the research report flow from the analysis, or interpretation, of the data?				
	rall appraisal: Include   Exclude  ments (Including reason for exclusion)		s S	eek furthe	r info 🗆

# Appendix D: JBI Critical Appraisal Checklist for Systematic Reviews and Research Syntheses

Year_		R	ecor	d Number	
			Record Number		
		Yes	No	Unclear	Not applicable
v question clearly and e	xplicitly				
	ate for				
arch strategy appropriat	e?				
	sed to				
	lies				
	two or				
	rors in				
	studies				
elihood of publication bia	as				
	•				
	Exclude on)			Seek furthe	r info □
	clusion criteria appropria question?  arch strategy appropriate ources and resources us tudies adequate? iteria for appraising study appraisal conducted by vers independently? methods to minimize er ion? ethods used to combine ? elihood of publication bia mendations for policy a oported by the reported of pecific directives for new opropriate? al: Include	arch strategy appropriate?  ources and resources used to tudies adequate? iteria for appraising studies? appraisal conducted by two or vers independently? methods to minimize errors in ion? ethods used to combine studies? elihood of publication bias amendations for policy and/or oported by the reported data? becific directives for new propriate?	clusion criteria appropriate for question?  arch strategy appropriate?  curces and resources used to tudies adequate?  iteria for appraising studies?  appraisal conducted by two or vers independently?  methods to minimize errors in ion?  ethods used to combine studies?  elihood of publication bias  mendations for policy and/or oported by the reported data?  pecific directives for new opropriate?  al: Include	clusion criteria appropriate for question?  arch strategy appropriate?  curces and resources used to tudies adequate? iteria for appraising studies?  appraisal conducted by two or vers independently?  methods to minimize errors in ion?  ethods used to combine studies?  elihood of publication bias  mendations for policy and/or oported by the reported data?  pecific directives for new propriate?  al: Include	clusion criteria appropriate for question?  arch strategy appropriate?  arch strategy

Author	Year		Record Number				
			Yes	No	Unclear	Not applicable	
22. Is the source of the operation identified?	oinion clearly						
23. Does the source of op the field of expertise?	inion have sta	nding in					
<ul><li>24. Are the interests of the relevant population the central focus of the opinion?</li><li>25. Is the stated position the result of an analytical process, and is there logic in the opinion expressed?</li><li>26. Is there reference to the extant literature?</li><li>27. Is any incongruence with the</li></ul>							
literature/sources logic		?					
Overall appraisal: Includ	e 🗆	Exclude		S	eek furthe	r info 🗆	
Comments (Including reas	on for exclusio	n)					

#### Appendix F: JBI Levels of evidence for effectiveness

#### Level 1 - Experimental Designs

- Level 1.a Systematic review of Randomized Controlled Trials (RCTs)
- Level 1.b Systematic review of RCTs and other study designs
- Level 1.c RCT
- Level 1.d Pseudo-RCTs

#### Level 2 - Quasi-experimental Designs

- Level 2.a Systematic review of quasi-experimental studies
- Level 2.b Systematic review of quasi-experimental and other lower study designs
- Level 2.c Quasi-experimental prospectively controlled study
- Level 2.d Pre-test post-test or historic/retrospective control group study

#### Level 3 - Observational - Analytic Designs

- Level 3.a Systematic review of comparable cohort studies
- Level 3.b Systematic review of comparable cohort and other lower study designs
- Level 3.c Cohort study with control group
- Level 3.d Case controlled study
- Level 3.e Observational study without a control group

#### Level 4 – Observational –Descriptive Studies

- Level 4.a Systematic review of descriptive studies
- Level 4.b Cross-sectional study
- Level 4.c Case series
- Level 4.d Case study

#### Level 5 - Expert Opinion and Bench Research

- Level 5.a Systematic review of expert opinion
- Level 5.b Expert consensus
- Level 5.c Bench research/ single expert opinion.

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June 2018