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Understanding the contribution of intellectual disability nurses: Scoping research

Volume 1 of 3: Scoping literature review report

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Abstract

Introduction

This scoping review of literature report is the first volume of a 3-volume project report. The RCN Foundation commissioned the University of West London and their collaborators to undertake scoping research on understanding the contribution of nurses to improving the health and well-being of children, adults and older people with intellectual disabilities, now and for the future. The overall aim of the research is to identify nursing-led and / or nursing centred interventions that are in place to address the challenging and changing needs of people with intellectual disabilities. The research sought to identify interventions, that can be implemented by nurses working in multi-disciplinary teams. The research identifies areas of good care delivery, innovative practices, and possible gaps in the provision of care for individuals with intellectual disabilities.

Objective

The objective of this review is to summarise evidence on the contribution of intellectual disability (ID) nurses to improving the health and well-being of children, adults and older people with intellectual disabilities, now and for the future.

Methods

We used the Preferred Reporting Items for Systematic Reviews and Meta-Analysis (for Scoping Reviews) (PRISMA-ScR) process and Joanna Briggs Institute (JBI) guidance to select the literature for review and to present the literature review report (Trico *et al.,* 2018; Peters *et al.,* 2017). A mixed methods approach to the review and synthesis was used due to the heterogeneous nature of the evidence. JBI tools were used to rate studies for quality. Thematic synthesis was used to generate analytical themes.We searched the Joanna Briggs Institute (JBI) Reports, Medline, Embase, PsycINFO, CINAHL, Academic Search Elite, ProQuest Dissertations and Theses (Global**)** also known as Index to Theses, ETHOS, UK Government publications, and professional organisations' publications.

Results

We retrieved 121 publications. Of these we excluded 35 after initial appraisal. We evaluated 86 publications and excluded 33 after appraisal

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and we included 53 publications in this review. We identified a wide range of interventions (154) undertaken by intellectual disability nurses in a variety of settings across the lifespan. We categorised the intellectual disability nursing interventions into three themes; *effectuating nursing procedures*, *enhancing impact of services*, and *enhancing quality of life.*

The majority of publications reported cross-sectional studies (77%), 6% of publications were literature reviews, and 17% were opinion papers. Only two of the primary studies investigated the effectiveness of intellectual disability nurse interventions. The majority of the publications focused on interventions related to adults (31). Not all publications focussed on a particular age group. One publication referred to maternity, five focussed on interventions relevant to children, ten identified interventions relevant to all age groups, five focussed on older adults, five focussed on end-of-life interventions and one publication was not clear.

Conclusions

We identified 154 interventions undertaken by intellectual disability nurses in a variety of settings. We categorised the interventions into three themes; *effectuating nursing procedures* (52 interventions), *enhancing impact of services* (73 interventions), and *enhancing quality of life* (41 interventions). Publications identifying the interventions undertaken by intellectual disability nurses in relation to maternity, children, older adults and end of life care were limited. Publications did not demonstrate the impact and effectiveness of interventions. This advocates for high quality research being essential in determining the impact and effectiveness of intellectual disability nursing interventions across the lifespan. We recommend that a searchable online compendium of intellectual disability nurse interventions be established and regularly reviewed.

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Introduction

The research project report is in three volumes; volume 1 of 3: Scoping literature review report (this volume); volume 2 of 3: Scoping survey research report; and volume 3 of 3: Compendium of intellectual disabilities nursing interventions. The scoping research focuses on investigating the contribution of intellectual disability nurses to improving the health and well-being of children, adults and older people with intellectual disabilities, now and for the future.

The overall aim of the research is to identify nursing led and or nursing centred interventions that are in place to address the challenging and changing needs of people with intellectual disabilities. The research seeks to identify interventions that can be implemented by nurses working in multi-disciplinary teams. The research identifies areas of good care delivery, any innovative practices, and possible gaps in the provision of care for individuals with intellectual disabilities. The research covers interventions in all four countries of the UK and it covers all settings including care provided by the NHS, the independent sector, charities, education and social care. The literature search was undertaken between 1 February 2020 and 31 May 2020. We did not set a time for the literature search because we anticipated limited robust research evidence.

Rationale

It is estimated that there are currently 1.5 million people with a intellectual disability in the UK and this population is changing and increasing, with approximately 2.16% of adults and 2.5% of children identified as having an intellectual disability (Mencap, 2020). Life expectancy of people living with intellectual disabilities is increasing, as well as the complexity of the health and social care needs and conditions of this population (Truesdale and Brown, 2017). There is a disparity between the health, and the healthcare needs of people with intellectual disabilities as compared to that of the general population and these disparities are avoidable (Kerr, 2004; van Schrojenstein Lantman-de Valk *et al*., 2007). People with intellectual disabilities are known to have much greater health needs than those of comparable age groups who do not have intellectual disabilities (Backer *et*

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al., 2009), and experience preventable higher mortality rates (LeDeR, 2020).

Research demonstrates that people with intellectual disabilities are often or more likely to be dependent on others for their health and healthcare outcomes (Campbell and Martin, 2009) and also that these outcomes could be improved through appropriate intellectual disability nursing interventions. People with intellectual disabilities are high and frequent users of all health services, including primary care, child health services, acute healthcare services and specialist intellectual disability services.

The avoidable disparity between the health, and the health needs of people with intellectual 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; Kavanagh *et al.,* 2017; LeDer, 2020). These disparities result from poor access to health services, limited options in lifestyle, and poor living standards, but could be improved through appropriate intellectual disability nursing interventions.

People with intellectual disabilities are known to have much greater health needs than those of comparable age groups who do not have intellectual 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 health related disorders as compared to the general population and that these health problems are commonly, and widely undiagnosed, misdiagnosed, and untreated (Llewellyn *et al.,* 2015; Emerson and Brigham, 2015). In addition, they experience higher rates of visual impairments, higher rates of epilepsy, hypertension and hypothyroidism, and obesity. People with intellectual disabilities are more likely to die from preventable causes (Mencap 2007; Heslop *et al.,* 2013; Heslop *et al*., 2014; Robertson *et al*., 2015; Bakker-van Gijssel *et al.,* 2017). The life expectancy of people with intellectual 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). It is therefore important to clarify the interventions

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intellectual disability nurses can play to minimise the potential consequences of the risks the result in the preventable premature death of people with intellectual disabilities.

International studies have demonstrated widespread concerns about the inequalities in health for people with intellectual disabilities (Melville *et al.,* 2006; Kavanagh *et al.,* 2017), and poor access to healthcare (Brown *et al.,* 2010). These disparities in health, and poorer health outcomes for people with intellectual disabilities have been attributed to service users' conditions, health organisations, and health service systems. Communication difficulties and limited understanding of the diagnostic, and treatment issues for people with intellectual disabilities, and mainstream healthcare professionals limited augmentative communication skills further limits the diagnosis and treatment of people with intellectual disabilities appropriately (Blair, 2013). People with intellectual disabilities have complex health needs, and comorbidity is common. Life-style related comorbidity is a significant contributory factor to disparities in health for people with intellectual disabilities. Cognitive impairments can limit people with intellectual disabilities' ability to health services without appropriate interventions.

People with intellectual 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 intellectual disabilities are linked to poor access to quality healthcare provision (Michael, 2008; Mencap, 2012), and therefore preventable. In recent years, UK government health policy has focused on improving people with intellectual disabilities' access to mainstream services. However, the continuing disparities in health experienced by people with intellectual disabilities suggest that policies alone are not enough.

Barriers to accessing health services experienced by people with intellectual disabilities contribute to health inequalities. The lack of role clarity of the professionals working with people with intellectual disabilities has been consistently identified as one of the most common barriers

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(Mafuba, 2009, 2013; Mafuba and Gates, 2015; Mafuba, Gates and Cozens, 2018b). Primary healthcare services have an important role in meeting the public health needs of people with intellectual disabilities but there is a lack of evidence as to the interventions intellectual disability nurses play in meeting these needs.

Poor uptake of health services amongst the population of people with intellectual disabilities is a longstanding issue (Allerton and Emerson, 2012; Robertson *et. al.,* 2014). Studies have shown that people with intellectual 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 health services for people with intellectual disabilities is challenging. McIlfatrick *et al.* (2011) have observed that the provision of health services for people with intellectual disabilities is opportunistic, despite evidence that point to a need for targeted activities (Chauhan *et al.,* 2010; Robertson *et. al.,* 2014). Preventative nursing interventions such as health screening are effective in identifying the health needs of people with intellectual disabilities (Emerson *et al*., 2011; Robertson *et. al.,* 2014).

The proportion of children with multiple and complex intellectual disabilities who are living into adulthood and the number of people with intellectual disabilities living into older age is also increasing. As a consequence of the increase in the number of children and young people with intellectual disabilities living into adulthood, there will be major implications for education, health, social care and criminal justice and secure services in the future. The population of older people with intellectual disabilities will increase four times faster than the overall adult intellectual disability population (NICE, 2018). By 2030, there will be a 30% increase in the number of adults with intellectual disabilities aged 50+ using social care services (NICE, 2018). As life expectancy has increased, more people with intellectual disabilities are experiencing chronic multi-morbidities. This will create substantial pressure on services, which has not yet been fully quantified (NICE, 2018). This will have significant implications on the interventions undertaken by intellectual disability nurses to support and meet the needs of this population.

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To effectively meet the health needs of people with intellectual disabilities it is important to clarify effective interventions intellectual disability nurses can undertake. It is also important to establish the evidence base for the most effective interventions to delivering nursing care to people with intellectual disabilities.

Objectives

The purpose of the scoping review of literature is to summarise the best evidence available on nursing led and or nursing centred interventions that are in place to address the needs of people with intellectual disabilities. The review focuses on multi-disciplinary team interventions across the lifespan which involve intellectual disabilities nurses.

There is a lack of clarity on effective interventions that can be carried out by intellectual disabilities nurses. It is no surprise that role expectations vary across the four countries of the United Kingdom. Lack of clarity on effective nursing interventions can result in confused and ambiguous expectations among healthcare professionals. This is likely to result in reduced quality of health and healthcare experiences for people with intellectual disabilities. Clarity of role expectations for nurses will be beneficial because it will improve communication, flexibility and responsiveness at every level of health policy implementation for people with intellectual disabilities.

This report presents the outcomes of the literature search, literature appraisal, literature selection process, data extraction and thematic synthesis of the evidence. We also present a preliminary compendium of nursing interventions.

Review question

The scoping literature reviews seeks to answer the following question;

> *What intellectual disability nursing-led interventions are in place to respond to the changing needs of the population living with intellectual disabilities, and what is the impact of these interventions?*

Terminology

For the purpose of this scoping review, we have used the term ‘intellectual disabilities’ as a way of acknowledging the international nature of the

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publications we have reviewed. However, we are aware that in the United Kingdom a variety of terms are used in practice (Gates and Mafuba, 2016).

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Methods

We adopted the search strategy for Boolean logic in order to search all databases to identify empirical (quantitative, qualitative, mixed methods) studies, synthesised evidence (literature reviews) and opinion papers which clearly identified nursing interventions. The PRISMA-ScR process and JBI guidance was used to select the literature for review and will be used to present the literature review report (Trico, *et al*., 2018; Peters, *et al*., 2017). A mixed methods approach to the review and synthesis was used due to the heterogeneous nature of the evidence. JBI tools were used to pool findings and rate them for quality. Thematic synthesis was used to generate analytical themes.

Protocol and registration

A literature review protocol was registered with the Open Science Framework (OFS) on 22 September 2020 under the title:
Scoping review on understanding the contribution of intellectual disabilities nurses to improve the health and wellbeing of children, adults and older people with intellectual disabilities, now and for the future'.
DOI: 10.17605/OSF.IO/CQ8SY

Eligibility criteria

Inclusion and exclusion criteria

Publications were included if they were 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 intellectual disability nursing interventions.

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, literature reviews were also included.

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Types of phenomena of interest

This component of the review considered intellectual disability nursing-led interventions to improve the health and well-being of children, adults and older people with intellectual disabilities.

Types of participants

We included empirical studies with intellectual disability nurses as participants working with people with intellectual disabilities across the lifespan. We included publications where relevant non-nurse healthcare professionals were also participants (in addition to intellectual disability nurses) where we deemed the findings to be relevant to the aims of the review. We included opinion papers that had no participants but which addressed themes pertinent to the objectives of the review. We included literature reviews that included studies which involving intellectual disability nurses and relevant others as participants, and which synthesised evidence pertinent to the current review.

Search terms

Group A: intellectual disability / intellectual disability / mental retardation / mental handicap / developmental disability / mental deficiency, intellectual difficulty.

Group B: intellectual (intellectual) disability nurse, community intellectual (intellectual) disability nurse, role, public health, intervention, health needs, effectiveness, impact, multi-disciplinary team, person centered, care, nursing.

Information sources

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; ProQuest; and Dissertations Abstracts, NICE.UK Government publications, and professional organisations' publications.

Search strategy

We adopted the search strategy for Boolean logic in order to search in all databases. *Table 1* below provides details of how search terms were used, databases searched and the results obtained. We also searched the

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

Table 1: Search results

Search 1 **CINAHL, Medline, Academic Search Elite, PsychINFO** **Domain A**: nurs* OR "multidisciplinary team*" **AND** **Domain B**: "intellectual disabilit*" OR "intellectual disabilit*" OR "mental retardation* OR "mental handicap*" OR "developmental disabilit*" OR "mental deficien*" **AND** **Domain C:** "public health" OR "health promotion" OR "health need*" OR impact* OR intervention* OR effectiv* OR communicat* OR wellbeing OR well-being OR "physical health" OR "mental health" OR "Health check*" OR "Healthy Lifestyle*" OR "Health Improvement* "OR Nutrition* OR "Oral health" OR "dental health" OR "Physical Activit*" OR "Sexual*" OR "Life Event*" Accident* OR trauma OR Bone* OR "Cardiovascular Disease*" OR Cancer OR Diabet* OR Epilep* OR "Gastrointestinal Disorder*" OR "Haematological Disorder*" OR Infection* OR Mobility OR balance OR co-ordination OR "foot care" OR Obes* OR "Metabolic Disorder*" OR "Respiratory Disorder*" OR "Sensory Impairment*" OR "Visual impairment" OR "Hearing Impairment" OR "Sleep Disorder" OR "Mental Ill-health" OR depression OR "Behaviour Challenge*" OR "Dementia*" OR Forensic OR "People who Offend" OR Pharmacotherapy Limited to English; -2020; Research Studies: References: 3440 Domain 1 and 2 in 'Title' only: 267 (duplicates removed **142)**

Selection of sources of evidence

Papers selected for retrieval were assessed by three reviewers for methodological validity, and relevance to the overall objective of this proposal prior to inclusion in the final review. We appraised quantitative (or mixed methods studies with quantitative components) empirical studies

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using the JBI critical appraisal of evidence of effectiveness checklist (see *appendix* A). We used the JBI critical appraisal checklist for qualitative research to select empirical qualitative (or mixed methods studies with qualitative components) studies (see *appendix B*). We used the JBI critical appraisal checklist for systematic reviews and research syntheses to appraise and select literature reviews (see *appendix C*). We used the JBI critical appraisal checklist for text and opinion papers to appraise and select opinion publications (see *appendix D*).

Data charting process

The reviewers independently carried out data extraction using a data extraction form table based on Timmins and McCabe (2005) (see *table 2*). Any disagreements that arose between the reviewers was resolved through discussion with a review panel comprising members of the research team.

Data items

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.

Critical appraisal within sources of evidence

We used JBI levels of evidence for effectiveness to rate each source of evidence (see *appendix E*).

Synthesis of results

We anticipated a paucity of work to have been undertaken in this area, and that data and material retrieved was likely to be heterogeneous and disparate in nature. Therefore, we employed a narrative approach to synthesis. We deemed the narrative approach to be more appropriate given heterogeneous nature of the evidence. This was also important in order to maximise the synthesised findings. The inclusion of diverse forms of evidence was 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

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the absence of robust randomised controlled trials is important in strengthening the findings and conclusions. We used the Braun, *et al.*'s (2019) approach to thematic analysis to generate analytical themes.

Results

Selection of sources of evidence

The PPRISMA-ScR process was used to select the literature for review and to present the literature review report (Tricco, *et al*., 2018). Empirical (quantitative, qualitative, mixed methods) studies, synthesised evidence (literature reviews) and opinion papers, (*n* = 53) (see *figure 1*) were included in the review.

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Figure 1: Literature appraisal and selection flow diagram.

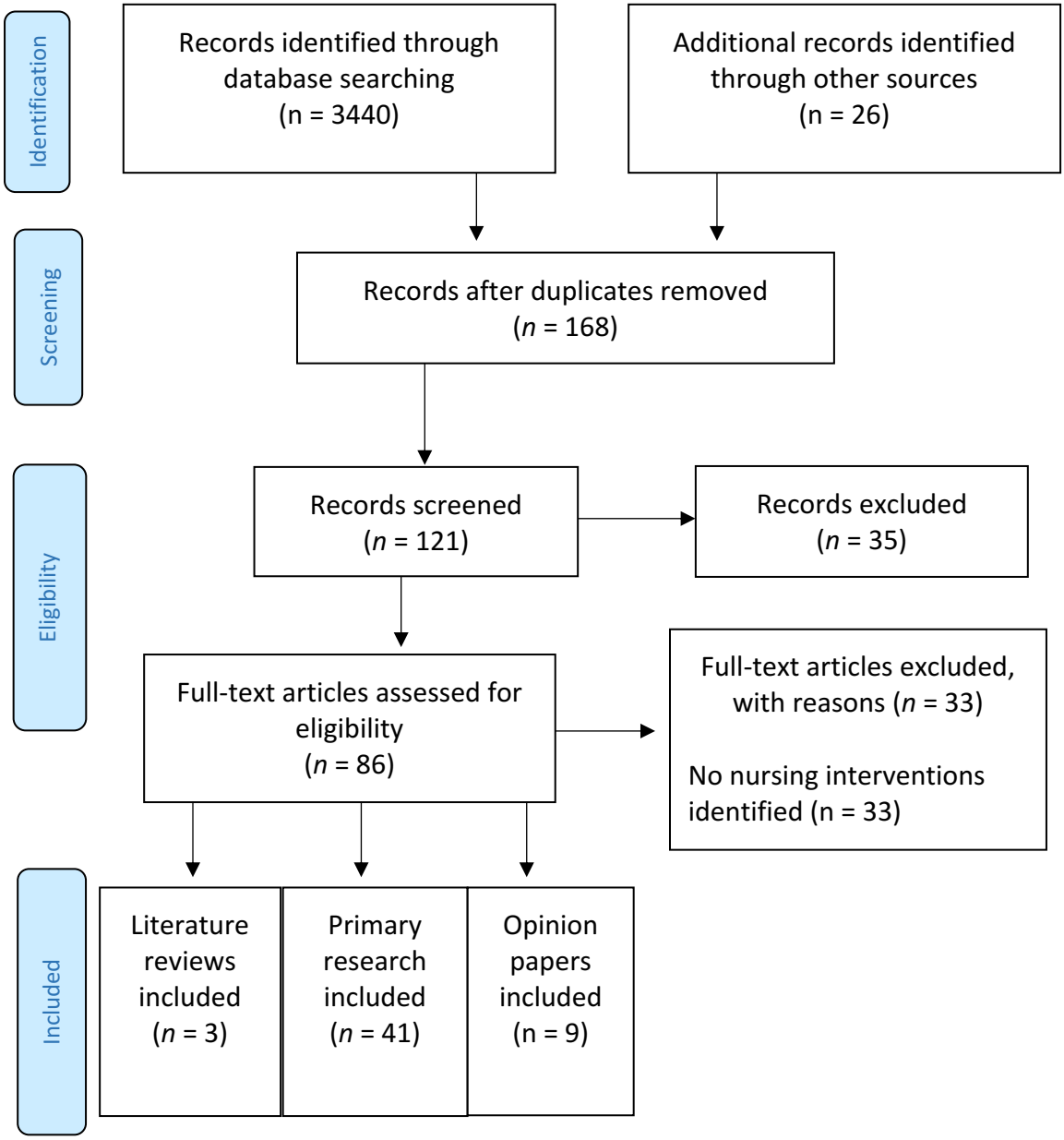

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Table 2: Critical appraisal of publications and evidence

Authors / Country	Critical Appraisal + JBI Level of Evidence	Aims / Purpose	Methods / Participants	Evidence	Conclusions of sources	Target age group	Emerging themes
Literature reviews (*n* = 3)							
1. Mafuba, K., Forster, M., Kupara, D., and Gates, B. (2018) / UK	**Aim(s) / Purpose** –clear **Source standing** – *Public health England* **Relevance** – clear **JBI evidence level** – 4a **Decision** – Include.	The review sought to summarise evidence available on the role and impact of intellectual disability nurses in meeting the public health needs of people with intellectual disabilities.	The Joanna Briggs Institute's (JBI) systematic review protocols and PRISMA process were used. Empirical (quantitative, qualitative, mixed methods) studies, synthesised evidence (literature reviews) and opinion papers were included (*n* = 36).	1. Information sharing 2. Assessment of need 3. Facilitating access to mainstream services 4. Facilitation of reasonable adjustments 5. Health promotion 6. Health education 7. Assessing effectiveness of interventions 8. Monitoring the effectiveness of treatments 9. Enabling and supporting healthy lifestyle choices 10. Addressing determinants of health 11. Surveillance	Although there is some evidence to support the emerging themes, the literatures are limited in robustness and scope.	All age groups	Enhancing impact of services Enhancing quality of life

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2. 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.	This article examined literature on the role of the nurse caring for people with a dual disability (DD) of intellectual disability and mental illness. The main objective of this review was not to give a full description of the studies, but provide a general overview of the key categories evident in the articles.	21 papers were reviewed, less than half (42%) were research studies. The review was undertaken using systematic literature review principles, rather than as a systematic review exercise.	1. Advocacy 2. Health promotion (including working with family) 3. Assessment 4. Behavioural interventions 5. Communication 6. Medication administration 7. Safety and risk management 8. Care planning	Nursing care of people with ID and mental illness has changed dramatically, with nurses working in both specialist DD and generic mental health services.	All age groups	Enhancing impact of services Enhancing quality of life Effectuating nursing procedures
3. Mafuba, K. (2009) / UK	**Aim(s) / Purpose** – clear **Source standing** – *Intellectual disability Practice.* **Relevance** – clear **JBI evidence level** – 4a.	The aim of the paper was to review the literature on community intellectual disability nurses' role in public health.	Literature review 9 studies	1. Health facilitation 2. Health promotion 3. Health education	The contribution of intellectual disability nursing to the health of people with intellectual disability needs to be evaluated.	All age groups	Enhancing impact of services Enhancing quality of life

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	Decision – Include.						
Empirical studies (including unpublished theses) (*n* = 40)							
1. Oulton, K., Wray, J., Hassiotis, A., Kenten, C., Russell, J., Tuffrey-Wijne, I., Whiting, M. and Gibson, F. (2019) / UK	**Aim(s) / Purpose** – clear **Source standing** – *BMC Pediatrics* – *Open Source* **Relevance** – clear **JBI evidence level** – 4b. **Decision** – Include.	The study sought to understand the organisational context for healthcare delivery to children and young people with intellectual disabilities, and compare staff views of their ability to identify and meet the needs of both those with and without intellectual disabilities.	Semi-structured interviews were conducted with senior staff across 15 children's hospitals and an anonymous survey was sent to clinical and non-clinical staff (*n* = 1681) (752 worked in a hospital with dedicated intellectual disability nurse provision). 48 senior staff took part in interviews, which included a subset of nine nurses and one allied health professional employed in a dedicated intellectual disability nurse role, or similar	1. Flagging and identifying needs 2. Making reasonable adjustments 3. Pre-admission support 4. Identifying equipment and resources 5. Facilitating specialist clinics 6. Providing signage 7. Parent support 8. Facilitating transition 9. Handling complaints 10. Staff training 11. Informal support and advice 12. Restraint practice 13. Positive behaviour support training 14. Engaging other agencies. 15. Facilitating communication 16. Mental capacity assessment	Intellectual disability nurse interventions within children's hospitals need to be more clearly defined.	Children	Enhancing impact of services Effectuating nursing procedures

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				17. Engaging senior managers			
2. Doody, O., Slevin, E. and Taggart, L. (2019)/ Ireland	**Aim(s) / Purpose** –clear **Source standing** – *Journal of Clinical Nursing* **Relevance** – clear **JBI evidence level** – 4b **Decision** – Include.	The study explored multidisciplinary team members' perspectives of clinical nurse specialists (CNSs) in intellectual disability nursing contribution in Ireland.	In total, 815 questionnaires were distributed to nurses, NMs and MDT members across five practice areas (community; early intervention; behaviour, creative, diversional and recreational activities; and health promotion), and 262 (*n* = 226 females and *n* = 36 males) (32% response rate).	1. Assessment of client needs 2. Evaluation of care interventions and outcomes. 3. Implementation of care. 4. Health promotion. 5. Providing advice to families. 6. Providing education/training to families. 7. Make recommendations relating to client care and client care issues. 8. Supporting staff to develop practice, guidelines/policies. 9. Consulting with other services/agencies. 10. Refer clients to another service/ agency. 11. Receiving referrals from another service/ agency.	Modern health care requires nurses to be flexible, work independently, have strong leadership qualities and work across professional boundaries.	Adults	Enhancing impact of services Enhancing quality of life

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3.Pennington, M., *et al*. (2019)/ UK	**Aim(s) / Purpose** – clear **Source standing** – *Journal of Intellectual Disability Research* **Relevance** – clear **JBI evidence level** – 1c **Decision** – Include.	This was part of a wider study on the development of a nurse-led approach to managing epilepsy in adults with an intellectual disability. Here the research article reports the impact of the intervention on costs.	Cluster randomised trial. Outcome and cost data were collected by research assistants blinded to treatment allocation. Participants (n = 20) at 16 sites (IQ 70 or above, 18-65 years). Nurses were trained and met the intellectual disability epilepsy specialist nurse competency framework. Total costs at 6 months were compared from the perspective of health and social services and society, with adjustments for pre specified participant and cluster characteristics at baseline including costs.	1. Clinical diagnosis 2. Managing epilepsy 3. Managing complex epilepsy 4. Assessing risk 5. Managing risk 6. The intervention was associated with lower per participant costs from a health and social services perspective of -£357 (2014/2015 GBP) (95%confidence interval -£986, £294) and from a societal perspective of -£631 (95% confidence interval - £1473, £181).	Intellectual disability nurses working to the epilepsy competency framework to help manage the epilepsy of adults with intellectual disability, are unlikely to increase the costs of supporting people with epilepsy and intellectual disability and may reduce them.	Adults	Effectuating nursing procedures

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4. Mafuba, K., Gates, B. and Cozens, M. (2018) / UK	**Aim(s) / Purpose** – clear **Source standing** – *Journal of Intellectual Disabilities* **Relevance** – clear **JBI evidence level** – 4b. **Decision** – Include.	The aim of this study was to explore how public health policy in the United Kingdom was reflected in community intellectual disability nurses' job descriptions and person's specifications. (This study was part one of a 3-phase sequential multiple methods study).	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) intellectual disability nurses' job descriptions and person specifications.	1. Facilitating access to healthcare services. 2. Promoting health. 3. Reducing health inequalities. 4. Providing healthcare advice.	The interventions of intellectual disability nurses in public health are complex.	All age groups	Enhancing impact of services Enhancing quality of life
5. Ring H., Howlett, J., Pennington, M., *et al.* (2018) / UK	**Aim(s) / Purpose** – clear **Source standing** – *Health Technology Assessment, NIHR* **Relevance** – clear **JBI evidence level** – 1c. **Decision** – Include.	To determine whether or not intellectual disability nurses, using a competency framework developed to optimise nurse management of epilepsy in people with an	Cluster-randomised two-arm trial. The experimental intervention was the Intellectual Disability Epilepsy Specialist Nurse (ENS) Competency Framework. Clusters (n = 17) were randomly assigned to either a treatment as usual	1. Analyses of the secondary outcomes revealed no significant differences between groups. 2. Subgroup analysis identified a significant interaction between treatment group and level of intellectual disability. 3. There was a suggestion in those with mild to moderate intellectual	Nurses with experience in intellectual disability and epilepsy could be well placed to deliver or facilitate the recommended epilepsy management for adults with an	Adults	Enhancing impact of services Enhancing quality of life Effectuating nursing procedures

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		intellectual disability, can cost-effectively improve clinical and quality-of-life outcomes in the management of epilepsy compared with treatment as usual.	control (n = 128) group or the competency framework active group (n = 184). In both groups, participants underwent 4 weeks of baseline data collection followed by a minimum of 24 weeks of intervention and 4 weeks of follow-up data collection. Analysis included descriptive statistics and qualitative examination of clinical interactions and carers' views about participants' epilepsy management during the trial.	disability that the competency framework may be associated with a small reduction in concerns over seizure severity (standard error 2.005, 95% confidence interval –0.554 to 7.307; p = 0.092). 4. Economic analysis suggested that the competency framework intervention was likely to be cost-effective, primarily because of a reduction in the costs of supporting participants compared with treatment as usual. Intellectual Disability Epilepsy Specialist Nurse roles; 5. Patient assessment 6. Medication management 7. Ordering and interpreting investigations 8. Providing education 9. Support and counselling to patients and families	intellectual disability . It might be predicted that ENSs would be ideally placed to champion and enhancing the unpredictable, complex and long-term needs of people with epilepsy.		

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6.Quinn, B.L., and Smolinski, M (2018) / USA	**Aim(s) / Purpose** –clear **Source standing** – *The Journal of School Nursing* **Relevance** – clear **JBI evidence level** – 4b **Decision** – Include.	The purpose of this study was to measure the effectiveness of an education program regarding best practices for assessing pain in students with intellectual disability	Educational sessions were presented to 248 school nurses. A one-group pre- and post-design with one longitudinal data collection period was employed. Data collected from nurses during three separate educational program sessions were aggregated. A total of 248 school nurses attended the three educational sessions for the follow-up survey. 39 (16% of the original sample) participated in the 6-month follow-up survey.	1. Pain and assessment 2. Objective clinical assessments (31%) 3. Parent consultation (28%) 4. Teacher consultation (20%) 5. Completing numeric rating scales (23%) 6. "Faces"- type assessment scales (33%) 7. Completing observational scales (46%) 8. Completing parent/guardian input scales (33%)	Large caseloads limited new practice adoption. Trainings and other resources should be made available to school nurses in order to make pain assessments for students with intellectual disability more thorough and efficient.	Children	Effectuating nursing procedures
7.Taua, C., Neville, C. and Scot, T. (2017)/ New Zealand	**Aim(s) / Purpose** –clear **Source standing** – *International Journal of Mental Health Nursing* **Relevance** – clear	The aim was to understand how nurses managed complex processes of determining and delivering inpatient mental	Appreciative inquiry methodology was used. Multicohort study: (i) people with intellectual disability and mental health issues; (ii) their usual	1. Focussed assessment to avoid diagnostic overshadowing. 2. Enabling creative communication. 3. Modifying mental health interventions to suit	These foundational concepts include creating a therapeutic environment and philosophy of	Adults	Enhancing impact of services Effectuating nursing procedures

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	JBI evidence level – 4b **Decision** – Include.	health care for people with intellectual disability.	carers (from community settings); and (iii) nurses in inpatient settings. This paper presents only the findings from group 3 (nurses, *n* = 13).	people with intellectual disabilities.	care, which considers safety in regard to behavioural presentations, cognizance of relevant contextual factors, confidence, and creative communication.		
8. Doody, O., Slevin, E. and Taggart, L. (2017) / Ireland	**Aim(s) / Purpose** – clear **Source standing** – *Journal of Clinical Nursing* **Relevance** – clear **JBI evidence level** – 4b. **Decision** – Include.	The study explored the contribution of clinical nurse specialists in intellectual disability nursing in Ireland.	Exploratory qualitative approach using focus groups. Nonprobability purposeful sample. Focus group semi-structured interviews (5 Focus groups. Participants – intellectual disability clinical nurse specialists (*n* = 31). Burnard's (2011) data analysis framework.	1. Needs assessment 2. Monitoring and evaluating care 3. Advocating for patients 4. Supporting families 5. Providing informal and formal advice 6. Delivering formal / informal education	To engage effectively in complex interventions, intellectual disability require assessment, evaluation and scholarship skills.	Adults	Enhancing impact of services Enhancing quality of life Effectuating nursing procedures
9. Cleary, J. and Doody, O. (2017)/ Ireland	**Aim(s) / Purpose** - clear **Source standing** –	The study aimed to explore nurses' experiences of caring for older	Husserlian phenomenology Purposive sample of nurses (*n* = 20) working	1. Caregiving at mid-stage (eating and drinking) and at end stage (toileting and incontinence).	It is recognised that staff are a key resource for supporting	Older adults	Enhancing impact of services

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	Journal of Clinical Nursing **Relevance** – clear **JBI evidence level** – 4b **Decision** – Include.	persons with intellectual disability and dementia.	in a long-established voluntary service providing community and residential services sample (*n* = 11) consisted of registered intellectual disability nurses (*n* = 9) and registered general nurses (*n* = 2).	1. Pain management. 2. Behavioural support. 3. Problem solving when uncertainty around care exists. 4. Education for peers to develop an understanding of the changes caused by dementia. 5. Providing environmental supports and staff training in the principles of person-centred dementia.	people with intellectual disability and dementia.		Effectuating nursing procedures
10. Auberry, K. and Cullen, D. (2016) / USA	**Aim(s) / Purpose** – clear **Source standing** – *Journal of Intellectual Disabilities* **Relevance** – clear **JBI evidence level** – 4b. **Decision** – Include.	The study sought to determine whether nurses working in the field of intellectual disability experience increased confidence when they implemented the American Association of Neuroscience Nurses	This was a 3-month long implementation pilot study of an evidence-based seizure algorithm for Indiana Developmental Disabilities Nurses Association (*n* = 15) working in the field of intellectual disabilities.	1. Providing seizure telephone triage in the community 2. Providing seizure guidance to people with intellectual disability living in the community	The treatment effect was statistically significant 3.169 ($p < 0.01$).	Adults	Enhancing quality of life Effectuating nursing procedures

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		(AANN) Seizure Algorithm during telephone triage.					
11. Drozd, M. and Clinch, C. (2016)/ UK	**Aim(s) / Purpose** – clear **Source standing** – *International Journal of Orthopaedic and Trauma Nursing* **Relevance** – clear **JBI evidence level** – 4b **Decision** – Include.	The aim of the study was to explore the experiences of orthopaedic and trauma nurses who have cared for people with a intellectual disability.	Descriptive survey design with two components to the data analysis:(i) the quantitative data generated from the questionnaire were analysed using simple descriptive statistical analysis;(ii) the qualitative data were analysed by identifying common themes using an interpretive thematic analysis. Registered nurses who had experiences of caring for people with	1. Co-ordinating communications 2. Making reasonable adjustments 3. Undertaking mental capacity assessments 4. Promoting greater independence 5. Prepare patient for surgery 6. Undertaking risk assessments. 7. Managing risk	There was evidence of good practices within orthopaedic and trauma settings such as the active involvement of family or a paid carer who is known to the patient and the modification of care and interventions along with specialist advice and support from the Acute Liaison	Adults	Enhancing impact of services Enhancing quality of life Effectuating nursing procedures

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			a intellectual disability in an orthopaedic or trauma hospital setting in England (*n* = 13).		Intellectual disability Nurse.		
12. Lovell, A. and Bailey, J. (2016)/ UK	**Aim(s) / Purpose** – clear **Source standing** – *Journal of Psychiatric & Mental Health Nursing* **Relevance** – clear **JBI evidence level** – 4b **Decision** – Include.	To identify and discuss the personal attributes required by intellectual disability nurses to work effectively with people with an offending background in secure and community settings.	Part of a larger research investigating nursing competencies for working with people with intellectual disability. Semi-structured interviews with intellectual disability nurses working in high, medium, and low secure and community settings (*n* = 39).	1. Supporting people with intellectual disabilities with a history of offending behaviour to develop relationships. 2. Supporting with substance misuse interventions.	Intellectual disability nurses work and support people with intellectual disability with complicated backgrounds.	Adults	Enhancing quality of life Effectuating nursing procedures
13. Brown, M., Chouliara, Z., MacArthur, J., McKechanie, A., Mack, S., Hayes, M., and Fletcher, J	**Aim(s) / Purpose** –clear **Source standing** – *Journal of Clinical Nursing* **Relevance** – clear **JBI evidence level** – 4b **Decision** – Include.	To study investigated the experiences of patients with intellectual dis-abilities, family and paid carers regarding the role of liaison nurses and the delivery of compassionate,	Semi structured interviews and focus groups were conducted. IPA data analysis. Data collected from participants with intellectual disabilities (n = 5) and families or paid carers (n = 13). Of the 18 participants, 7 were involved in individual interviews	1. Trouble shooting 2. Explaining what and when 3. Managing anxiety 4. Matching info with capacity to understand 5. Empowering and increasing confidence 6. Managing multiple transitions	The findings provide the first 'anatomy' of compassionate, person- centred care and provide a model for operationalising this approach in practice. The applicability of the model will	Adults	Enhancing impact of services Enhancing quality of life Effectuating nursing procedures

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(2016) / UK		person-centred care.	and 11 within focus groups.		have to be evaluated further with this and other vulnerable groups.		
14. Lovell, A., Smith, D. and Johnson, P. (2015)/ UK	**Aim(s) / Purpose** –clear **Source standing** – *Journal of Clinical Nursing* **Relevance** – clear **JBI evidence level** – 4b **Decision** – Include	The study explored the perceptions of intellectual disability nurses/ care staff in relation to contributory factors to staff injuries sustained during incidents involving physical intervention.	Semi-structured interviews with staff involved in 10 specific incidents of physical restraint over a three-month period (2 staff from each incident (*n* = 20) participants). Analysis of the incident forms and case notes.	1. De-escalation and preventing crisis and the subsequent need for physical intervention. 2. Building and maintaining meaningful professional working relationships with service users. 3. Physical interventions.	Nurses need to respond to incidents of aggression and violence to maintain the safety of the person, their peers and the staff themselves.	Adults	Enhancing quality of life Effectuating nursing procedures
15. MacArthur, J., Brown, M., McKechani, A., Mack, S., Hayes, M. and Fletcher, J. (2015) / UK	**Aim(s) / Purpose** – clear **Source standing** – *Journal of Advanced Nursing* **Relevance** – clear **JBI evidence level** – 4b. **Decision** – Include.	To examine the role of intellectual disability liaison nurses in facilitating reasonable and achievable adjustments to support access to general hospital services for people	Mixed methods. 6 intellectual disability liaison nurses collected data from 323 referrals. Interviews and focus groups were held with 85 participants (adults with intellectual disabilities (*n* = 5), carers (*n* = 16), primary care staff (*n* = 39),	1. Facilitating reasonable adjustments. 2. Assessing patient need. 3. Sharing Information relating to care needs. 4. Providing behavioural advice. 5. Providing communication advice. 6. Providing psychological support.	Intellectual disability liaison nurses undertake important interventions through needs assessment, facilitating access to appropriate services and providing advice.	Adults	Enhancing impact of services Enhancing quality of life Effectuating nursing procedures

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		with intellectual disabilities.	general hospital (*n* = 19) and intellectual disability liaison nurses (*n* = 6).	7. Providing carer educational support. 8. Undertaking pre-morbid baseline assessments. 9. Providing eating and drinking advice and guidelines. 10. Providing diagnostic advice			
16. Chapman, H.M. (2015) / UK (PhD Thesis)	**Aim(s) / Purpose** – clear **Source standing** – *PhD Thesis* **Relevance** – clear **JBI evidence level** – 4b. **Decision** – Include.	To explore the effects of the health consultation experience for people with intellectual disabilities, particularly in terms of their self-concept.	A constructivist grounded theory approach, based on symbolic interactionism, was used. Purposive and snowballing sampling was used to recruit 25 participants with intellectual disabilities through a GP practice, self-advocacy groups and a health facilitator. Nine individual interviews, three interviews with two participants, three focus groups (n=7, n=5 and n=3).	1. Health consultation 2. Health facilitation 3. Making reasonable adjustments 4. Undertaking health checks	Fundamental attitude change by health professionals, supported by specific educational initiatives to enhancing their understanding of the service user perspective, is needed to reduce health inequalities.	Adults	Effectuating nursing procedures Enhancing impact of services

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17. Marriott, A., Turner, S., Ashby, S. and Rees, D. (2015) / UK	**Aim(s) / Purpose** – clear **Source standing** – *Tizard Intellectual disability Review* **Relevance** – clear **JBI evidence level** – 4d. **Decision** – Include.	The study reviewed cancer screening for people with intellectual disabilities and explored the barriers which limit their participation in screening programmes. It describes the screening liaison nurse role and presents case examples of the work they do.	Two case studies of the screening liaison nurse role.	1. Making reasonable adjustments 2. Developing easy to understand letters and information. 3. Training mainstream screening staff regarding the needs of people with intellectual disabilities. 4. Supporting women to manage cervical screening.	Intellectual disability nurses need to work collaboratively to improve access to mainstream cancer screening services	Adults	Enhancing impact of services Effectuating nursing procedures

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18. Wagemans, A.M.A., van Schrojenstein Lantman-de Valk, H.M.J., Proot, I.M., et al (2015) / Netherlands	**Aim(s) / Purpose** - clear **Source standing** – *Journal of Policy and Practice in Intellectual Disabilities* **Relevance** – clear **JBI evidence level** – 4b **Decision** – Include.	The study explored these themes, see below through the eyes of the nurses: Who feels responsible, who takes responsibility, and do the patient's representative, the patient, and the doctor share the decision?	This study was part of a research project about end-of-life decisions, in which a group of 12 intellectual disability physicians were invited to participate. The greater research project consisted of three interviews studies (interviews with the relatives, the doctors, and the nurses), this article concerns only the interview study with nurses (*n* = 10 ID nurses were ID nurses).	1. Being at the centre of communication. 2. Caring for the patient. 3. Interpreting complaints and symptoms. 4. Informing doctors and the relatives. 5. Shaping the nature of end-of-life care and influence end-of-life decisions. 6. Giving information. 7. Advance care planning. 8. Detecting deterioration. 9. Supporting relatives and helping medical staff to make decisions.	A method should be developed in which all stakeholders are involved in a timely process of deliberating on what is needed to provide good care to patients with ID.	End of life	Enhancing impact of services Enhancing quality of life Effectuating nursing procedures

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19. Lloyd, J.L. and Coulson, N.S. (2014) / UK	**Aim(s) / Purpose** – clear **Source standing** – *Journal of Intellectual disabilities* **Relevance** – clear **JBI evidence level** – 4.b **Decision** – Include.	The study explored intellectual disability nurses' experiences of supporting women with intellectual 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 intellectual disability nurses recruited from Derbyshire Healthcare NHS Foundation Trust.	1. Preparing women psychologically for cancer screening 2. Managing the challenges of supporting women with complex needs	Intellectual disability nurses play a significant role in Enhancing the effectiveness of public health interventions.	Adults	Enhancing impact of services
20. Arrey, S. K. (2014) / UK PhD Thesis	**Aim(s) / Purpose** – clear **Source standing** – *British Library* **Relevance** – clear **JBI evidence level** – 3e. **Decision** – Include. This study was extensive and	The study sought to understand how intellectual disability nurses and palliative care professionals (PCPs) identified and responded to the distress of people with communication difficulties and an intellectual	Hermeneutic phenomenology incorporating a constructivist perspective was used. Purposive sampling. Semi structured interviews. Thematic analysis. 13 participants (intellectual disability nurses – (*n* = 8) + 5	1. Building relationships 2. Facilitating communication 3. Providing insight into how people with communication difficulties and intellectual disabilities in palliative care settings communicate distress. 4. Sharing professional knowledge. 5. Training	To deliver effective interventions, intellectual disability nurses need to support other health and healthcare professionals who work directly with people with intellectual disabilities.	End of life	Enhancing impact of services

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	included 3 separate studies.	disability in palliative care settings.	palliative care professionals).	6. Facilitating collaborative working.			
21. Lee, A. and Kiemle, G. (2014) / UK	**Aim(s) / Purpose** – clear **Source standing** – *Journal of Applied Research in Intellectual Disabilities* **Relevance** – clear **JBI evidence level** – 4b **Decision** – Include.	The research investigated the experiences of nurses supporting individuals diagnosed with ID and personality disorder. It aimed to provide insight into how clients were understood emotionally and conceptually, what challenges participants faced, what motivated them and what they perceived their training and support needs to be.	In-depth, semi-structured interviews were used with (n = 9) ID nurses working with clients with a forensic history and ID. Interpretative phenomenological analysis (IPA) was used.	1. Building therapeutic relationships with people with ID and personality disorder. 2. Providing emotional support.	Knowledge coupled with positive staff attitudes and healthy therapeutic relationships are vital ingredients in the effective treatment of clients with intellectual disability and or personality disorder.	Adults	Enhancing impact of services Effectuating nursing procedures
22. Bailey, M., Doody, O. and Lyons, R. (2014)/ Ireland	**Aim(s) / Purpose** – clear **Source standing** –	The aim of the study was to describe the provision of community	Mixed methods study - exploratory descriptive survey utilising a cross-sectional self-reporting questionnaire.	1. Providing information 2. Support the family 3. Supporting and advising staff 4. Coordinating services	Community nurses can support persons with an intellectual	End of life	Enhancing impact of services

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	British Journal of Intellectual Disabilities, **Relevance** – clear **JBI evidence level** – 4b **Decision** – Include.	nursing support for persons with an intellectual disability and palliative/end-of-life care needs in one HSE region in Ireland.	Descriptive analysis for the statistical summaries and thematic analysis was used for the qualitative data. Participants (public health nurses, community nurses, practice nurses, hospice at home nurses and palliative care nurses, currently working in one region in Ireland. Response rate of 32% (*n* = 94).	5. Symptom management 6. Making referrals within the MDT 7. Pressure relief and skin care, 8. Assessing patients 9. Diet and nutrition management 10. Planning for end of life 11. Home nursing care delivery 12. Providing palliative care 13. Completing hospital/ hospice referrals 14. Managing end of life care 15. Finding resources for end of life care	disability and palliative/end-of-life care needs with communication, assessment of needs, pain and symptom management through a collaborative working approach. Non-ID nurses see ID nurses as a source of support when providing end of life care.		Enhancing quality of life Effectuating nursing procedures
23. Dalgarno, M.F. and Riordan, S.A. (2014) / UK	**Aim(s) / Purpose** – clear **Source standing** – *Journal of Intellectual Disabilities and Offending Behaviour* **Relevance** – clear	The aim of this study was to examine the views of practising forensic intellectual disability nurses on their lived experience of performing their role.	This is a qualitative research method based upon the Interpretative phenomenological analysis (IPA) approach and semi-structured interviews used with (*n* = 4) ID nurses working within the same NHS Trust.	1. Supporting service users to problem solve 2. Listen to offence histories 3. Empower service users 4. Enable development of skills 5. Undertaking risk assessments and management.	The nurses' role is highly skilled encapsulating a very wide range of behaviours, skills, attitudes and beliefs.	Adults	Enhancing quality of life Effectuating nursing procedures

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	JBI evidence level – 4b **Decision** – Include.						
24. Lovell, A., Bailey, J., Kingdon, A. and Gentile, D. (2014) / UK	**Aim(s) / Purpose** – clear ***Source standing*** – *Journal of Advanced Nursing.* **Relevance** – clear **JBI evidence level** – 4b. **Decision** – Include.	To identify and discuss the competencies required by intellectual disability nurses to work effectively with people with an offending background in low, medium, high secure and community settings.	Seven focus groups and 39 interviews with nurses (*n* = 20)	1. CBT (Cognitive Behaviour Therapy) training 2. Facilitating multi-disciplinary working and inter- agency liaison. 3. Record keeping 4. Building therapeutic relationships	ID nurse competencies are transferable across settings	Adults	Enhancing impact of services Enhancing quality of life Effectuating nursing procedures
25. Mafuba, K. and Gates, B. (2015) / UK	**Aim(s) / Purpose** – clear **Source standing** – *British Journal of Intellectual Disabilities.*	This paper reports on one stage of a 3-phase sequential multiple methods study that explored and explained the	A 9-item online questionnaire survey of community intellectual disability nurses (UK-wide) (n = 171) (band 5: *n* = 19;	1. Promoting health 2. Facilitating access to health services 3. Providing health education 4. Undertaking health prevention, health	Intellectual disability nurses can make important contributions in public health interventions that	Adults	Enhancing quality of life

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	Relevance – clear **JBI evidence level** – 3e. **Decision** – Include	contribution of community intellectual disability nurses in the implementation of public health policies for people with intellectual disabilities.	band 6: *n* = 67; band 7: *n* = 59; band 8: *n* = 26). Non-proportional quota sampling.	protection and health surveillance.	can improve the health and healthcare outcomes for people with intellectual disabilities.		
26. Mafuba, K. (2013) / UK. PhD Thesis	**Aim(s) / Purpose** – clear **Source standing** – *British Library* **Relevance** – clear **JBI evidence level** – 3e. **Decision** – Include.	The 3-phase study investigated the public health roles of the community intellectual disability nurse.	Phase 1 was a documentary analysis of job descriptions, and or person specifications (*n* = 203). Phase 2 used a Grounded Theory analysis (*n* = 17 intellectual disability nurse consultants). Phase 3 involved an online questionnaire survey (*n* = 171 community ID nurses).	1. Promoting health 2. Facilitating access to health services 3. Providing health education 4. Undertaking health prevention, health protection and health surveillance 5. Providing leadership 6. Developing appropriate policies	Intellectual disability nurse public health interventions have a positive impact on meeting the public health needs of people with intellectual disabilities.	All age groups	Enhancing impact of services Enhancing quality of life
27. Doody, C., Markey, K. and Doody, O. (2013) /	**Aim(s) / Purpose** – clear **Source standing** –	To explore the experiences of registered intellectual disability nurses	Heideggerigan phenomenology. Semi-structured interviews. Thematic	1. Preparing other nursing specialisms to care holistically for people with intellectual disabilities.	Because of their knowledge of people with intellectual disabilities,	Older adults	Enhancing impact of services

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Ireland	*Journal of Clinical Nursing* **Relevance** – clear **JBI evidence level** – 4b. **Decision** – Include.	caring for the older person with intellectual disability.	analysis (Burnard's framework). Purposive sample of intellectual disability nurses (*n* = 7).		intellectual disability nurses have a key role in facilitating access to services.		
28. Brown, M., MacArthur, J., McKechanie, A., Mack, S., Hayes, M. and Fletcher, J. (2012) / UK	**Aim(s) / Purpose** – clear **Source standing** – *Journal of Intellectual disability Research* **Relevance** – clear **JBI evidence level** – 4b. **Decision** – Include.	The aim of the study was to examine the impact and outcomes of four Intellectual disability Liaison Nurse Services in south-east Scotland on the healthcare experiences of people with intellectual disabilities attending for general hospital care.	Mixed-methods and thematic analysis 85 participants including; patients with intellectual disabilities (*n* = 5), carers (*n* = 16), primary care healthcare professionals (*n* = 39) and general hospital professionals (*n* = 19) and intellectual disability liaison nurses (*n* = 6).	1. Managing risk 2. Providing advice 3. Educational support. 4. Providing psychological support. 5. Undertaking pre-morbid baseline assessment. 6. Producing guidelines and accessible information 7. Mediating 8. Facilitating 9. Influencing 10. Advocating 11. Communicating 12. Collaborating 13. Educating	The intellectual disability liaison nurse interventions impact on clinical patient care; education and practice development strategic organisational developments.	Adults	Enhancing impact of services Enhancing quality of life Effectuating nursing procedures

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29. Jenkins, R. (2012) / UK	**Aim(s) / Purpose** – clear **Source standing** – *British Journal of Nursing* **Relevance** – clear **JBI evidence level** – 4d. **Decision** – Include.	This study explored the implications for registered nurses in meeting the health needs of older people with intellectual disabilities.	Case study developed around older people with intellectual disabilities (*n* = 6; age range – 45 – 75+).	1. Diagnosing mental health problems, constipation, hearing and visual problems, and strokes	To engage effectively in complex interventions, intellectual disability nurses require a wide range of knowledge and assessment skills that are essential in identifying the complex public health needs of people with intellectual disabilities.	Adults Older adults	Effectuating nursing procedures
30. Marsham, M. (2012) / UK	**Aim(s) / Purpose** – clear **Source standing** – *British Journal of Intellectual Disabilities* **Relevance** – clear **JBI evidence level** – 4b. **Decision** – Include.	The aim of the study was to explore the therapeutic role from the perspective of community intellectual disability nurses.	Descriptive phenomenology. Semi-structured interviews based on Critical Incident Technique. Systematic content analysis. Practicing community intellectual disability nurses with more than 2 years' experience of	1. Managing long-term conditions 2. Facilitating self-management. 3. Escalating treatment pathways. 4. Facilitating development of coping skills. 5. Reducing challenging behaviour. 6. Facilitating access to healthcare.	Community intellectual disability nurses engage in a wide range of therapeutic interventions.	Adults	Enhancing impact of services Enhancing quality of life Effectuating nursing procedures

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			managing an adult caseload (*n* = 7).	7. Assessing people's understanding of their needs.			
31. Taggart, L., Truesdale-Kennedy, M. and McIlfatrick, S. (2011) / UK	**Aim(s) / Purpose** – clear **Source standing** – *Journal of Intellectual disability Research* **Relevance** – clear **JBI evidence level** – 4b. **Decision** - Include	The aim of this study was to examine how community nurses and residential staff support women with intellectual disabilities to access breast screening services	6 focus groups and thematic content analysis. Participants were community intellectual disability nurses (*n* = 29) and residential care staff.	1. Raising breast awareness. 2. Providing information on healthier lifestyles. 3. Supporting women to self-examine and report any abnormalities. 4. Developing health education material 5. Training health and social care staff	Effective public health interventions by I intellectual disability nurses need to be holistic.	Adults	Enhancing impact of services Enhancing quality of life
32. Campbell, A.K. (2011) / New Zealand.	**Aim(s) / Purpose** – clear **Source standing** – *British Journal of Developmental Disabilities.* **Relevance** – clear **JBI evidence level** – 4b **Decision** – Include.	The aims of this study were to 1) describe nurses' emotional response to violent incidents and 2) explore the support they require in dealing with constant exposure to workplace violence the	The setting for this study was a 10-bed unit for adults with intellectual disabilities and challenging behaviour. *n* = 6 registered nurses.	1. Managing violence and challenging behaviour.	This study has highlighted that working with individuals with intellectual disability and challenging behaviour is an emotionally distressing job due to the constant anxiety related to the	Adults	Effectuating nursing procedures

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		purpose of this study.			anticipation of violence.		
33. Ng, J. S. W. (2011) / UK PhD Thesis	**Aim(s) / Purpose** – clear **Source standing** – *British Library* **Relevance** – clear **JBI evidence level** – 4b. **Decision** – Include.	The study explored the perceived knowledge and skills of intellectual 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 intellectual disabilities in residential care homes.	Grounded theory. Thematic analysis. In-depth interviews (*n* = 36) intellectual disability nurses.	1. Undertaking baseline physical health assessments. 2. Assess changing health conditions.	Ongoing assessment of needs and inter-professional working are essential to maintaining and promoting the health and wellbeing of people with intellectual disabilities.	End of life	Effectuating nursing procedures

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34. Mason, T. and Phipps, D. (2010)/ UK	**Aim(s) / Purpose** –clear **Source standing** – *Issues in Mental Health Nursing* **Relevance** – clear **JBI evidence level** – 4b **Decision** – Include.	The research aimed to identify the main skills and competencies of forensic ID nurses; to establish if these perceived main skills and competencies differ between forensic and non-forensic intellectual disability nurses; and to identify the perceived areas of forensic intellectual disability nursing skills and competencies that require developing.	Two sample populations were forensic intellectual disability nurses from the high, medium, and low secure psychiatric services and non-forensic intellectual disability nurses from generic services. An information gathering schedule was used to collect data (*n* = 643) (53.5% response rate).	1. Management of violence. 2. Control and restraint. 3. Control of medication. 4. Risk assessment and risk management. 5. Managing self-harm. 6. De-escalation. 7. Implementing early interventions. 8. Relationship formation with service users. 9. Implementing assessment strategies. 10. Offence-specific interventions. 11. Family therapy. 12. Psychological interventions.	There are differences in the perceptions of what constitutes forensic intellectual disability skills, and competencies between the forensic and non-forensic intellectual disability nurses.	Adults	Enhancing quality of life Effectuating nursing procedures
35. McKeon, M. (2009) / Ireland	**Aim(s) / Purpose** – clear **Source standing** – *Journal of*	The aim of the study was to provide a baseline of clinical nursing skills used in intellectual	Questionnaire survey (questionnaire used a nursing skills list from The Royal Marsden Hospital Manual of Clinical Effectuating	1. Violence prevention 2. Needs assessment	The results of the study help to identify, plan, and direct the type and level of nursing skills	Adults	Enhancing quality of life Effectuating nursing procedures

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	Intellectual Disabilities **Relevance** – clear **JBI evidence level** – 4b. **Decision** – Include	disability nursing. The objectives were to determine the types and levels of clinical nursing skills used in intellectual disability nursing.	nursing procedures (Mallett and Dougherty, 2000)). 26 questionnaires were completed, 18 from a residential setting and 8 from a community living setting.		taught to the intellectual disability nursing students and provides an insight into the current nursing skills used in the intellectual disabilities field.		
36. 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 was to investigated the advocacy role of intellectual disability nurses in Wales.	Grounded theory. Focus groups of Registered intellectual disability nurses (*n* = 18) working in small residential settings.	1. Advocating for service users	The advocacy role of the intellectual disability nurse is important to the delivery of public health services to people with intellectual disabilities.	Adults	Enhancing impact of services.
37. Slevin, E. and Sines, D. (2005) / UK	**Aim(s) / Purpose** – clear **Source standing** – *Journal of Nursing Studies* **Relevance** – clear	The study investigated the role of intellectual disability nurses in their day-to-day work with people who challenge.	Grounded theory. Theoretical sampling (*n = 22* intellectual disability nurses). In-depth face-to-face interviews.	1. Promoting amelioration of detrimental effects of challenging behaviour. 2. Undertaking assessments 3. Educating staff in residential homes, or in schools	Needs assessment underlie intellectual disability nurse interventions when working	Adults	Enhancing impact of services Enhancing quality of life

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	JBI evidence level – 4b. **Decision** – Include.			4. Monitoring and evaluating care interventions	with people with challenging needs		Effectuating nursing procedures
38. Llewellyn, P. (2005) / UK	**Aim(s) / Purpose** – clear **Source standing** – *British Library* **Relevance** – clear **JBI evidence level** – 4b. **Decision** – Include.	This study explored the advocacy role of intellectual disability nurses.	3-stage mixed method study within a Grounded Theory methodology, augmented by situational analyses and mapping. Stage 2 - Focus groups with intellectual disability nurses (*n* = 6).	1. Advocating for people with intellectual disabilities. 2. Enabling things to happen for people with intellectual disabilities 3. Encouraging clients to make their own decisions	Intellectual disability nurses have many different advocacy roles	Adults	Enhancing impact of services Enhancing quality of life
39. 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.	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	A clinic led by two intellectual disability nurses was held for all people aged 10 years and over (*n* = 464).	1. Health screening 2. Health promotion	To be effective intellectual disability nurses need to combine health screening with health promotion.	Children (10-18) Adults Older Adults	Enhancing impact of services Enhancing quality of life

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	Decision – Include.	evaluated the impact of health promotion classes on participants' weight loss.					
40. 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 study explored what the most appropriate healthcare role was for delivering health care in a special school catering for children with a broad range of severe intellectual disabilities.	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 intellectual disability nurses).	1. Liaising with professionals and significant others such as parents and relatives 2. Providing hygiene advice 3. Providing dietary advice 4. Continence promotion	Effective public health interventions by intellectual disability nurses need to engage all stakeholders at individual and population levels	Children	Enhancing impact of services Enhancing quality of life
41. Barr, O., Gilgunn, J., Kane, T. and Moore, G. (1999) / UK	**Aim(s) / Purpose** – clear **Source standing** – *Journal of Advanced Nursing.* **Relevance** – clear	Introduce health screening for people with intellectual disabilities in an area in Northern Ireland.	Health screening project (Screening for weight, blood pressure, urine-analysis, breast cancer, testicular cancer, eye test, hearing test). 373 people with intellectual disabilities.	1. Health screening 2. Eye testing 3. Hearing testing	The primary intervention of community intellectual disability nurses is raising the profile of the health needs of people	Adults	Enhancing quality of life Effectuating nursing procedures

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	JBI evidence level – 4b **Decision** – Include.				with intellectual disabilities.		
Opinion papers (*n* = 9)							
1. Cope, G. and Shaw, T. (2019) / UK	**Aim(s) / Purpose** – clear **Source standing** – *Foundation of Nursing Studies* **Relevance** – clear **JBI evidence level** – 5c. **Decision** – Include.	The report was commissioned by the then Chief Nurse for NHS England, Professor Jane Cummings and subsequently supported by Health Education England (London Region) to raise the profile of the unique and important contribution that intellectual disability nurses make across health and social care.	Project report This was a scoping exercise involved a small advisory group of intellectual disability nurses from practice, education and research. Twitter tweet chats, an online survey and face-to-face stakeholder events were used to engage practising intellectual disability nurses. Data collection and analysis were not methodological.	1. Empowering the person with a intellectual disability to have a fulfilling life 2. Supporting families 3. Promote choices 4. Promote human rights 5. Reduce the impact of health inequalities 6. Advocate for and influence the care given 7. Support / provide information on health conditions 8. Promote health and wellbeing (physical and mental health) 9. Facilitating reasonable adjustments 10. Providing easy read information	Not applicable	All age groups	Enhancing impact of services Enhancing quality of life Effectuating nursing procedures

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				11. Supporting admissions and outpatients			
1. McCarron, M., Sheerin, F., Roche, L., Ryan, AM., Griffiths, C., Keenan, P., Doody, O., D'Eath, M., Burke, E., McCallion, P. (2018) / Ireland	**Aim(s) / Purpose** – clear **Source standing** – *Health Service Executive, Ireland* **Relevance** – clear **JBI evidence level** – 4b. **Decision** – Include.	The aim of the project was to determine the future role of the registered nurse intellectual disability who provides health and social care services to individuals with an intellectual disability and to their families and carers in this changing landscape.	Project report Literature review and documentary analysis. Questionnaire surveys. Key informant interviews. Regional focus groups.	1. Providing support and advice in primary care 2. Liaison in maternity services 3. Providing health screening, assessment and health promotion in primary care 4. Liaising with health, social care, disability services and multi-disciplinary team in primary care 5. Liaison in (children's / adolescent / adult / older adult / end of life) secondary and tertiary health care, and schools (for children). 6. Liaison in palliative care 7. Bereavement counselling 8. Promotion of optimal physical health 9. Providing psychosocial support 10. Promotion of mental health 11. Advocating	This report provides an overarching framework to assist all nurses working in disability services to respond to the varying support requirements of individuals with an intellectual disability and their families. In the adoption of person-centredness as the philosophy underpinning intellectual disability nursing practice in all settings, nurses are provided with approaches to advance the health and social	Maternity All age groups End of life	Enhancing impact of services Enhancing quality of life Effectuating nursing procedures

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				12. Supporting community integration 13. Supporting communication and social connectedness 14. Providing support with the decision-making 15. Working with families 16. Development and implementation of behaviour support plans.	care support requirement of individuals with an intellectual disability, develop the profession's capacity and capability to do this and measure its outcome on the health and overall lives of those they serve.		
2. Delahunty, L. (2017) / UK	**Aim(s) / Purpose** – clear **Source standing** – *Nursing Children and Young People.* The author is a psychology research Assistant at the University of Edinburgh. **Relevance** – clear **JBI evidence level** – 5c.	This article describes intellectual disability, the kind of support children with intellectual disabilities need, and how nursing staff might use the Child and Adolescent Intellectual disability Screening Questionnaire (CALDS-Q) to help	Opinion paper.	1. Identify children with potential intellectual disability. 2. Act as a link between schools and other services. 3. Facilitate transition from nursery into school or transition into adult services. 4. Monitor children's development. 5. Identify children who should be prioritised for further intellectual disability assessment.	Intellectual disability nurses have a role in promoting the health and wellbeing of children with intellectual disabilities in education settings.	Children	Enhancing impact of services Enhancing quality of life Effectuating nursing procedures

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	Decision – Include.	identify children who should be formally assessed for intellectual disability.					
3.Northway, R., Cushing, K., Duffin, S., Payne, T., Price, P. and Sutherland, K. (2017) / UK	**Aim(s) / Purpose** – clear **Source standing** – *Intellectual disability Practice*. We included this paper because it was written by an eminent professor of intellectual disability and intellectual disability nursing students. The paper identified a wide range of	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 intellectual disability nurses at different lifespan stages (200+ delegates (intellectual disability nurses, students, people with intellectual disabilities and their families, nurses from other fields, and other professionals).	1. Family support 2. Positive behavioural support 3. Safeguarding of children and adults 4. Health liaison 5. Making reasonable adjustments. 6. Health promotion and education 7. Medication monitoring 8. Promotion of health checks and screening, personal and sexual relationships 9. Nutrition and dysphagia management	In order to effectively promote the health and wellbeing of people with intellectual disabilities, intellectual disability nurses need to engage in a wide range of roles and they need to assimilate emergent roles	Maternity All age groups	Enhancing impact of services Enhancing quality of life Effectuating nursing procedures

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	new and emerging public health roles of intellectual disability nurses. **Relevance** – clear **JBI evidence level** – 5b. **Decision** – Include.		Thematic analysis was used.	10. Facilitating transition from child to adult services and other life stages 11. Supporting the communication of people with intellectual disabilities 12. Providing advice about available services 13. Awareness raising and education 14. Involvement in pre-natal screening - providing support in relation to diagnosis. 15. Developmental assessment 16. Providing advice and support to schools 17. Mental health promotion and support 18. Promotion of resilience 19. Dementia assessment 20. Promoting employment 21. Supporting individuals to remain in their home			
4.Nelson, S. and Carey, E.	**Aim(s) / Purpose** – clear	This article highlights the importance of the	Opinion paper.	1. Promotion of the health and well-being	Ongoing assessment of needs is an	Older adults	Enhancing quality of life

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(2016) / Ireland	**Source standing** – *Intellectual disability Practice.* The authors include an intellectual disability nursing student and an intellectual disability nurse tutor. We included this paper because it is well researched and supported by extensive references of significance. **Relevance** – clear **JBI evidence level** – 5c. **Decision** – Include	role of intellectual disability nurses in assessing mobility, as part of the holistic assessment of older adults with intellectual disability, and describes a variety of resources practitioners can use.		2. Assessment of mobility decline in older people with intellectual disabilities. 3. Supporting maintenance of optimal health.	essential intervention in maintaining and promoting the health and wellbeing of people with intellectual disabilities.		Effectuating nursing procedures
5.Adams, D. and Shah, C. (2016) / UK	**Aim(s) / Purpose** – clear **Source standing** – *Intellectual disability Practice.*	The article examines the reasons why medication is prescribed, best practice, the side	Opinion paper.	1. Reviewing and assisting with the withdrawal of antipsychotic medication 2. Reducing prescribing of antipsychotic medicines	Monitoring the effectiveness of treatments is essential to the promotion of the health and	All age groups	Enhancing impact of services Enhancing quality of life

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	The two authors are experienced senior pharmacists. The article was subjected to double-blind review and was checked for plagiarism. **Relevance** – clear **JBI evidence level** – 5b. **Decision** – Include.	effects and the issues that are involved with the withdrawal of psychotropic medicines, in particular antipsychotics, in people with intellectual disabilities.		3. Maintaining and Enhancing the general physical health and well-being of people with intellectual disabilities 4. Providing constipation advice 5. Monitoring medication effectiveness 6. Improving communication between healthcare professionals in primary and secondary care.	wellbeing of people with intellectual disabilities.		
6. Morton-Nance, S. (2015) / UK	**Aim(s) / Purpose** – clear **Source standing** – *Intellectual disability Practice.* The author is a hospital intellectual disability liaison nurse specialist. The paper is well researched and	This article aims to explore the evolving role of the intellectual disability nurse and their unique contribution, specifically within the acute setting, and examines the nature of specialist nursing in practice.	Opinion paper.	1. Pre-admission screening 2. Clinical assessment 3. Advocating for people with intellectual disabilities 4. Advising hospital staff on reasonable adjustments 5. Assisting with capacity/risk assessments 6. Advising on and providing a plan of care for complex admissions and discharge 7. Educating people with intellectual disabilities,	The public health roles of intellectual disability nurses need to extent to acute care settings through advocacy, facilitation of reasonable adjustments, health facilitation, health liaison and	All age groups	Enhancing impact of services Enhancing quality of life Effectuating nursing procedures

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	has been subjected to double-blind review. **Relevance** – clear **JBI evidence level** – 5c. **Decision** – Include.			family members and carers 8. Raising awareness of intellectual disabilities and autism 9. Serving as a contact person for community and inpatient services 10. Providing advice on treatment options	raising awareness.		
7.Sheerin, F.K. (2012) / Ireland	**Aim(s) / Purpose** – Unclear **Source standing** – *British Journal of Intellectual Disabilities*. The author is an experienced intellectual disability nurse based in the School of Nursing and Midwifery at Trinity College, Dublin. **Relevance** – clear **JBI evidence level** – 5c.	Aim of the paper is not clearly stated.	Opinion paper / review of policy development and research evidence.	1. Assessment of need 2. Health surveillance and health promotion 3. Enablement and empowerment 4. Addressing health inequalities	Intellectual disability nurses have an important role through needs assessment and addressing health in-equalities through empowerment and enablement.	Not clear	Enhancing quality of life Effectuating nursing procedures

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	Decision – Include.						
8.DoH (2007) / England, UK	**Aim(s) / Purpose** – Unclear **Source standing** – Department of Health (England). The guidance highlights important roles of intellectual disability nurses. **Relevance** – clear **JBI evidence level** – 5c. **Decision** – Include.	The guidance aims to highlight how intellectual disability nurses' contribution can be made even more effective in the future.	Department of Health guidance	1. Health promotion 2. Health facilitation 3. Teaching other health and social care professionals 4. Service development	Ensuring that the health needs of people with intellectual disabilities are met in the future presents a challenge for commissioners of education and of services.	All age groups	Enhancing impact of services Enhancing quality of life

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Characteristics of sources of evidence

For each source of evidence, we present characteristics for which data were charted and provide the citations in *table 2.*

Critical appraisal within sources of evidence

We used the JBI levels of evidence for effectiveness to rate the sources of evidence (see *table 2*).

Results of individual sources of evidence

We grouped literature reviews, empirical studies and opinion publications and reported them in order of the year of publication, with the most recent first.

Literature reviews (n = 3)

In the UK, Mafuba *et al.,* (2018b) undertook a literature review which sought to summarise evidence available on the role and impact of intellectual disability nurses in meeting the public health needs of people with intellectual disabilities. The JBI systematic review protocols and PRISMA process were used. Empirical (quantitative, qualitative, mixed methods) studies, synthesised evidence (literature reviews) and opinion papers were included (*n* = 36). Intellectual disability nursing interventions reported are; health surveillance, information sharing, assessment of need, facilitating access to mainstream services, facilitation of reasonable adjustments, promoting health, health education, assessing effectiveness of interventions, monitoring the effectiveness of treatments, enabling and supporting healthy lifestyle choices, and addressing determinants of health. Although there is evidence to support the emerging themes, some of the literatures included in the review are limited in robustness and scope. The interventions identified are relevant to all age groups. *Themes (Enhancing impact of services. Enhancing quality of life).*

In a literature review undertaken in Australia, Taua, Hepworth and Neville (2012) synthesized researches that investigated the interventions undertaken by nurses caring for people with a dual disability of intellectual disability and mental illness. 21 publications were included in

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the review, and less than half (42%) were empirical studies. The review was undertaken using systematic literature review principles, rather than as a systematic literature review exercise. Although it is unclear if any of the studies included in the review had intellectual disability nurses as participants some of the interventions identified are relevant to the current review. Among other interventions, the review identified assessment, advocacy, health promotion (including working with family), facilitating communication and risk management which could be argued to have relevance to the practice of intellectual disability nurses. The interventions identified focussed on all age groups. *Themes (Enhancing impact of services. Enhancing quality of life. Effectuating nursing procedures).*

A scoping literature review publication by Mafuba (2009) in the UK summarises evidence on community intellectual disability nurses' public health interventions. The literature review included nine studies. Health facilitation, health promotion, and health education were identified as interventions undertaken by intellectual disability nurses as part of their public health roles. The author recommended that the contribution of intellectual disability nursing to the health of people with intellectual disability needs to be evaluated. The interventions identified focussed on all age groups. *Themes (Enhancing impact of services. Enhancing quality of life).*

Empirical studies (including unpublished theses) (n = 41)

Oulton *et al.* (2019) undertook a study in the UK which, sought to understand the organisational context for healthcare delivery to children and young people with intellectual disabilities, and compared staff views of their ability to identify and meet the needs of both those with and without intellectual disabilities. Semi-structured interviews were conducted with senior staff across 15 children's hospitals and an anonymous survey was sent to clinical and non-clinical staff (*n* = 1681) (752 worked in a hospital with dedicated intellectual disability nurse provision). 48 senior staff took part in interviews, which included a subset of nine nurses and one allied health professional employed in a dedicated

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intellectual disability nurse role, or similar. Flagging and identifying needs, making reasonable adjustments, pre-admission support, identifying equipment and resources, facilitating specialist clinics, providing signage, providing parent support, facilitating transition, handling complaints, staff training, providing, informal support and advice, restraint practice, positive behaviour support training, engaging other agencies, facilitating communication, mental capacity assessment, and engaging senior managers were identified as interventions undertaken by intellectual disability nurses. The authors concluded that intellectual disability nurse interventions within children's hospitals need to be more clearly defined. The interventions identified focussed on children. *Themes (Enhancing impact of services. Effectuating nursing procedures).*

In Ireland Doody, Slevin and Taggart (2019) reported on a study which, explored multidisciplinary team members' perspectives of clinical nurse specialists (CNSs) in intellectual disability nursing. In total, 815 questionnaires were distributed to nurses, and other members of the multi-disciplinary team (MDT) members across five practice areas (community early intervention; behaviour, creative, diversional and recreational activities; and health promotion), and 262 (*n* = 226 females and *n* = 36 males) (32% response rate). The study identified assessment of client needs, evaluation of care interventions and outcomes, implementation of care, health promotion, provision of advice to families, providing education / training to families, making recommendations relating to client care and client care issues, supporting staff to develop practice, guidelines/policies, consulting with other services/agencies, referring clients to another service/ agency, and receiving referrals from another service/ agency as interventions undertaken by intellectual disability nurses. The authors also concluded that modern health care requires intellectual disability nurses to be flexible, work independently, have strong leadership qualities and work across professional boundaries. The interventions identified focussed on adults. *Themes (Enhancing impact of services. Enhancing quality of life).*

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Pennington *et al*. (2019) published a paper in the UK which, was part of a wider cluster randomised trial study on the development of a nurse-led approach to managing epilepsy in adults with an intellectual disability. This publication reports on the impact of the intervention on costs. Outcome and cost data were collected by research assistants blinded to treatment allocation (participants (*n* = 20) at 16 sites (IQ 70 or above, 18-65 years)). Nurses were trained and met the intellectual disability epilepsy specialist nurse competency framework. Clinical diagnosis, managing epilepsy, managing complex epilepsy, assessing risk, and managing risk were identified as the interventions undertaken by intellectual disability nurses working with adults with intellectual disability and epilepsy. The authors also concluded that intellectual disability nurses working to the epilepsy competency framework to help manage the epilepsy of adults with intellectual disability, are unlikely to increase the costs of supporting people with epilepsy and intellectual disability and may reduce them. The interventions identified focussed on adults. *Theme (Effectuating nursing procedures).*

In the UK-wide, the study by Mafuba, Gates and Cozens (2018b) explored how public health policy was reflected in community intellectual disability nurses' job descriptions and person's specifications. This study was part one of a 3-phase sequential multiple methods study. Other publications from this study are also included in this review. 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) intellectual disability nurses' job descriptions and person specifications. The study identified facilitating access to healthcare services, promoting health, reducing health inequalities, and providing healthcare advice as interventions undertaken by intellectual disability nurses. The authors concluded the interventions undertaken by intellectual disability nurses are complex. The interventions identified focussed on all age groups. *Themes (Enhancing impact of services. Enhancing quality of life).*

Ring *et al.* (2018) published a paper in the UK which, was part of a wider cluster randomised trial study on the development of a nurse-led

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approach to managing epilepsy in adults with an intellectual disability. The cluster-randomised two-arm trial study sought to determine whether or not intellectual disability nurses, using a competency framework developed to optimise nurse management of epilepsy in people with an intellectual disability, can cost-effectively improve clinical and quality-of-life outcomes in the management of epilepsy compared with treatment as usual. The experimental intervention was the intellectual disability epilepsy specialist nurse (ENS) competency framework. Clusters (*n* = 17) were randomly assigned to either a treatment as usual control (*n* = 128) group or the competency framework active group (*n* = 184). In both groups, participants underwent 4 weeks of baseline data collection followed by a minimum of 24 weeks of intervention and 4 weeks of follow-up data collection. Analysis included descriptive statistics and qualitative examination of clinical interactions and carers' views about participants' epilepsy management during the trial. Analyses of the secondary outcomes revealed no significant differences between groups. Subgroup analysis identified a significant interaction between treatment group and level of intellectual disability. There was a suggestion in those with mild to moderate intellectual disability that the competency framework may be associated with a small reduction in concerns over seizure severity (standard error 2.005, 95% confidence interval –0.554 to 7.307; p = 0.092). Economic analysis suggested that the competency framework intervention was likely to be cost-effective, primarily because of a reduction in the costs of supporting participants compared with treatment as usual.

Interventions undertaken by intellectual disability epilepsy specialist nurses were reported as patient assessment, medication management, ordering and interpreting investigations, providing education, and supporting and counselling to patients and families. The authors Nurses with experience in intellectual disability and epilepsy could be well placed to deliver or facilitate the recommended epilepsy management for adults with an intellectual disability. It might be predicted that ENSs would be ideally placed to champion and enhancing the unpredictable, complex and long-term needs of people with epilepsy and intellectual disability.

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The interventions identified focussed on adults. *Themes (Enhancing impact of services. Enhancing quality of life. Effectuating nursing procedures).*

In the USA, Quinn and Smolinski (2018) reported on a study which, was aimed at measuring the effectiveness of an education program regarding best practices for assessing pain in students with intellectual disability. In the study, educational sessions were presented to 248 school nurses. A one-group pre- and post-design with one longitudinal data collection period was employed. Data collected from nurses during three separate educational program sessions were aggregated. A total of 248 school nurses attended the three educational sessions for the follow-up survey. 39 (16% of the original sample) participated in the 6-month follow-up survey. What is unclear from the study if any of the nurses were intellectual disability nurses. The study identified pain and assessment, objective clinical assessments (31%), parent consultation (28%), teacher consultation (20%), completing numeric rating scales (23%), completing "Faces"- type assessment scales (33%), completing observational scales (46%), and completing parent/guardian input scales (33%) as interventions undertaken by nurses working with children with intellectual disability and epilepsy. The study concluded that large caseloads limited the ability of nurses to adopt new practices. The interventions identified focussed on children. *Theme (Effectuating nursing procedures).*

Taua *et al.* (2017) reported on a multicohort study undertaken in New Zealand. The aim of the study was to understand how nurses managed complex processes of determining and delivering inpatient mental health care for people with intellectual disability. Appreciative inquiry methodology was used. People with intellectual disability and mental health issues, their usual carers (from community settings), and nurses in inpatient settings were the participants. This paper presents only the findings from group 3 (nurses, n = 13). Focussed assessment to avoid diagnostic overshadowing, enabling creative communication, and modifying mental health interventions to suit people with intellectual disability were identified as interventions undertaken by nurses. The

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interventions identified focussed on adults. *Themes (Enhancing impact of services. Effectuating nursing procedures).*

A recent study carried out by Cleary and Doody (2017) in Ireland explored nurses' experiences of caring for older people with intellectual disability and dementia. Husserlian phenomenology and purposive sample of nurses (*n* = 20) working in a long-established voluntary service providing community and residential services sample (*n* = 11) consisted of registered intellectual disability nurses (*n* = 9) and registered general nurses (*n* = 2) was used. Caregiving at mid-stage (eating and drinking) and at end stage (toileting and incontinence), pain management, behavioural support, problem solving when uncertainty around care exists, providing education for peers to develop an understanding of the changes caused by dementia, and providing environmental supports and staff training in the principles of person-centred dementia were reported as interventions undertaken by intellectual disability nurses. The interventions identified focussed on older adults. *Themes (Enhancing impact of services. Effectuating nursing procedures).*

In the USA, a 3-month study by Auberry and Cullen (2016) sought to determine whether nurses working in the field of intellectual disability 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 intellectual disabilities) during telephone triage. Participant nurses were intellectual disability nurses from Indiana Developmental Disabilities Nurses Association (*n* =15) who provided nursing care to individuals with intellectual 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 nursing interventions identified were; providing seizure telephone triage in the community, and providing seizure guidance to people with intellectual disability living in the community. The authors

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concluded that intellectual disability nurses undertake important interventions in providing seizure guidance to people with intellectual disability living in the community. The interventions identified focussed on older adults. *Themes (Enhancing quality of life. Effectuating nursing procedures).*

Drozd and Clinch (2016) undertook a study in the UK which, to explored the experiences of orthopaedic and trauma nurses who cared for people with an ID (*n* = 13). Descriptive survey design with two components to the data analysis was used. The study identified co-ordinating communications, making reasonable adjustments, undertaking mental capacity assessments, promoting greater independence, preparing patients for surgery, undertaking risk assessments, and managing risk as interventions undertaken by nurses. The authors concluded that the modification of care and interventions along with specialist advice and support from the Acute Liaison Intellectual Disability Nurse (ALIDN) was important in Effectuating nursing interventions. The interventions identified focussed on adults. *Themes (Enhancing impact of services. Enhancing quality of life. Effectuating nursing procedures).*

Lovell and Bailey (2016) undertook a study in the UK which sought to identify and discuss the personal attributes required by intellectual disability nurses to work effectively with people with an offending background in secure and community settings. The publication was part of a larger research investigating nursing competencies for working with people with intellectual disability. Semi-structured interviews were undertaken with intellectual disability nurses working in high, medium, and low secure and community settings (*n* = 39). Supporting people with intellectual disability with a history of offending behaviour to develop relationships, and supporting with substance misuse were identified as interventions undertaken by intellectual disability nurses. The study concluded that intellectual disability nurses work and support people with intellectual disability with complicated backgrounds. The interventions identified focussed on adults. *Themes (Enhancing quality of life. Effectuating nursing procedures).*

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In the UK Brown *et al.* (2016) investigated the experiences of patients with intellectual disability, family and paid carers regarding the role of liaison nurses and the delivery of compassionate, person-centred care. Semi structured interviews and focus groups were conducted. Data was collected from participants with intellectual disabilities (*n* = 5) and families or paid carers (*n* = 13). Of the 18 participants, 7 were involved in individual interviews and 11 within focus groups. Interpretive Phenomenological Analysis (IPA) was used. The study identified intellectual disability nursing interventions as trouble shooting, explaining what and when, managing anxiety, matching info with capacity to understand, empowering and increasing confidence, and managing multiple transitions. The interventions identified focussed on adults. *Themes (Enhancing impact of services. Enhancing quality of life. Effectuating nursing procedures).*

Lovell *et al.* (2015) undertook a study in the UK which, explored the perceptions of intellectual disability nurses and care staff in relation to contributory factors to staff injuries sustained during incidents involving physical interventions. Semi-structured interviews with staff involved in 10 specific incidents of physical restraint over a three-month period (2 staff from each incident (*n* = 20) participants) participated in the study. In addition, incident forms and case notes were analysed. The study reported that intellectual disability nurses were involved in de-escalation and preventing crisis and the subsequent need for physical intervention, building and maintaining meaningful professional working relationships with service users, and physical interventions. The authors concluded nurses need to respond to incidents of aggression and violence to maintain the safety of the person, their peers and the staff themselves. The interventions identified focussed on adults. *Themes (Enhancing quality of life. Effectuating nursing procedures).*

MacArthur *et al.* (2015) examined the role of intellectual disability liaison nurses in facilitating reasonable and achievable adjustments to support access to general hospital services for people with intellectual disabilities in the UK. Interviews and focus groups were held with 85 participants (adults with intellectual disabilities (*n* = 5), carers (*n* = 16), primary care

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staff (*n* = 39), general hospital (*n* = 19) and intellectual disability liaison nurses (*n* = 6). The study identifies facilitating reasonable adjustments, assessing patient need, sharing Information relating to care needs, provision of behavioural advice, provision of communication advice, provision of psychological support, provision of carer educational support, undertaking pre-morbid baseline assessments, provision of eating and drinking advice and guidelines, and provision of diagnostic advice were identified as important interventions undertaken by intellectual disability liaison nurses. The authors concluded that intellectual disability liaison nurses undertake important interventions that enhancing the effectiveness of other healthcare services. The interventions identified focussed on adults. *Themes (Enhancing impact of services. Enhancing quality of life. Effectuating nursing procedures).*

In her PhD thesis study undertaken in the UK Chapman (2015) explored the effects of the health consultation experience for people with intellectual disabilities, particularly in terms of their self-concept. A constructivist Grounded Theory approach, based on symbolic interactionism was used. Purposive and snowball sampling was used to recruit 25 participants with intellectual disability through a GP practice, self-advocacy groups and a health facilitator. Nine individual interviews, three interviews with two participants, three focus groups (*n* = 7, *n* = 5 and *n* = 3) were conducted. Health consultation, health facilitation, making reasonable adjustments, and undertaking health checks were reported as key interventions undertaken by intellectual disability nurses. The interventions identified focussed on adults. *Themes (Enhancing impact of services. Effectuating nursing procedures).*

In the UK Marriott *et al.* (2015) reviewed cancer screening for people with intellectual disabilities and explored the barriers which limit their participation in screening programmes. It describes the screening liaison nurse role and presents two case examples of the work they do. The study identifies making reasonable adjustments, developing easy to understand letters and information, training mainstream screening staff regarding the needs of people with intellectual disabilities, and supporting women with

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intellectual disabilities to manage cervical screening. The study concluded that intellectual disability nurses need to work collaboratively to improve access to mainstream cancer screening services by people with intellectual disabilities. The interventions identified focussed on adults. *Themes (Enhancing impact of services. Effectuating nursing procedures).*

Mafuba and Gates (2015) published a paper reporting on one stage of a 3-phase sequential multiple methods study that explored and explained the contribution of community intellectual disability nurses in the implementation of public health policies for people with intellectual disability in the UK. A 9-item online questionnaire survey of non-proportional quota sampled community intellectual disability nurses (UK-wide) (*n* = 171) (band 5: *n* = 19; band 6: *n* = 67; band 7: *n* = 59; band 8: *n* = 26). Promoting health, facilitating access to health services, providing health education, undertaking health prevention, undertaking health protection and health surveillance were the interventions identified. The study concluded that intellectual disability nurses can make important contributions in public health interventions that can improve the health and healthcare outcomes for people with intellectual disabilities. The interventions identified focussed on adults. *Theme (Enhancing quality of life).*

Wagemans *et al.* (2015) undertook a study in the Netherlands which, explored who feels responsible, who takes responsibility, and whether patients' representatives, the patients, and the doctors shared decision-making about end-of-life care. This publication was part of a research project about end-of-life decisions, in which a group of 12 intellectual disability physicians were invited to participate. The greater research project consisted of three interview studies (with the relatives, with the doctors, and with nurses), this article concerns only the interview study with nurses (*n* = 10 nurses were intellectual disability nurses). Nursing interventions identified were; being at the centre of communication, caring for the patient, interpreting complaints and symptoms, informing doctors and the relatives, shaping the nature of end-of-life care and influence end-of-life decisions, giving information, advance care planning,

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detecting deterioration, and supporting relatives and helping medical staff to make decisions. The study concluded that a method should be developed in which all stakeholders are involved in a timely process of deliberating on what is needed to provide good care to patients with intellectual disabilities. The interventions identified focussed on end of life. *Themes (Enhancing impact of services. Enhancing quality of life. Effectuating nursing procedures).*

Lloyd and Coulson (2014) in the UK explored intellectual disability nurses' experiences of supporting women with intellectual disability 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 were used (*n* = 10 intellectual disability nurses). Preparing women psychologically for cancer screening, and managing the challenges of supporting women with complex needs were reported as interventions undertaken by intellectual disability nurses. The study concluded that intellectual disability nurses play a significant role in Enhancing the effectiveness of health interventions. The interventions identified focussed on adults. *Theme (Enhancing impact of services).*

In a PhD thesis study undertaken in the UK, Arrey (2014) sought to understand how intellectual disability nurses and palliative care professionals (PCPs) identified and responded to the distress of people with communication difficulties and an intellectual disability in palliative care settings.

Hermeneutic phenomenology incorporating a constructivist perspective, purposive sampling, semi structured interviews, and thematic analysis were used. 13 participants (*n* = 8 intellectual disability nurses and 5 other palliative care professionals) participated in the study. Building relationships, facilitating communication, provision of insight into how people with communication difficulties and intellectual disabilities in palliative care settings communicate distress, sharing professional knowledge, training, and facilitating collaborative working were identified

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as key nursing interventions. The study concluded that in order to deliver effective interventions, intellectual disability nurses need to support other health and healthcare professionals who work directly with people with intellectual disabilities. The interventions identified focussed on end-of-life care. *Theme (Enhancing impact of services).*

In the UK, Lee and Kiemle (2014) investigated the experiences of nurses supporting individuals diagnosed with intellectual disability and personality disorder. The study aimed to provide insight into how clients were understood emotionally and conceptually, what challenges participants faced, what motivated them and what they perceived their training and support needs to be. In-depth, semi-structured interviews were used with (*n* = 9) intellectual disability nurses working with clients with a forensic history and intellectual disability. Interpretative phenomenological analysis (IPA) was used. Building therapeutic relationships with people with intellectual disability and personality disorder, and provision of emotional support were identified as important nursing interventions. The study also concluded that healthy therapeutic relationships are vital ingredients in the effective treatment of clients with intellectual disability and or personality disorders. The interventions identified focussed on adults. *Themes (Enhancing impact of services. Effectuating nursing procedures).*

Bailey *et al.* (2014) reported on a study undertaken in Ireland which, described the provision of community nursing support for persons with an intellectual disability and palliative/end-of-life care needs in one region in Ireland. Exploratory descriptive survey utilising a cross-sectional self-reporting questionnaire study design was used. Descriptive analysis for the statistical summaries and thematic analysis was used for the qualitative data. Participants (public health nurses, community nurses, practice nurses, hospice at home nurses and palliative care nurses, working in one region in Ireland participated in the study (response rate of 32% (*n* = 94)). Provision of information, supporting the family, supporting and advising staff, coordinating services, symptom management, making referrals within the MDT, pressure relief and skin

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care, assessing patients, diet and nutrition management, planning for end of life, home nursing care delivery, provision of palliative care, completing hospital/ hospice referrals, managing end of life care, and finding resources for end of life care were identified as important nursing interventions in end of life care. The study concluded that community intellectual disability nurses can effectively support persons with an intellectual disability and palliative/end-of-life care needs. The study also concluded that the non- intellectual disability nurses see intellectual disability nurses as a source of support when providing end of life care. The interventions identified focussed on end of life. *Themes (Enhancing impact of services. Enhancing quality of life. Effectuating nursing procedures).*

A study undertaken in the UK by Dalgarno and Riordan (2014) examined the views of practising forensic intellectual disability nurses on their lived experience of performing their role. IPA and semi-structured interviews were used with (*n* = 4) intellectual disability nurses working within the same NHS Trust. Supporting service users to problem solve, listening to offence histories, empowering service users, enabling development of skills, and undertaking risk assessments and management were the reported interventions undertaken by intellectual disability nurses. The authors concluded that the intellectual disability nurses' role is highly skilled encapsulating a very wide range of behaviours, skills, attitudes and beliefs. The interventions identified focussed on adults. *Themes (Enhancing quality of life. Effectuating nursing procedures).*

Lovell *et al.* (2014) sought to identify and discuss the competencies required by intellectual disability nurses to work effectively with people with an offending background in low, medium, high secure and community settings in the UK. Seven focus groups and 39 interviews with intellectual disability nurses (*n* = 20) were undertaken. Interventions undertaken by these nurses were cognitive behaviour therapy (CBT) training, facilitating multi-disciplinary working and inter- agency liaison, record keeping, and building therapeutic relationships. The authors concluded that intellectual disability nurse competencies are transferable

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across settings. The interventions identified focussed on adults. *Themes (Enhancing impact of services. Enhancing quality of life. Effectuating nursing procedures).*

Mafuba (2013) in a 3-phase PhD thesis study investigated the public health roles of the community intellectual disability nurses. Phase 1 was a documentary analysis of job descriptions, and or person specifications (*n* = 203). Phase 2 used a Grounded Theory analysis (*n* = 17 intellectual disability nurse consultants). Phase 3 involved an online questionnaire survey (*n* = 171 community intellectual disability nurses). Interventions undertaken by community intellectual disability nurses were described as promoting health, facilitating access to health services, providing health education, undertaking health prevention, undertaking health protection and health surveillance, providing leadership, and developing appropriate policies. The study concluded that intellectual disability nurse public health interventions have a positive impact on meeting the health needs of people with intellectual disabilities. The interventions identified focussed on all age groups. *Themes (Enhancing impact of services. Enhancing quality of life).*

A study undertaken in Ireland by Doody *et al.* (2013) explored the experiences of registered intellectual disability nurses caring for the older person with intellectual disability. Heideggerigan phenomenology, semi-structured interviews, thematic analysis (Burnard's framework), and purposive sampling of intellectual disability nurses (*n* = 7) were used. Preparing other nursing specialisms to care holistically for people with intellectual disabilities was identified as an important intervention undertaken by intellectual disability nurses. The study concluded that because of their knowledge of people with intellectual disabilities, intellectual disability nurses have a key role in facilitating access to services. The interventions identified focussed on older adults. *Theme (Enhancing impact of services).*

In the UK Brown *et al.* (2012) examined the impact and outcomes of four intellectual disability liaison nursing services in south-east Scotland on the

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healthcare experiences of people with intellectual disabilities attending for general hospital care. Mixed-methods and thematic analysis were used. Eight-five participants including; patients with intellectual disabilities (*n* = 5), carers (*n* = 16), primary care healthcare professionals (*n* = 39) and general hospital professionals (*n* = 19) and intellectual disability liaison nurses (*n* = 6). The study identified managing risk, providing advice, educational support, providing psychological support, undertaking pre-morbid baseline assessment, producing guidelines and accessible information, mediating, facilitating, influencing, advocating, communicating, collaborating, and educating as key interventions undertaken by intellectual disability liaison nurses. The authors concluded that intellectual disability liaison nursing interventions impact on clinical patient care; education and practice development strategic organisational developments. The interventions identified focussed on adults. *Themes (Enhancing impact of services. Enhancing quality of life. Effectuating nursing procedures).*

A study undertaken by Jenkins (2012) in the UK explored the implications for registered nurses in meeting the health needs of older people with intellectual disabilities. Case study methodology was used with older people with intellectual disabilities (*n* = 6; age range – 45 – 75+). Diagnosing mental health problems, constipation, hearing and visual problems, and strokes were identified as important interventions. The study concluded that in order to engage effectively in complex interventions, intellectual disability nurses require a wide range of knowledge and assessment skills that are essential in identifying the complex public health needs of people with intellectual disabilities. The interventions identified focussed on adults and older adults. *Theme (Effectuating nursing procedures).*

A study undertaken in the UK by Marsham (2012) explored the nursing therapeutic role from the perspective of community intellectual disability nurses. Descriptive phenomenology, semi-structured interviews and systematic content analysis were used. Practicing community intellectual disability nurses with more than 2 years' experience of managing an adult

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caseload (*n* = 7) participated in the study. Managing long-term conditions, facilitating self-management, escalating treatment pathways, facilitating development of coping skills, reducing challenging behaviour, facilitating access to healthcare, and assessing people's understanding of their needs were described as interventions undertaken by community intellectual disability nurses. The author also concluded that community intellectual disability nurses engaged in a wide range of therapeutic interventions. The interventions identified focussed on adults. *Themes (Enhancing impact of services. Enhancing quality of life. Effectuating nursing procedures).*

Taggart *et al. (*2011) examined how community nurses and residential staff support women with intellectual disabilities to access breast screening services. The study involved 6 focus groups with community intellectual disability nurses and residential care staff (*n* = 29) and thematic content analysis was used to analyse the data. Raising breast awareness, provision of information on healthier lifestyles, supporting women to self-examine and report any abnormalities, developing health education material, and training health and social care staff were identified as interventions undertaken by community intellectual disability nurses. The authors concluded that effective public health interventions by intellectual disability nurses need to be holistic. The interventions identified focussed on adults. *Themes (Enhancing impact of services. Enhancing quality of life).*

The New Zealand stud by Campbell (2011) described nurses' emotional response to violent incidents and explored the support they required in dealing with constant exposure to workplace violence. The setting for this study was a 10-bed unit for adults with intellectual disability and challenging behaviour. The participants intellectual disability registered nurses (*n* = 6). The study identified managing violence and challenging behaviour as an important intervention undertaken by nurses. This study concluded that working with individuals with intellectual disability and challenging behaviour is an emotionally distressing job due to the

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constant anxiety related to the anticipation of violence. The interventions identified focussed on adults. *Theme (Effectuating nursing procedures).*

In a UK PhD thesis study Ng (2011) explored the perceived knowledge and skills of intellectual disability nurses in the context of how they assessed, recognised and discovered patients' illnesses and how they provided end of life care needs to terminally ill people with profound intellectual disabilities in residential care homes. Grounded theory. Grounded Theory, in-depth interviews, and thematic analysis were with intellectual disability nurses (*n* = 36). The study identified undertaking baseline physical health assessments, and assessing changing health conditions as important roles undertaken by intellectual disability nurses working with people with intellectual disability who have end of life care needs. The author concluded that ongoing assessment of needs and inter-professional working are essential to maintaining and promoting the health and wellbeing of people with intellectual disability who are terminally ill. The interventions identified focussed on end of life care. *Theme (Effectuating nursing procedures).*

Mason and Phipps (2010) reported on a study undertaken in the UK which, aimed to identify the main skills and competencies of forensic intellectual disability nurses. The purpose of the study was to establish if these perceived main skills and competencies differ between forensic and non-forensic intellectual disability nurses, and to identify the perceived areas of forensic intellectual disability nursing skills and competencies that require developing. Participants were divided into two study groups; (1) forensic intellectual disability nurses from the high, medium, and low secure psychiatric services, and (2) non-forensic intellectual disability nurses from generic services. An information gathering questionnaire was used to collect data (*n* = 643) (53.5% response rate). Management of violence, control and restraint, control of medication, risk assessment and risk management, managing self-harm, de-escalation, implementing early interventions, relationship formation with service users, implementing assessment strategies, offence-specific interventions, family therapy, and psychological interventions were the main interventions undertaken by

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intellectual disability nurses who participated in this study. The study concluded that there are differences in the perceptions of what constitutes forensic intellectual disability skills, and competencies between the forensic and non-forensic intellectual disability nurses. The interventions identified focussed on adults. *Themes (Enhancing quality of life. Effectuating nursing procedures).*

In Ireland McKeon (2009)'s study aimed at providing a baseline of clinical nursing skills used in intellectual disability nursing. The objectives were to determine the types and levels of clinical nursing skills used in intellectual disability nursing. The study used a questionnaire survey (questionnaire used a nursing skills list from The Royal Marsden Hospital Manual of Clinical (Mallett and Dougherty, 2000)) (*n* = 26, 18 from a residential setting and 8 from a community living setting). In this study violence prevention, and needs assessment were identified as interventions undertaken by intellectual disability nurses. The interventions identified focussed on adults. *Themes (Enhancing quality of life. Effectuating nursing procedures).*

Llewellyn and Northway (2007) reported on a study undertaken in the UK. The study investigated the advocacy role of intellectual disability nurses in Wales. Grounded theory and focus groups were used with registered intellectual disability nurses (*n* = 18) working in small residential settings. Advocating for service users was reported as an important intervention undertaken by intellectual disability nurses. The authors concluded that the advocacy role of the intellectual disability nurse is important to the delivery of health services to people with intellectual disability. The interventions identified focussed on adults. *Theme (Enhancing impact of services.*

In a study undertaken in the UK, Slevin and Sines (2005) investigated the role of intellectual disability nurses in their day-to-day work with people who challenge. Grounded theory and in-depth face-to-face interviews were used (*n* = 22 intellectual disability nurses). The study identified; promoting amelioration of detrimental effects of challenging behaviour,

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undertaking assessments, educating staff in residential homes or in school, and monitoring and evaluating care interventions as key interventions undertaken by intellectual disability nurses when working with people with intellectual disability and challenging behaviours. The authors concluded that needs assessment underlay intellectual disability nurse interventions when working with people with challenging needs. The interventions identified focussed on adults. *Themes (Enhancing impact of services. Enhancing quality of life. Effectuating nursing procedures).*

In the UK, Llewellyn (2005)'s study explored the advocacy role of intellectual disability nurses. This was a 3-stage mixed method study within a Grounded Theory methodology, augmented by situational analyses and mapping. This publication relates to stage 2 in which focus groups were undertaken with intellectual disability nurses (*n* = 6). Advocating for people with intellectual disabilities, and enabling things to happen for people with intellectual disabilities were identified as key advocacy interventions undertaken by intellectual disability nurses. The interventions identified focussed on adults. *Themes (Enhancing impact of services. Enhancing quality of life).*

Marshall *et al.* (2003) undertook a follow-up study in Northern Ireland, UK of 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 participants' weight loss. A clinic led by intellectual disability nurses (*n* = 2) was held for all people aged 10 years and over (*n* = 464). The study identified health screening and health promotion as important interventions undertaken by intellectual disability nurses. The study concluded that to be effective intellectual disability nurses need to combine health screening with health promotion when working with children, adults and older adults with intellectual disabilities living with obesity. The interventions identified focussed on children, adults, and older adults. *Themes (Enhancing impact of services. Enhancing quality of life).*

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Marshall and Foster (2002) explored what the most appropriate healthcare role was for delivering health care in a special school catering for children with a broad range of severe intellectual disabilities in the UK. Four in-depth focus group interviews (8-10 interviewees per group) and stratified random sampling were used. Participants were; teachers, classroom assistants, parents, occupational therapists, physiotherapists, speech and language therapists, social workers, and community intellectual disability nurses. Liaising with professionals and significant others such as parents and relatives, providing hygiene advice, providing dietary advice, and continence promotion were reported as important interventions undertaken by community intellectual disability nurses who participated in the study. The authors concluded that effective interventions by intellectual disability nurses need to engage all stakeholders at individual and population levels. The interventions identified focussed on children. *Themes (Enhancing impact of services. Enhancing quality of life).*

In a study undertaken in the UK, Barr *et al.* (1999) introduced health screening for people with intellectual disability in an area in Northern Ireland. The health screening project involved screening for weight, blood pressure, urine-analysis, breast cancer, testicular cancer, eye test, hearing test. 373 people with intellectual disabilities were screened by community intellectual disability nurses. Health screening, eye testing, and hearing testing were the reported interventions undertaken by intellectual disability nurses. The authors concluded that the primary intervention of community intellectual disability nurses was raising the profile of the health needs of people with intellectual disabilities. The interventions identified focussed on adults. *Themes (Enhancing quality of life. Effectuating nursing procedures).*

Opinion papers (n = 9)

The project report by Cope and Shaw (2019) was commissioned by the then Chief Nurse for NHS England, UK. The project was also supported by Health Education England (London Region) to raise the profile of the unique and important contribution that intellectual disability nurses make

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across health and social care services. This report was a scoping exercise which, involved a small advisory group of intellectual disabilities nurses from practice, education and research. Twitter chats, an online survey and face-to-face stakeholder events were used to engage practising nurses. Empowering the person with an intellectual disability to have a fulfilling life, supporting families, promoting choices, promoting human rights, reducing the impact of health inequalities, advocating for and influence the care given, supporting / providing information on health conditions, promoting health and wellbeing (physical and mental health), facilitating reasonable adjustments, providing easy read information, and supporting admissions and outpatients were identified as some of the important interventions undertaken by intellectual disability nurses in both health and social care setting. The interventions identified focussed on all age groups. *Themes (Enhancing impact of services. Enhancing quality of life. Effectuating nursing procedures).*

In Ireland McCarron *et al.* (2018) reported on a project that was aimed at determining the the future role of the registered nurse intellectual disability who provides health and social care services to individuals with an intellectual disability and to their families and carers in a changing landscape. The project report was based on a review of literature, documentary analysis, questionnaire surveys, key informant interviews, and regional focus groups. This report provides an overarching framework to assist all nurses working in disability services to respond to the varying support requirements of individuals with an intellectual disability and their families. The intellectual disability nurse interventions identified in the report were; providing support and advice in primary care, liaison in maternity services, providing health screening, assessment and health promotion in primary care, liaising with health, liaising with social care, liaising with disability services and multi-disciplinary team in primary care, liaison in (children's / adolescent / adult / older adult / end of life) secondary and tertiary health care, and schools (for children), liaison in palliative care, bereavement counselling, promotion of optimal physical health, providing psychosocial support, promotion of mental health, advocating, supporting community integration, supporting

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communication and social connectedness, provision of support with the decision-making, working with families, and development and implementation of behaviour support plans. The interventions identified focussed on maternity, all age groups, and end of life care. *Themes (Enhancing impact of services. Enhancing quality of life. Effectuating nursing procedures).*

In the UK, Delahunty (2017) published an opinion article which, described IDs, the kind of support children with intellectual disabilities need, and how nursing staff might use the Child and Adolescent Intellectual Disability Screening Questionnaire (CAIDS-Q) to help identify children who should be formally assessed for intellectual disability. Identifying children with potential intellectual disability, acting as a link between schools and other services, facilitating transition from nursery into school or transition into adult services, identifying children who should be prioritised for further intellectual disability assessment, and monitoring children's development are described as some of the interventions that could be undertaken by intellectual disability nurses. The author argued that intellectual disability nurses have important roles in promoting the health and wellbeing of children with intellectual disabilities in education settings. The interventions identified focussed on children. *Themes (Enhancing impact of services. Enhancing quality of life. Effectuating nursing procedures).*

Northway *et al.* (2017) published an article which, describes an activity undertaken at a conference in Cardiff (Walse), UK in 2016. This was not an opinion paper but the research was not methodological. Delegates were asked to identify the roles of intellectual disability nurses at different lifespan stages (*n* = 200+ delegates (intellectual disability nurses, students, people with intellectual disabilities and their families, nurses from other fields, and other professionals). Thematic analysis was used to identify themes. The intellectual disability nurses interventions described include; providing family support, providing positive behavioural support, safeguarding of children and adults, health liaison, making reasonable adjustments, health promotion and education, medication monitoring,

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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 intellectual disabilities, providing advice about available services, awareness raising and education, involvement in pre-natal screening - providing support in relation to diagnosis, developmental assessment, providing advice and support to schools, mental health promotion and support, promotion of resilience, dementia assessment, promoting employment, and supporting individuals to remain in their home. The authors concluded that in order to effectively promote the health and wellbeing of people with intellectual disabilities, intellectual disability nurses need to engage in a wide range of roles and they need to assimilate emergent roles. The interventions identified focussed on all age groups. *Themes (Enhancing impact of services. Enhancing quality of life. Effectuating nursing procedures).*

In Ireland, an opinion paper written by Nelson and Carey (2016) highlighted the importance of the role of intellectual disability nurses in assessing mobility, as part of the holistic assessment of older adults with intellectual disabilities, and describes a variety of resources practitioners can use. Promotion of the health and well-being, assessment of mobility decline in older people with intellectual disabilities, and supporting maintenance of optimal health are identified as interventions that could be undertaken by intellectual disability nurses. The authors concluded that ongoing assessment of needs is an essential intervention in maintaining and promoting the health and wellbeing of people with intellectual disabilities. The interventions identified focussed on all age groups. *Themes (Enhancing impact of services. Enhancing quality of life. Effectuating nursing procedures).*

Adams and Shah (2016), in the UK, published an opinion article which, 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 intellectual disabilities. The article highlights; reviewing and assisting with

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the withdrawal of antipsychotic medication, reducing prescribing of antipsychotic medicines, maintaining and Enhancing the general physical health and well-being of people with intellectual disabilities, providing constipation advice, monitoring medication effectiveness, and improving communication between healthcare professionals in primary and secondary care as some of the interventions undertaken by intellectual disability nurses in this area of practice. The authors concluded that monitoring the effectiveness of treatments is essential to the promotion of the health and wellbeing of people with intellectual disabilities. The interventions identified focussed on all age groups. *Themes (Enhancing impact of services. Enhancing quality of life).*

In the UK, Morton-Nance (2015) wrote an opinion article which, explores the evolving role of intellectual disability nurses and their unique contribution, specifically within the acute setting, and examines the nature of specialist nursing in practice. The paper identifies; pre-admission screening, clinical assessment, advocating for people with intellectual disabilities, advising hospital staff on reasonable adjustments, assisting with capacity/risk assessments, advising on and providing a plan of care for complex admissions and discharge, educating people with intellectual disabilities, educating family members and carers, raising awareness of intellectual disabilities and autism, serving as a contact person for community and inpatient services, and providing advice on treatment options as important interventions undertaken by intellectual disability nurses in acute care settings. The interventions identified focussed on all age groups. *Themes (Enhancing impact of services. Enhancing quality of life. Effectuating nursing procedures).*

This opinion paper was written in Ireland by Sheerin (2012). The aim of the paper is not clearly stated but includes a review of policy development and research evidence in intellectual disability nursing practice. The paper identifies assessment of need, health surveillance and health promotion, enablement and empowerment, addressing health inequalities as important interventions undertaken by intellectual disability nurses in supporting people with intellectual disabilities. The interventions

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identified focussed on is unclear. *Themes (Enhancing impact of services. Enhancing quality of life).*

The guidance (DoH, 2007) published by the Department of Health of England, UK highlights how ID nurse contributions can be made even more effective in the future. Health promotion, health facilitation, teaching other health and social care professionals, and service development are highlighted as roles and interventions that intellectual disability nurses need to engage in. The interventions identified focussed on all age groups. *Themes (Enhancing impact of services. Enhancing quality of life).*

Synthesis of results

In *table 3* we summarize and present the charting results as they relate to the review questions and objectives. We identified 154 interventions undertaken by ID nurses. We categorised the interventions into three themes; *Effectuating nursing procedures* (52 interventions), *Enhancing impact of services* (73 interventions), and *Enhancing quality of life* (41 interventions). Of the 54 publications we have included; two referred to maternity, five related to children, ten related to adults, thirty-one related to all age groups, five related to older adults, five related to end-of-life care, and one was unclear. The discrepancy in the numbers is due to the fact that some publications were related to more than one category of lifespan. Out of all the 154 interventions we have identified, only 2 were underpinned by some evidence of effectiveness.

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Table 3: ID nursing interventions

Intervention	Lifespan	Theme	Evidence of effectiveness of intervention	Evidence source(s)
1. Act as a link between schools and other services	Children	Enhancing impact of services	No	1. Delahunty, L. (2017) / UK
2. Addressing determinants of health and health inequalities	All age groups	Enhancing quality of life	No	1. Cope, G. and Shaw, T. (2019) / UK 2. Mafuba, K., Forster, M., Kupara, D., and Gates, B. (2018b) / UK **3.** Sheerin, F.K. (2012) / Ireland
3. Advance care planning	End of life	Enhancing impact of services Enhancing quality of life	No	1.Wagemans, A.M.A., van Schrojenstein Lantman-de Valk, H.M.J., Proot, I.M., et al (2015) / Netherlands
4. Advising hospital staff on reasonable adjustments	All age groups	Enhancing impact of services	No	1. Morton-Nance, S. (2015) / UK
5. Advising on and providing a plan of care for complex admissions and discharge	All age groups	Enhancing impact of services	No	1. Morton-Nance, S. (2015) / UK

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Intervention	Lifespan	Theme	Evidence of effectiveness of intervention	Evidence source(s)
6. Advocating for people with intellectual disabilities and / or their families	All age groups	Enhancing impact of services Enhancing quality of life	No	1. Cope, G. and Shaw, T. (2019) / UK 2. McCarron, M., Sheerin, F., Roche, L., Ryan, AM., Griffiths, C., Keenan, P., Doody, O., D'Eath, M., Burke, E., McCallion, P. (2018) / Ireland 3. Ring H., Howlett, J., Pennington, M., *et al.* (2018) / UK 4. Doody, O., Slevin, E. and Taggart, L. (2017) / Ireland 5. Brown, M., Chouliara, Z., MacArthur, J., McKechanie, A., Mack, S., Hayes, M., and Fletcher, J (2016) / UK 6. Morton-Nance, S. (2015) / UK 7. Dalgarno, M.F. and Riordan, S.A. (2014) / UK 8. Taua, C., Hepworth, J. and Neville, C. (2012)/ Australia 9. Brown, M., MacArthur, J., McKechanie, A., Mack, S., Hayes, M. and Fletcher, J. (2012) / UK 10. Llewellyn, P. and Northway, R. (2007) / UK 11. Llewellyn, P. (2005) / UK 12. Morton-Nance, S. (2015) / UK
7. Assess changing health conditions and detecting deterioration	End of life	Enhancing quality of life Effectuating nursing procedures	No	1.Ng, J. S. W. (2011) / UK, PhD Thesis 2.Wagemans, A.M.A., van Schrojenstein Lantman-de Valk, H.M.J., Proot, I.M., *et al.,* (2015) / Netherlands
8. Assessing effectiveness of interventions	All age groups	Enhancing impact of services	No	1. Mafuba, K., Forster, M., Kupara, D., and Gates, B. (2018) / UK

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Intervention	Lifespan	Theme	Evidence of effectiveness of intervention	Evidence source(s)
9. Assessment of needs	All age groups	Effectuating nursing procedures	No	1. McCarron, M., Sheerin, F., Roche, L., Ryan, AM., Griffiths, C., Keenan, P., Doody, O., D'Eath, M., Burke, E., McCallion, P. (2018) / Ireland 2. Quinn, B.L., and Smolinski, M (2018) / USA 3.Doody, O., Slevin, E. and Taggart, L. (2017) / Ireland 4. Delahunty, L. (2017) / UK 5. Northway, R., Cushing, K., Duffin, S., et al. (2017) 6. Nelson, S. and Carey, E. (2016) / Ireland 7. MacArthur, J., Brown, M., McKechani, A., Mack, S., Hayes, M. and Fletcher, J. (2015) / UK 8. Morton-Nance, S. (2015) / UK 9. Chapman, H.M. (2015) / UK 10. Bailey, M., Doody, O. and Lyons, R. (2014)/ Ireland 11. Brown, M., MacArthur, J., McKechanie, A., Mack, S., Hayes, M. and Fletcher, J. (2012) / UK **12.** Sheerin, F.K. (2012) / Ireland 13. Ng, J. S. W. (2011) / UK, PhD Thesis 14. Mason, T. and Phipps, D. (2010)/ UK 15. McKeon, M. (2009) / Ireland 16. Slevin, E. and Sines, D. (2005) / UK
10. Assessing people's	Adults	Enhancing quality of life	No	1. Marsham, M. (2012) / UK

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Intervention	Lifespan	Theme	Evidence of effectiveness of intervention	Evidence source(s)
understanding of their needs 11. Assessing risk	Adults	Effectuating nursing procedures	No	1.Pennington, M., *et al*. (2019)/ UK 2. Dalgarno, M.F. and Riordan, S.A. (2014) / UK 3. Mason, T. and Phipps, D. (2010)/ UK
12. Assessment of mobility decline in older people with intellectual disabilities	Older adults	Effectuating nursing procedures	No	1. Nelson, S. and Carey, E. (2016) / Ireland
13. Assisting with capacity/risk assessments	All age groups	Enhancing impact of services	No	1. Morton-Nance, S. (2015) / UK
14. Awareness raising and education	All age groups	Enhancing quality of life	No	1. Northway, R., Cushing, K., Duffin, S., Payne, T., Price, P. and Sutherland, K. (2017) / UK
15. Behavioural intervention and support	Adults Older adults	Effectuating nursing procedures	No	1. Cleary, J. and Doody, O. (2017)/ Ireland 2. Taua, C., Hepworth, J. and Neville, C. (2012)/ Australia
16. Bereavement counselling	End of life	Effectuating nursing procedures	No	1. McCarron, M., Sheerin, F., Roche, L., Ryan, AM., Griffiths, C., Keenan, P., Doody, O., D'Eath, M., Burke, E., McCallion, P. (2018) / Ireland
17. Building therapeutic relationships	Adults	Enhancing quality of life Effectuating nursing procedures	No	1.Lovell, A., Smith, D. and Johnson, P. (2015)/ UK 2.Arrey, S. K. (2014) / UK PhD Thesis 3. Lee, A. and Kiemle, G. (2014) / UK 4. Lovell, A., Bailey, J., Kingdon, A. and Gentile, D. (2014) / UK 5. Mason, T. and Phipps, D. (2010)/ UK

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Intervention	Lifespan	Theme	Evidence of effectiveness of intervention	Evidence source(s)
18. Care planning	All age groups	Effectuating nursing procedures	No	1. Taua, C., Hepworth, J. and Neville, C. (2012)/ Australia
19. Caregiving	Older adults End of life	Effectuating nursing procedures	No	1. Doody, O., Slevin, E. and Taggart, L. (2019)/ Ireland 2. Cleary, J. and Doody, O. (2017)/ Ireland 3. Wagemans, A.M.A., van Schrojenstein Lantman-de Valk, H.M.J., Proot, I.M., et al (2015) / Netherlands
20. Clinical diagnosis	Adults Older adults	Effectuating nursing procedures	No	1.Pennington, M., *et al*. (2019)/ UK 2.Jenkins, R. (2012) / UK
21. Collaborating	Adults	Enhancing effectives	No	1. Brown, M., MacArthur, J., McKechanie, A., Mack, S., Hayes, M. and Fletcher, J. (2012) / UK
22. Co-ordinating communications	All age groups	Enhancing effectives	No	1. Drozd, M. and Clinch, C. (2016)/ UK 2. Brown, M., MacArthur, J., McKechanie, A., Mack, S., Hayes, M. and Fletcher, J. (2012) / UK 3.Arrey, S. K. (2014) / UK PhD Thesis 4.Wagemans, A.M.A., van Schrojenstein Lantman-de Valk, H.M.J., Proot, I.M., et al (2015) / Netherlands
23. Completing hospital/ hospice referrals	End of life	Effectuating nursing procedures	No	1.Bailey, M., Doody, O. and Lyons, R. (2014)/ Ireland
24. Consulting with other services / agencies	Adults	Enhancing impact of services	No	1. Doody, O., Slevin, E. and Taggart, L. (2019)/ Ireland
25. Continence promotion	Children	Enhancing quality of life	No	1. Marshall, D. and Foster, I. (2002) / UK

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Intervention	Lifespan	Theme	Evidence of effectiveness of intervention	Evidence source(s)
26. Control and restraint practice	Children Adults	Effectuating nursing procedures	No	1. Oulton, K., Wray, J., Hassiotis, A., Kenten, C., Russell, J., Tuffrey-Wijne, I., Whiting, M. and Gibson, F. (2019) / UK 2.Lovell, A., Smith, D. and Johnson, P. (2015)/ UK 3. Mason, T. and Phipps, D. (2010)/ UK
27. Control of medication	Adults	Effectuating nursing procedures	No	1. Mason, T. and Phipps, D. (2010)/ UK
28. Coordinating services	Older adults End of life	Enhancing impact of services	No	1.Cleary, J. and Doody, O. (2017)/ Ireland 2.Bailey, M., Doody, O. and Lyons, R. (2014)/ Ireland
29. Counselling patients and families	Adults	Enhancing quality of life	No	1. Ring H., Howlett, J., Pennington, M., *et al.* (2018) / UK
30. De-escalation and preventing crisis	Adults	Effectuating nursing procedures	No	1.Lovell, A., Smith, D. and Johnson, P. (2015)/ UK 2.Mason, T. and Phipps, D. (2010)/ UK
31. Delivering formal / informal education	Adults	Enhancing impact of services	No	1.Doody, O., Slevin, E. and Taggart, L. (2017) / Ireland
32. Dementia assessment	Older adults	Effectuating nursing procedures	No	1. Northway, R., Cushing, K., Duffin, S., Payne, T., Price, P. and Sutherland, K. (2017) / UK
33. Developing appropriate policies	All age groups	Enhancing impact of services	No	1.Mafuba, K. (2013) / UK. PhD Thesis

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Intervention	Lifespan	Theme	Evidence of effectiveness of intervention	Evidence source(s)
34. Developing easy to understand letters, guidelines and information	Adults	Enhancing impact of services	No	1.Brown, M., MacArthur, J., McKechanie, A., Mack, S., Hayes, M. and Fletcher, J. (2012) / UK 2.Marriott, A., Turner, S., Ashby, S. and Rees, D. (2015) / UK
35. Developing health education material	Adults	Enhancing impact of services Enhancing quality of life	No	1. Taggart, L., Truesdale-Kennedy, M. and McIlfatrick, S. (2011) / UK
36. Development and implementation of behaviour support plans	All age groups	Effectuating nursing procedures	No	1. McCarron, M., Sheerin, F., Roche, L., Ryan, AM., Griffiths, C., Keenan, P., Doody, O., D'Eath, M., Burke, E., McCallion, P. (2018) / Ireland
37. Developmental assessment	Children	Effectuating nursing procedures	No	1. Northway, R., Cushing, K., Duffin, S., Payne, T., Price, P. and Sutherland, K. (2017) / UK 2. Delahunty, L. (2017) / UK
38. Diet and nutrition management	End of life	Effectuating nursing procedures	No	1.Bailey, M., Doody, O. and Lyons, R. (2014)/ Ireland
39. Educating people with intellectual disabilities, family members, staff, and carers	All age groups End of life	Enhancing impact of services Enhancing quality of life	No	1. Cleary, J. and Doody, O. (2017)/ Ireland 2. Morton-Nance, S. (2015) / UK 3. MacArthur, J., Brown, M., McKechani, A., Mack, S., Hayes, M. and Fletcher, J. (2015) / UK 4. Dalgarno, M.F. and Riordan, S.A. (2014) / UK

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Intervention	Lifespan	Theme	Evidence of effectiveness of intervention	Evidence source(s)
				5. Brown, M., MacArthur, J., McKechanie, A., Mack, S., Hayes, M. and Fletcher, J. (2012) / UK 6. Slevin, E. and Sines, D. (2005) / UK
40. Enabling and empowering	Not stated	Enhancing quality of life	No	**1.** Sheerin, F.K. (2012) / Ireland
41. Enabling and supporting healthy lifestyle choices	All age groups	Enhancing quality of life	No	1. Mafuba, K., Forster, M., Kupara, D., and Gates, B. (2018) / UK
42. Enabling creative communication	Adults	Enhancing impact of services	No	1. Taua, C., Neville, C. and Scot, T. (2017)/ New Zealand
43. Enabling things to happen	Adults	Enhancing impact of services	No	1. Llewellyn, P. (2005) / UK
44. Encouraging clients to make their own decisions	Adults	Enhancing quality of life	No	1. Llewellyn, P. (2005) / UK
45. Engaging other agencies	Children	Enhancing impact of services	No	1. Oulton, K., Wray, J., Hassiotis, A., Kenten, C., Russell, J., Tuffrey-Wijne, I., Whiting, M. and Gibson, F. (2019) / UK
46. Engaging senior managers	Children	Enhancing impact of services	No	1. Oulton, K., Wray, J., Hassiotis, A., Kenten, C., Russell, J., Tuffrey-Wijne, I., Whiting, M. and Gibson, F. (2019) / UK

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Intervention	Lifespan	Theme	Evidence of effectiveness of intervention	Evidence source(s)
47. Escalating treatment pathways	Adults	Enhancing impact of services	No	1. Marsham, M. (2012) / UK
48. Evaluation of care interventions and outcomes	Adults	Effectuating nursing procedures	No	1. Doody, O., Slevin, E. and Taggart, L. (2019)/ Ireland
49. Eye testing	Adults	Effectuating nursing procedures	No	1. Barr, O., Gilgunn, J., Kane, T. and Moore, G. (1999) / UK
50. Facilitating access to health services (Health facilitation)	All age groups	Enhancing impact of services	No	1. Mafuba, K., Forster, M., Kupara, D., and Gates, B. (2018) / UK 2. Mafuba, K., Gates, B. and Cozens, M. (2018) / UK 3. Mafuba, K. and Gates, B. (2013) / UK 4.Mafuba, K. (2013) / UK. PhD Thesis 5. Brown, M., MacArthur, J., McKechanie, A., Mack, S., Hayes, M. and Fletcher, J. (2012) / UK 6. Mafuba, K. (2009) / UK 7. DoH (2007) / England, UK
51. Facilitating collaborative working	End of life	Enhancing impact of services	No	1.Arrey, S. K. (2014) / UK PhD Thesis
52. Facilitating communication	All age groups End of life	Enhancing impact of services	No	1.Oulton, K., Wray, J., Hassiotis, A., Kenten, C., Russell, J., Tuffrey-Wijne, I., Whiting, M. and Gibson, F. (2019) / UK 2. Northway, R., Cushing, K., Duffin, S., Payne, T., Price, P. and Sutherland, K. (2017) / UK 3.Adams, D. and Shah, C. (2016) / UK

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Intervention	Lifespan	Theme	Evidence of effectiveness of intervention	Evidence source(s)
				4.Wagemans, A.M.A., van Schrojenstein Lantman-de Valk, H.M.J., Proot, I.M., et al (2015) / Netherlands 5. Morton-Nance, S. (2015) / UK 6.Wagemans, A.M.A., van Schrojenstein Lantman-de Valk, H.M.J., Proot, I.M., et al (2015) / Netherlands 7.Arrey, S. K. (2014) / UK PhD Thesis
53. Facilitating development of coping skills	Adults	Enhancing quality of life	No	1. Marsham, M. (2012) / UK
54. Facilitating multi-disciplinary working and inter- agency liaison	All age groups	Enhancing impact of services	No	1. Morton-Nance, S. (2015) / UK 2. Lovell, A., Bailey, J., Kingdon, A. and Gentile, D. (2014) / UK
55. Facilitating reasonable adjustments	All age groups	Enhancing impact of services	No	1. Cope, G. and Shaw, T. (2019) / UK 2. Mafuba, K., Forster, M., Kupara, D., and Gates, B. (2018) / UK 3. MacArthur, J., Brown, M., McKechani, A., Mack, S., Hayes, M. and Fletcher, J. (2015) / UK
56. Facilitating self-management	Adults	Enhancing impact of services	No	1. Marsham, M. (2012) / UK
57. Facilitating specialist clinics	Children	Effectuating nursing procedures	No	1. Oulton, K., Wray, J., Hassiotis, A., Kenten, C., Russell, J., Tuffrey-Wijne, I., Whiting, M. and Gibson, F. (2019) / UK

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Intervention	Lifespan	Theme	Evidence of effectiveness of intervention	Evidence source(s)
58. Facilitating transitions	All age groups	Enhancing impact of services	No	1. Delahunty, L. (2017) / UK 2. Northway, R., Cushing, K., Duffin, S., Payne, T., Price, P. and Sutherland, K. (2017) / UK
59. Family therapy / support	Adults	Effectuating nursing procedures	No	1. Oulton, K., Wray, J., Hassiotis, A., Kenten, C., Russell, J., Tuffrey-Wijne, I., Whiting, M. and Gibson, F. (2019) / UK 2. Mason, T. and Phipps, D. (2010)/ UK
60. Finding resources for end of life care	End of life	Enhancing impact of services	No	1.Bailey, M., Doody, O. and Lyons, R. (2014)/ Ireland
61. Flagging and identifying needs	Children	Enhancing impact of services	No	1. Oulton, K., Wray, J., Hassiotis, A., Kenten, C., Russell, J., Tuffrey-Wijne, I., Whiting, M. and Gibson, F. (2019) / UK
62. Focussed assessment to avoid diagnostic overshadowing	Adults	Effectuating nursing procedures	No	1. Taua, C., Neville, C. and Scot, T. (2017)/ New Zealand

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Intervention	Lifespan	Theme	Evidence of effectiveness of intervention	Evidence source(s)
63. Giving information and advice	Adults End of life	Enhancing impact of services Enhancing quality of life	No	1. Oulton, K., Wray, J., Hassiotis, A., Kenten, C., Russell, J., Tuffrey-Wijne, I., Whiting, M. and Gibson, F. (2019) / UK 2. Cope, G. and Shaw, T. (2019) / UK 3. Mafuba, K., Gates, B. and Cozens, M. (2018) / UK 4. McCarron, M., Sheerin, F., Roche, L., Ryan, AM., Griffiths, C., Keenan, P., Doody, O., D'Eath, M., Burke, E., McCallion, P. (2018) / Ireland 5. Northway, R., Cushing, K., Duffin, S., Payne, T., Price, P. and Sutherland, K. (2017) / UK 6.Doody, O., Slevin, E. and Taggart, L. (2019)/ Ireland 7.Doody, O., Slevin, E. and Taggart, L. (2017) / Ireland 8.MacArthur, J., Brown, M., McKechani, A., Mack, S., Hayes, M. and Fletcher, J. (2015) / UK 9.Wagemans, A.M.A., van Schrojenstein Lantman-de Valk, H.M.J., Proot, I.M., et al (2015) / Netherlands 10. Morton-Nance, S. (2015) / UK 11. Bailey, M., Doody, O. and Lyons, R. (2014)/ Ireland 12. Brown, M., MacArthur, J., McKechanie, A., Mack, S., Hayes, M. and Fletcher, J. (2012) / UK 13. Marshall, D. and Foster, I. (2002) / UK

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Intervention	Lifespan	Theme	Evidence of effectiveness of intervention	Evidence source(s)
64. Handling complaints	Children	Enhancing impact of services	No	1. Oulton, K., Wray, J., Hassiotis, A., Kenten, C., Russell, J., Tuffrey-Wijne, I., Whiting, M. and Gibson, F. (2019) / UK
65. Health education	All age groups	Enhancing quality of life	No	1. Mafuba, K., Forster, M., Kupara, D., and Gates, B. (2018) / UK 2. Mafuba, K. and Gates, B. (2013) / UK 3.Mafuba, K. (2013) / UK. PhD Thesis 4.Taggart, L., Truesdale-Kennedy, M. and McIlfatrick, S. (2011) / UK 5. Mafuba, K. (2009) / UK
66. Health liaison	All age groups	Enhancing impact of services	No	1. Northway, R., Cushing, K., Duffin, S., Payne, T., Price, P. and Sutherland, K. (2017) / UK 2. Morton-Nance, S. (2015) / UK
67. Health prevention	All age groups	Enhancing impact of services	No	1. Mafuba, K. and Gates, B. (2013) / UK 2.Mafuba, K. (2013) / UK. PhD Thesis

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Intervention	Lifespan	Theme	Evidence of effectiveness of intervention	Evidence source(s)
68. Health promotion	Maternity All age groups	Enhancing quality of life	No	1. Cope, G. and Shaw, T. (2019) / UK 2. Doody, O., Slevin, E. and Taggart, L. (2019)/ Ireland 3. McCarron, M., Sheerin, F., Roche, L., Ryan, AM., Griffiths, C., Keenan, P., Doody, O., D'Eath, M., Burke, E., McCallion, P. (2018) / Ireland 4. Mafuba, K., Forster, M., Kupara, D., and Gates, B. (2018) / UK 5. Mafuba, K., Gates, B. and Cozens, M. (2018) / UK 6. Northway, R., Cushing, K., Duffin, S., Payne, T., Price, P. and Sutherland, K. (2017) / UK 7. Adams, D. and Shah, C. (2016) / UK 8. Nelson, S. and Carey, E. (2016) / Ireland 9. Mafuba, K. and Gates, B. (2013) / UK 10. Mafuba, K. (2013) / UK. PhD Thesis 11. Taua, C., Hepworth, J. and Neville, C. (2012)/ Australia 12. Sheerin, F.K. (2012) / Ireland 13. Taggart, L., Truesdale-Kennedy, M. and McIlfatrick, S. (2011) / UK 14. Mafuba, K. (2009) / UK 15. DoH (2007) / England, UK 16. Marshall, D., McConkey, R. and Moore, G. (2003) / UK
69. Health protection	All age groups	Enhancing impact of services	No	1. Mafuba, K. and Gates, B. (2013) / UK

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Intervention	Lifespan	Theme	Evidence of effectiveness of intervention	Evidence source(s)
				2. Mafuba, K. (2013) / UK. PhD Thesis
70. Health screening	All age groups	Effectuating nursing procedures	No	1. McCarron, M., Sheerin, F., Roche, L., Ryan, AM., Griffiths, C., Keenan, P., Doody, O., D'Eath, M., Burke, E., McCallion, P. (2018) / Ireland 2. Marshall, D., McConkey, R. and Moore, G. (2003) / UK 3. Barr, O., Gilgunn, J., Kane, T. and Moore, G. (1999) / UK
71. Health surveillance	All age groups	Enhancing impact of services	No	1. Mafuba, K., Forster, M., Kupara, D., and Gates, B. (2018) / UK 2. Mafuba, K. and Gates, B. (2013) / UK 3. Mafuba, K. (2013) / UK. PhD Thesis 4. Sheerin, F.K. (2012) / Ireland
72. Home nursing care delivery	Adults	Effectuating nursing procedures	No	1. Barr, O., Gilgunn, J., Kane, T. and Moore, G. (1999) / UK
73. Identify children requiring further intellectual disability diagnostic assessment	Children	Effectuating nursing procedures	No	1. Delahunty, L. (2017) / UK
74. Identifying equipment and resources	Children	Enhancing impact of services	No	1. Oulton *et al.* (2019)
75. Implementing early interventions	Adults	Effectuating nursing procedures	No	1. Mason, T. and Phipps, D. (2010)/ UK

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Intervention	Lifespan	Theme	Evidence of effectiveness of intervention	Evidence source(s)
76. Influencing	Adults	Enhancing impact of services	No	1. Brown, M., MacArthur, J., McKechanie, A., Mack, S., Hayes, M. and Fletcher, J. (2012) / UK
77. Informal support and advice	Children	Enhancing quality of life Enhancing impact of services	No	1. Oulton, K., Wray, J., Hassiotis, A., Kenten, C., Russell, J., Tuffrey-Wijne, I., Whiting, M. and Gibson, F. (2019) / UK
78. Information sharing	All age groups End of life	Enhancing impact of services	No	1. Mafuba, K., Forster, M., Kupara, D., and Gates, B. (2018) / UK 2. Wagemans, A.M.A., van Schrojenstein Lantman-de Valk, H.M.J., Proot, I.M., *et al.* (2015) / Netherlands
79. Interpreting complaints and symptoms	End of life	Effectuating nursing procedures	No	1.Wagemans, A.M.A., van Schrojenstein Lantman-de Valk, H.M.J., Proot, I.M., et al (2015) / Netherlands
80. Liaising with health, social care, disability services and multi-disciplinary team in primary care and secondary care	All age groups End of life	Enhancing impact of services	No	1. McCarron, M., Sheerin, F., Roche, L., Ryan, AM., Griffiths, C., Keenan, P., Doody, O., D'Eath, M., Burke, E., McCallion, P. (2018) / Ireland 2. Marshall, D. and Foster, I. (2002) / UK
81. Liaison in maternity services	Maternity	Enhancing impact of services	No	1. McCarron, M., Sheerin, F., Roche, L., Ryan, AM., Griffiths, C., Keenan, P., Doody, O., D'Eath, M., Burke, E., McCallion, P. (2018) / Ireland

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Intervention	Lifespan	Theme	Evidence of effectiveness of intervention	Evidence source(s)
82. Liaison in palliative care	End of life	Enhancing impact of services	No	1. McCarron, M., Sheerin, F., Roche, L., Ryan, AM., Griffiths, C., Keenan, P., Doody, O., D'Eath, M., Burke, E., McCallion, P. (2018) / Ireland
83. Make recommendations relating to client care and client care issues	Adults	Enhancing impact of services	No	1. Doody, O., Slevin, E. and Taggart, L. (2019)/ Ireland
84. Making and facilitating reasonable adjustments	All age groups End of life care	Enhancing impact of services	No	1. Oulton, K., Wray, J., Hassiotis, A., Kenten, C., Russell, J., Tuffrey-Wijne, I., Whiting, M. and Gibson, F. (2019) / UK 2. Cope, G. and Shaw, T. (2019) / UK 3. Mafuba, K., Forster, M., Kupara, D., and Gates, B. (2018) / UK 4. Northway, R., Cushing, K., Duffin, S., Payne, T., Price, P. and Sutherland, K. (2017) / UK 5. Cleary, J. and Doody, O. (2017)/ Ireland 6. Drozd, M. and Clinch, C. (2016)/ UK 7. MacArthur, J., Brown, M., McKechani, A., Mack, S., Hayes, M. and Fletcher, J. (2015) / UK 8.Marriott, A., Turner, S., Ashby, S. and Rees, D. (2015) / UK 9. Morton-Nance, S. (2015) / UK

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Intervention	Lifespan	Theme	Evidence of effectiveness of intervention	Evidence source(s)
85. Making referrals within the MDT	End of life	Enhancing impact of services	No	1.Bailey, M., Doody, O. and Lyons, R. (2014)/ Ireland
86. Managing violence and challenging behaviour	All age groups	Effectuating nursing procedures	No	1. Campbell, A.K. (2011) / New Zealand. 2. Marsham, M. (2012) / UK 3. Mason, T. and Phipps, D. (2010)/ UK 4. McKeon, M. (2009) / Ireland 5. Slevin, E. and Sines, D. (2005) / UK
87. Managing anxiety	Adults	Effectuating nursing procedures	No	1.Brown, M., Chouliara, Z., MacArthur, J., McKechanie, A., Mack, S., Hayes, M., and Fletcher, J (2016) / UK
88. Managing end of life care	End of life	Effectuating nursing procedures	No	1.Bailey, M., Doody, O. and Lyons, R. (2014)/ Ireland
89. Managing epilepsy	Adults	Effectuating nursing procedures	No	1.Pennington, M., *et al*. (2019)/ UK
90. Managing long-term conditions	Adults	Effectuating nursing procedures	No	1. Marsham, M. (2012) / UK
91. Managing risk	Adults	Effectuating nursing procedures	No	1.Pennington, M., *et al*. (2019)/ UK 2. Drozd, M. and Clinch, C. (2016)/ UK 3. Dalgarno, M.F. and Riordan, S.A. (2014) / UK 4. Brown, M., MacArthur, J., McKechanie, A., Mack, S., Hayes, M. and Fletcher, J. (2012) / UK 5. Taua, C., Hepworth, J. and Neville, C. (2012)/ Australia 6. Mason, T. and Phipps, D. (2010)/ UK

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Intervention	Lifespan	Theme	Evidence of effectiveness of intervention	Evidence source(s)
92. Managing self-harm	Adults	Effectuating nursing procedures	No	1. Mason, T. and Phipps, D. (2010)/ UK
93. Managing the challenges of supporting women with complex needs	Adults	Effectuating nursing procedures	No	1. Lloyd, J.L. and Coulson, N.S. (2014) / UK
94. Matching information with capacity to understand	Adults	Enhancing impact of services	No	1.Brown, M., Chouliara, Z., MacArthur, J., McKechanie, A., Mack, S., Hayes, M., and Fletcher, J (2016) / UK
95. Medication administration, management, and monitoring	All age groups	Effectuating nursing procedures	No	1. Ring H., Howlett, J., Pennington, M., *et al.* (2018) / UK 2. Northway, R., Cushing, K., Duffin, S., Payne, T., Price, P. and Sutherland, K. (2017) / UK 3. Adams, D. and Shah, C. (2016) / UK 4. Taua, C., Hepworth, J. and Neville, C. (2012)/ Australia
96. Mental capacity assessment	Children Adults	Enhancing impact of services	No	1. Oulton, K., Wray, J., Hassiotis, A., Kenten, C., Russell, J., Tuffrey-Wijne, I., Whiting, M. and Gibson, F. (2019) / UK 2. Drozd, M. and Clinch, C. (2016)/ UK

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Intervention	Lifespan	Theme	Evidence of effectiveness of intervention	Evidence source(s)
97. Modifying mental health interventions to suit people with ID	Adults	Enhancing impact of services	No	1. Taua, C., Neville, C. and Scot, T. (2017)/ New Zealand
98. Monitoring and evaluating care interventions	Adults	Enhancing impact of services	No	1.Doody, O., Slevin, E. and Taggart, L. (2017) / Ireland 2. Slevin, E. and Sines, D. (2005) / UK
99. Monitoring effectiveness of medications and treatments	All age groups	Enhancing impact of services	No	1. Adams, D. and Shah, C. (2016) / UK
100. Nutrition and dysphagia management	All age groups	Effectuating nursing procedures	No	1. Northway, R., Cushing, K., Duffin, S., Payne, T., Price, P. and Sutherland, K. (2017) / UK
101. Offence-specific interventions	Adults	Effectuating nursing procedures	No	1. Mason, T. and Phipps, D. (2010)/ UK
102. Ordering and interpreting investigations	Adults	Enhancing impact of services	No	1. Ring H., Howlett, J., Pennington, M., *et al.* (2018) / UK
103. Pain assessment	Children	Effectuating nursing procedures	No	1. Quinn, B.L., and Smolinski, M (2018) / USA
104. Pain management	Older adults	Effectuating nursing procedures	No	1. Cleary, J. and Doody, O. (2017)/ Ireland
105. Planning for end of life	End of life	Enhancing impact of services	No	1.Bailey, M., Doody, O. and Lyons, R. (2014)/ Ireland

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Intervention	Lifespan	Theme	Evidence of effectiveness of intervention	Evidence source(s)
106. Positive behaviour support training	Children	Enhancing impact of services	No	1. Oulton, K., Wray, J., Hassiotis, A., Kenten, C., Russell, J., Tuffrey-Wijne, I., Whiting, M. and Gibson, F. (2019) / UK
107. Positive behaviour support	All ages groups	Effectuating nursing procedures	No	1. Northway, R., Cushing, K., Duffin, S., Payne, T., Price, P. and Sutherland, K. (2017) / UK
108. Pre-admission screening	All age groups	Effectuating nursing procedures	No	1. Morton-Nance, S. (2015) / UK
109. Pre-admission support	Children	Enhancing impact of services	No	1. Oulton, K., Wray, J., Hassiotis, A., Kenten, C., Russell, J., Tuffrey-Wijne, I., Whiting, M. and Gibson, F. (2019) / UK
110. Pre-natal screening - providing support in relation to diagnosis	Maternity	Effectuating nursing procedures	No	1. McCarron, M., Sheerin, F., Roche, L., Ryan, AM., Griffiths, C., Keenan, P., Doody, O., D'Eath, M., Burke, E., McCallion, P. (2018) / Ireland
111. Prepare patients for surgery	Adults	Effectuating nursing procedures	No	1. Drozd, M. and Clinch, C. (2016)/ UK
112. Preparing women psychologically for cancer screening	Adults	Enhancing impact of services	No	1. Lloyd, J.L. and Coulson, N.S. (2014) / UK
113. Pressure relief and skin care	End of life	Effectuating nursing procedures	No	1.Bailey, M., Doody, O. and Lyons, R. (2014)/ Ireland
114. Promote choices	All age groups	Enhancing quality of life	No	1. Cope, G. and Shaw, T. (2019) / UK

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Intervention	Lifespan	Theme	Evidence of effectiveness of intervention	Evidence source(s)
115. Promote human rights	All age groups	Enhancing quality of life	No	1. Cope, G. and Shaw, T. (2019) / UK
116. Promoting amelioration of detrimental effects of challenging behaviour	Adults	Enhancing quality of life	No	1. Slevin, E. and Sines, D. (2005) / UK
117. Promoting employment	Adults	Enhancing quality of life	No	1. Northway, R., Cushing, K., Duffin, S., Payne, T., Price, P. and Sutherland, K. (2017) / UK
118. Promoting independence	Adults	Enhancing quality of life	No	1. Drozd, M. and Clinch, C. (2016)/ UK
119. Promoting health checks and screening, personal and sexual relationships	Adults	Enhancing quality of life	No	1. Northway, R., Cushing, K., Duffin, S., Payne, T., Price, P. and Sutherland, K. (2017) / UK
120. Promoting personal and sexual relationships	Adults	Enhancing quality of life	No	1. Northway, R., Cushing, K., Duffin, S., Payne, T., Price, P. and Sutherland, K. (2017) / UK
121. Promotion of resilience	All age groups	Enhancing quality of life	No	1. Northway, R., Cushing, K., Duffin, S., Payne, T., Price, P. and Sutherland, K. (2017) / UK 2. Dalgarno, M.F. and Riordan, S.A. (2014) / UK
122. Providing behavioural advice	Adults	Enhancing impact of services	No	1. MacArthur, J., Brown, M., McKechani, A., Mack, S., Hayes, M. and Fletcher, J. (2015) / UK

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Intervention	Lifespan	Theme	Evidence of effectiveness of intervention	Evidence source(s)
123. Providing diagnostic advice	Adults	Enhancing impact of services	No	1. MacArthur, J., Brown, M., McKechani, A., Mack, S., Hayes, M. and Fletcher, J. (2015) / UK
124. Providing dietary advice	Children	Enhancing impact of services	No	1. Marshall, D. and Foster, I. (2002) / UK
125. Providing emotional support to people with personality disorder	Adults	Enhancing quality of life	No	1. Lee, A. and Kiemle, G. (2014) / UK
126. Providing leadership	All age groups	Enhancing impact of services	No	1. Mafuba, K. (2013) / UK. PhD Thesis
127. Providing palliative care	End of life	Effectuating nursing procedures	No	1. Bailey, M., Doody, O. and Lyons, R. (2014)/ Ireland
128. Providing psychological support	Maternity All age groups End of care	Enhancing quality of life	No	1. McCarron, M., Sheerin, F., Roche, L., Ryan, AM., Griffiths, C., Keenan, P., Doody, O., D'Eath, M., Burke, E., McCallion, P. (2018) / Ireland 2. MacArthur, J., Brown, M., McKechani, A., Mack, S., Hayes, M. and Fletcher, J. (2015) / UK 3. Brown, M., MacArthur, J., McKechanie, A., Mack, S., Hayes, M. and Fletcher, J. (2012) / UK
129. Providing seizure guidance to people with intellectual disability living	Adults	Enhancing impact of services	Yes	1. Auberry, K. and Cullen, D. (2016) / USA

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Intervention	Lifespan	Theme	Evidence of effectiveness of intervention	Evidence source(s)
in the community				
130. Providing seizure telephone triage in the community	Adults	Enhancing impact of services	Yes	1. Auberry, K. and Cullen, D. (2016) / USA
131. Providing support in primary care	All age groups	Enhancing impact of services	No	1. McCarron, M., Sheerin, F., Roche, L., Ryan, AM., Griffiths, C., Keenan, P., Doody, O., D'Eath, M., Burke, E., McCallion, P. (2018) / Ireland
132. Providing support with the decision-making	All age groups	Enhancing impact of services Enhancing quality of life	No	1. McCarron, M., Sheerin, F., Roche, L., Ryan, AM., Griffiths, C., Keenan, P., Doody, O., D'Eath, M., Burke, E., McCallion, P. (2018) / Ireland
133. Psychological interventions	Adults	Effectuating nursing procedures	No	1. Mason, T. and Phipps, D. (2010)/ UK
134. Receiving referrals from another service/ agency	Adults	Effectuating nursing procedures	No	1. Doody, O., Slevin, E. and Taggart, L. (2019)/ Ireland
135. Record keeping	Adults	Enhancing impact of services	No	1. Lovell, A., Bailey, J., Kingdon, A. and Gentile, D. (2014) / UK
136. Reducing use of antipsychotic medicines	All age groups	Enhancing quality of life	No	1. Adams, D. and Shah, C. (2016) / UK

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Intervention	Lifespan	Theme	Evidence of effectiveness of intervention	Evidence source(s)
137. Refer clients to another service/ agency	Adults	Enhancing impact of services	No	1. Doody, O., Slevin, E. and Taggart, L. (2019)/ Ireland
138. Safeguarding of children and adults	All age groups	Enhancing quality of life	No	1. Northway, R., Cushing, K., Duffin, S., Payne, T., Price, P. and Sutherland, K. (2017) / UK
139. Service development	All age groups	Enhancing impact of services	No	1. DoH (2007) / England, UK
140. Shaping the nature of end-of-life care and influence end-of-life decisions	End of life	Enhancing impact of services	No	1. Wagemans, A.M.A., van Schrojenstein Lantman-de Valk, H.M.J., Proot, I.M., et al (2015) / Netherlands
141. Supporting admissions and outpatients	All age groups	Enhancing impact of services	No	1. Cope, G. and Shaw, T. (2019) / UK
142. Supporting social connectedness	Maternity All age groups	Enhancing quality of life	No	1. McCarron, M., Sheerin, F., Roche, L., Ryan, AM., Griffiths, C., Keenan, P., Doody, O., D'Eath, M., Burke, E., McCallion, P. (2018) / Ireland
143. Supporting community integration	All age groups	Enhancing quality of life	No	1. McCarron, M., Sheerin, F., Roche, L., Ryan, AM., Griffiths, C., Keenan, P., Doody, O., D'Eath, M., Burke, E., McCallion, P. (2018) / Ireland

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Intervention	Lifespan	Theme	Evidence of effectiveness of intervention	Evidence source(s)
144. Supporting families	All age groups	Enhancing quality of life Enhancing impact of services	No	1. Cope, G. and Shaw, T. (2019) / UK 2. McCarron, M., Sheerin, F., Roche, L., Ryan, AM., Griffiths, C., Keenan, P., Doody, O., D'Eath, M., Burke, E., McCallion, P. (2018) / Ireland 3. Doody, O., Slevin, E. and Taggart, L. (2017) / Ireland 4. Northway, R., Cushing, K., Duffin, S., Payne, T., Price, P. and Sutherland, K. (2017) / UK 5. Bailey, M., Doody, O. and Lyons, R. (2014)/ Ireland
145. Supporting individuals to remain in their home	All age groups	Enhancing quality of life	No	1. Northway, R., Cushing, K., Duffin, S., Payne, T., Price, P. and Sutherland, K. (2017) / UK
146. Supporting people with intellectual disabilities with a history of offending behaviour to develop relationships	Adults	Enhancing quality of life	No	1.Lovell, A. and Bailey, J. (2016)/ UK
147. Supporting relatives and helping medical staff to make decisions	End of life	Enhancing quality of life Enhancing impact of services	No	1.Wagemans, A.M.A., van Schrojenstein Lantman-de Valk, H.M.J., Proot, I.M., et al (2015) / Netherlands
148. Supporting staff to develop practice	Adults	Enhancing impact of services	No	1. Doody, O., Slevin, E. and Taggart, L. (2019)/ Ireland

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Intervention	Lifespan	Theme	Evidence of effectiveness of intervention	Evidence source(s)
guidelines and policies				
149. Support with substance misuse interventions	Adults	Enhancing impact of services	No	1.Lovell, A. and Bailey, J. (2016)/ UK
150. Support women to manage cervical screening	Adults	Enhancing impact of services	No	1.Marriott, A., Turner, S., Ashby, S. and Rees, D. (2015) / UK
151. Support women to self-examine breasts	Adults	Enhancing impact of services	No	1. Taggart, L., Truesdale-Kennedy, M. and McIlfatrick, S. (2011) / UK
152. Symptom management	End of life	Effectuating nursing procedures	No	1.Bailey, M., Doody, O. and Lyons, R. (2014)/ Ireland
153. Training and raising awareness	All age groups End of life	Enhancing impact of services Enhancing quality of life	No	1.Oulton, K., Wray, J., Hassiotis, A., Kenten, C., Russell, J., Tuffrey-Wijne, I., Whiting, M. and Gibson, F. (2019) / UK 2.Doody, O., Slevin, E. and Taggart, L. (2019)/ Ireland 3.Cleary, J. and Doody, O. (2017)/ Ireland 4.Marriott, A., Turner, S., Ashby, S. and Rees, D. (2015) / UK 5. Morton-Nance, S. (2015) / UK 6.Arrey, S. K. (2014) / UK PhD Thesis 7.Lovell, A., Bailey, J., Kingdon, A. and Gentile, D. (2014) / UK 8.Doody, C., Markey, K. and Doody, O. (2013) /Ireland 9. Taggart, L., Truesdale-Kennedy, M. and McIlfatrick, S. (2011) / UK

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Intervention	Lifespan	Theme	Evidence of effectiveness of intervention	Evidence source(s)
				10. DoH (2007) / England, UK
154. Trouble shooting	Adults	Enhancing impact of services	No	1.Brown, M., Chouliara, Z., MacArthur, J., McKechanie, A., Mack, S., Hayes, M., and Fletcher, J (2016) / UK

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Discussion

In this scoping literature review we have located publications that have specifically identified intellectual disability nursing centered interventions that are in place to respond to the changing needs of the population living with intellectual disabilities. However, apart from one study undertaken in the USA (Auberry and Cullen, 2016) the effectiveness of these interventions has not been demonstrated.

As reported earlier we categorised the 154 interventions identified into three themes; *effectuating nursing procedures* (52 interventions), *enhancing impact of services* (73 interventions), and *enhancing quality of life* (41 interventions). Here we discuss our findings using these themes. Within these themes we have organised the discussion chronologically, following the life span approach, that is, maternity, all age groups, children, adults, older adults, and end-of-life care.

What is clear from this scoping review is the wide range of interventions that intellectual disability nurses undertake in a complex sphere of practice. It is clear from the extent of these interventions that intellectual disability nurses need to constantly adapt and engage in a wide range of roles, and that they need to constantly assimilate emergent roles (Northway *et. al.,* 2017). What also emerges from the current literature under review is the complexity and changing needs of people with intellectual disabilities, the changing environments in which intellectual disability nurses are practising, and the increasing expectation for intellectual disability nurses to meet health needs of people across the lifespan. In effectuating nursing procedures, the scoping review has identified a wide range of nursing procedures that intellectual disability nurses currently undertake. To enhance the impact of services the need for intellectual disability nurses to engage in inter-professional working cannot be over-emphasised. In this review we have also identified the wide range of roles undertaken by intellectual disability nurses, across the lifespan and in a wide range of settings that focus on enhancing the quality of life of people with intellectual disabilities.

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Effectuating nursing procedures

In this theme we identified 52 (34%) interventions undertaken by intellectual disability nurses. The interventions in this theme relate to practice where intellectual disability nurses work to deliver direct care to people with intellectual disabilities.

Maternity

In the UK, the National Health Service (NHS) provides routine screening services. In this review McCarron *et al.,* (2018) highlighted the need for intellectual disability nurses to work with people with access pre-natal screening services. Providing support in this area is important because without such support it is likely that pregnant women with intellectual disabilities may be unable to access appropriate maternity support.

All age groups

Intellectual disability nurses undertake a wide range of needs assessments for people with intellectual disabilities in a wide range of settings and across the lifespan (McCarron et al., 2018); Quinn and Smolinski, 2018; Doody, Slevin and Taggart, 2017; Delahunty, 2017; Sutherland, 2017; Nelson and Carey, 2016; MacArthur *et al*., 2015; Morton-Nance, 2015; Chapman, 2015; Bailey, 2014; Brown *et al.,* 2012; Sheerin, 2012; Ng, 2011; Mason and Phipps, 2010; McKeon, 2009; Slevin and Sines, 2005). Complex and changing needs require continuous assessment in order to maintain and improve the health and wellbeing of people with intellectual disabilities. Evidence-based needs assessment is more likely to result in the development and implementation of effective interventions.

Evidence in this scoping review demonstrate that intellectual disability nurses undertake health screening (McCarron *et al*., 2018; Marshall *et al.,* 2003; Barr *et al.,* 1999); pre-admission screening (Morton-Nance, 2015; and pre-natal screening as well as providing support in relation to diagnosis (Northway *et al.,* 2017). Undertaking screening is an important intervention and has potential to reduce the consequences of

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undiagnosed health needs which, are prevalent in the population of people with intellectual disabilities.

Another important intervention undertaken by intellectual disability nurses across the lifespan is care planning (Taua, Hepworth and Neville, 2012). Dahm and Wadwnsten (2008) have highlighted the importance of care planning to the delivery of effective nursing interventions. It is perhaps surprising that only one study in this review identified this intervention as an important role undertaken by intellectual disability nurses.

Other important nursing procedures identified in the literatures are; nutrition and dysphagia management (Northway *et al.,* 2017), managing violence and challenging behaviour (Campbell, 2011; Mason and Phipps, 2010; McKeon, 2009; Slevin and Sines, 2005); positive behaviour support (Northway *et al*., 2017); and development and implementation of behaviour support plans (McCarron *et al*., 2018). What is clear from these studies is the complexity and varied nature of the nursing procedures undertaken by intellectual disability nurses across the lifespan. This complexity requires intellectual disability nurses to be adaptable in order to deliver effective care to people with intellectual disabilities.

Taua *et al.* (2012) have argued that one of the important roles undertaken by ID nurses is to facilitate communication. In this review a number of studies have also identified facilitating communication as an important role for intellectual disability nurses (Oulton *et al.,* 2019; Northway *et al.,* 2017; Adams and Shah, 2016; Wagemans *et al.,* 2015; Arrey, 2014). Effective interventions by intellectual disability nurses need to engage all stakeholders, and this requires effective communication. This communication needs to be multi-faceted and involve parents and relatives, be inter-professional, intra-agency, and inter-agency. intellectual disability nurses are in a unique position because in most cases they are the healthcare professional with a complete picture of a person with an intellectual disability, as well as being at the centre of

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communication (Wagemans *et al.,* 2015). Effective communication is an important intervention in intellectual disability nursing practice because it underpins effective delivery of healthcare to people with intellectual disabilities.

Children

As discussed earlier, ID nurses also need to have skills to assess a wide range of the needs of children with ID. However, this review has identified a limited number of studies which have identified interventions undertaken by intellectual disability nurses in this area. Northway *et al.* (2017) have highlighted the need for intellectual disability nurses to be involved in developmental assessments. In addition, Delahunty (2017) has reported that intellectual disability nurses who participated in their study were involved in identifying children requiring further intellectual disability diagnostic assessment. What emerges from this scoping review is that intellectual disability nurses need to be able to work across the lifespan, including working directly with children who often have enduring complex needs.

Other nursing procedures reported in some studies in this review are; facilitating specialist clinics (Oulton *et al.,* 2019); implementing early interventions (Mason and Phipps, 2010); and implementing control and restraint procedures in the physical management of challenging behaviours (Oulton *et al.,* 2019; Lovell *et al*., 2015; Mason and Phipps, 2010). These interventions further illustrate the complexity of the roles of intellectual disability nurses. What is however, not clear from these studies is the evidence-bases for these interventions, and robust evidence to demonstrate their effectiveness and impact.

Adults

Undertaking nursing procedures is fundamental to the role of intellectual disability nurses. The literatures included in this review show that intellectual disability nurses undertake a wide range of assessment activities when working with adults. They assess risk (Pennington *et al*., 2019; Dalgarno and Riordan, 2014; Mason and Phipps, 2010), undertake

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focussed assessment in order to avoid diagnostic overshadowing (Taua *et al.,* 2017), receive and assess referrals from other services and agencies (Doody, Slevin and Taggart, 2019), undertake pain assessments (Quinn and Smolinski, 2018), are involved in physical health assessments such as eye testing (Barr *et al.,*1999), and assess and prepare patients for surgery (Drozd and Clinch, 2016). These publications demonstrate that intellectual disability nurses work with people with diverse and complex needs. It is more likely that these nurses require knowledge and competence to use a wide range of assessment tools, as well as knowledge of different and unrelated health care needs.

The studies in this scoping review show that intellectual disability also manage a wide range of complex needs and activities such as; anxiety (Brown *et al.,* 2016), epilepsy (Pennington *et al*., 2019), long-term conditions (Marsham, 2012), risk (Pennington *et al*., 2019; Drozd and Clinch, 2016; Dalgarno and Riordan, 2014; Brown *et al*., 2012; Taua *et al*., 2012; Mason and Phipps, 2010), medication (Mason and Phipps, 2010; Ring *et al.*, 2018; Northway *et al.,* 2017; Adams and Shah, 2016; Taua *et al.,* 2012), self-harm (Mason and Phipps, 2010), and the challenges of supporting women with complex needs (Lloyd and Coulson, 2014). In addition, the publications in this review demonstrate that ID nurses are involved in; delivering nursing interventions in homes (Barr *et al*., 1999), family therapy and support (Oulton *et al.,* 2019; Mason and Phipps, 2010), de-escalation and crisis prevention practice (Lovell *et al*., 2015; Mason and Phipps, 2010), psychological interventions (Mason and Phipps, 2010), offence-specific interventions (Mason and Phipps, 2010), behavioural interventions and support (Cleary and Doody, 2017), control and restraint practice (Oulton *et al.,* 2015; Mason and Phipps, 2010), and building therapeutic relationships (Lovell *et al*., 2015; Arrey, 2014; Lee and Kiemle, 2014; Lovell *et al.,* 2014; Mason and Phipps, 2010). Furthermore, they administer and monitor medication (Mason and Phipps, 2010; Ring *et al.*, 2018; Northway *et al.,* 2017; Adams and Shah, 2016; Taua *et al.,* 2012), evaluate care interventions and outcomes (Doody *et al.,* 2019). What is evident from these publications is that intellectual disability nurses have a wide range of skills required to directly manage a wide range of complex

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health and healthcare needs in a wide range of contexts and settings. This may require intellectual disability nurses to constantly learn and develop new skills. The literatures suggest that intellectual disability nurses may have to switch between a wide range of activities in a day's work, and are likely to require well advanced multi-tasking skills.

Older adults

We identified a limited number of nursing procedures undertaken by intellectual disability nurses working with older adults with intellectual disabilities. The interventions identified in the literatures under review in relation to older adults include; undertaking clinical diagnosis (Drozd and Clinch, 2016; Brown *et al.,* 2012; Arrey, 2014), undertaking assessments of mobility decline in older (Nelson and Carey, 2016), undertaking dementia assessments (Northway *et al.,* 2017), undertaking behavioural interventions and support (Cleary and Doody, 2017), providing direct care (Doody *et al*., 2019; Cleary and Doody, 2017; Wagemans *et al*., 2015). It might very well be that intellectual disability nurses may not work in nursing homes where older adults with intellectual disabilities may reside. Alternatively, it may very well be that this is a result of people with intellectual disabilities dying prematurely.

End of life care

Similar to intellectual disability nursing practice in relation to older adults, we unearthed a limited number of papers identifying interventions undertaken by intellectual disability nurses in this vital area of practice. This is concerning, given the impact of bereavement emotional and psychological wellbeing. Also, of concern is the limited number of studies undertaken in this area. However, the interventions identified in the literatures we have reviewed are wide ranging, and important to the experience of good quality end of life care. These include; assessing changing health conditions and detecting deterioration (Ng, 2011; Wagemans *et al.,* 2015), interpreting complaints and symptoms (Wagemans *et al.,* 2015), completing hospital or hospice referrals (Bailey *et al.,* 2014), diet and nutrition management (Bailey *et al.,* 2014), managing end of life care (Bailey *et al.,* 2014), pressure relief and skin care

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(Bailey *et al.,* 2014), bereavement counselling (McCarron *et al.,* 2018), and facilitating communication (Oulton *et al.,* 2019; Northway *et al.,* 2017; Adams and Shah, 2016; Wagemans *et al.,* 2015; Morton-Nance, 2015; Wagemans *et al*., 2015; Arrey, 2014). The range of interventions require well developed direct care knowledge and skills, care co-ordination skills, as well as skills to deliver psychological support. In one sense this complexity illustrates the uniqueness of the knowledge and skills of intellectual disability nurses in relation to people with intellectual disabilities across the lifespan with diverse backgrounds and needs.

Enhancing impact of services

In this theme we identified 73 (47%) interventions undertaken by intellectual disability nurses. The interventions in this theme relate to activities where intellectual disability nurses work with other professionals and organisations in order for them to provide better care to people with intellectual disabilities.

Maternity

We identified only one publication that identified intellectual disability nursing roles that focused on Enhancing the impact and or effectiveness of maternity services. The intervention identified is liaison with maternity services (McCarron *et al.,* 2018). The dearth of literatures identifying interventions undertaken by intellectual disability nurses in relation to maternity is perhaps not surprising given that midwifery is a separate profession from nursing. However, intellectual disability nurses need to work collaboratively with maternity services through health facilitation and health liaison. Intellectual disability nurses need to work collaboratively to improve access to mainstream services (Marriott, *et. al.,* 2015). Working collaboratively in this area is likely to be complex and varied. This requires intellectual disability nurses to develop a complex repertoire of knowledge and skills.

All age groups

Evidence from the publications in this review suggests that intellectual disability nurses spend a significant amount of time in their practice in

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roles that focus on ensuring that other professionals and services effectively support people with ID. Consequently, there is a significantly broader list of interventions and activities. These interventions are at individual, organisational and strategic levels. The interventions undertaken by intellectual disability nurses we identified are; assessing effectiveness of interventions (Mafuba *et al.,* 2018), monitoring effectiveness of medications and treatments (Adams and Shah, 2016), providing support with the decision-making (McCarron *et al.,* 2018), facilitating access to health services (Mafuba *et al.,* 2018a; Mafuba *et al.* 2018b); Mafuba and Gates, 2013; Mafuba, 2013; Brown *et al.,* 2012; Mafuba, 2009; DoH, 2007), facilitating the making of and implementation of reasonable adjustments (Cope and Shaw, 2019; (Mafuba *et al.,* 2018a; MacArthur *et al*., 2015), facilitating transitions (Delahunty, 2017; Northway *et al.,* 2017), undertaking health liaison activities (Northway *et al.,* 2017; Morton-Nance, 2015), engaging in public health activities including health prevention (Mafuba and Gates, 2013; Mafuba, 2013), health protection (Mafuba and Gates, 2013; Mafuba, 2013) and health surveillance (Mafuba *et al.,* 2018a; Mafuba and Gates, 2013; Mafuba, 2013; Sheerin, 2012). It is evident from these publications that intellectual disability nurses play a significant role in enhancing the effectiveness of preventative interventions implemented by other organisations and professionals. It is clear that in order to enhancing their own effectiveness, intellectual disability nurses need to work collaboratively in improving access to mainstream services. Literature included in this review highlighted a number of different interventions undertaken by intellectual disability nurses which, can contribute to the effectiveness of services when supporting people with intellectual disabilities. For example, working with main stream services to put reasonable adjustments in place, and training mainstream staff regarding the needs of people with intellectual disabilities. This is important because intellectual disability nurses need to support other healthcare professionals who work directly with people with intellectual disabilities across the lifespan.

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To further enhancing the impact and effectiveness of other healthcare professionals and agencies intellectual disability nurses are also involved in information sharing (Mafuba *et al.,* 2018., Wagemans *et al.,* 2015), liaising with other professionals and agencies (McCarron *et al.,* 2018; Marshall and Foster, 2002), make and facilitate reasonable adjustments (Oulton *et al.,* 2019; Cope and Shaw, 2019; Mafuba *et al.,* 2018; Northway et al., 2017; Cleary and Doody, 2017; Drozd and Clinch, 2016; MacArthur *et al.,* 2015; Marriott *et al.,* 2015; Morton-Nance, 2015), provide support in primary care (McCarron *et al*., 2018), facilitating multi-disciplinary and inter-agency working (Morton-Nance, 2015; Lovell *et al*., 2014), advise hospital staff on reasonable adjustments (Morton-Nance, 2015), advise on and provide plans of care for complex admissions and discharge (Morton-Nance, 2015), train and raise awareness on IDs (Oulton *et al.,* 2019; Doody *et al*., 2019; Cleary and Doody, 2017; Marriott *et al*., 2015; Arrey, 2014; Lovell *et al*., 2014; Taggart *et al.,* 2011; DoH, 2007), educate people with IDs, family members, staff, and carers (Cleary and Doody, 2017; Morton-Nance, 2015; MacArthur *et al.,* 2015; Dalgarno and Riordan, 2014; Brown *et al.,* 2012; Slevin and Sines, 2005), advocate for people with IDs and / or their families (Cope and Shaw, 2019; McCarron et al., 2018; Ring *et al.*, 2018; Doody *et al*., 2017; Brown *et al*., 2016; Morton-Nance, 2015; Dalgarno and Riordan, 2014; Taua *et al.,* 2012; Brown *et al.,* 2012; Llewellyn and Northway, 2007; Llewellyn, 2005), support admissions to hospital and outpatients (Cope and Shaw, 2019), and support families (Cope and Shaw, 2019; McCarron, *et al.,* 2018; Doody et al., 2017; Northway et al., 2017; Bailey *et al.,* 2014). These publications demonstrate that effective interventions by intellectual disability nurses is important in ensuring that other professionals and healthcare agencies effectively meet the needs of people with intellectual disabilities. Intellectual disability nurses therefore, need to engage all stakeholders at individual, community, and population levels.

Although this is limited, we found some evidence in the publications we reviewed that demonstrate that intellectual disability nurses also undertake strategic level interventions. In this regard the DoH (2007) hights the need for intellectual disability nurses to engage with service

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development. In their PhD thesis study Mafuba (2013) reported that intellectual disability nurses were involved in developing appropriate policies that facilitate improved access to services by people with intellectual disabilities. It is evident here that strategic interventions by intellectual disability nurses is important for successful access to services by people with intellectual disabilities.

Children

We found only three publications that explicitly identified roles and interventions undertaken by intellectual disability nurses in order to improve mainstream services for children. The study by Oulton *et al.* (2019) reported interventions by intellectual disability nurses as; pre-admission support, flagging and identifying needs, identifying equipment and resources, undertaking mental capacity assessment, engaging other agencies, engaging senior managers, providing informal support and advice, giving information and advice, providing positive behaviour support training, and handling complaints. Marshall and Foster (2002) reported that intellectual disability nurses were involved in providing dietary advice. Delahunty (2017) reported that when working with children to improve services, intellectual disability nurses acted as a links between schools and other services. As in other areas of intellectual disability nursing practice noted earlier, the limited number studies which identified interventions undertaken by intellectual disability nurses in this area is concerning. This is important and we concur with Delahunty (2017) that interventions by intellectual disability nurses are essential in Enhancing the effectiveness of transition services. intellectual disability nurses are often in more regular contact with children, they support and therefore better placed to facilitate links between services. Increasingly, in our own experiences more intellectual disability nurses are taking on roles in school nursing services. This development is likely to improve how services respond to the healthcare needs pf children with intellectual disabilities.

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Adults

The publications included in this review identified a wide range of interventions undertaken by intellectual disability nurses in a wide range of services. Two interventions identified by Auberry and Cullen (2016) in a study undertaken in the USA were statistically tested for effectiveness. It is important however, to point out that even if the majority of the interventions have not been tested for their effectiveness, experientially, people with in most case value interventions undertaken by intellectual disability nurses. These interventions include; undertaking mental capacity assessments (Oulton *et al.,* 2019; Drozd and Clinch, 2016), modifying mental health interventions to suit people with IDs (Taua *et al.,* 2017), providing diagnostic advice (MacArthur *et al*., 2015). Providing seizure guidance to people with intellectual disability living in the community (Auberry and Cullen, 2016), providing seizure telephone triage in the community (Auberry and Cullen, 2016), ordering and interpreting investigations (Ring *et al.*, 2018), preparing women psychologically for cancer screening (Lloyd and Coulson, (2014), developing easy to understand letters, guidelines and information (Brown *et al*., 2012; Marriott *et al.,* 2015), developing health education material (Taggart *et al.,* 2011; Cope and Shaw, 2019; Mafuba *et al.,* 2018a; McCarron *et al.,* 2018; Northway *et al.,* 2017), delivering formal / informal education (Doody *et al.,* 2017), and supporting staff to develop practice guidelines and policies (Doody *et al.,* 2019), providing support with substance misuse interventions (Lovell and Bailey, 2016), providing support women to manage cervical screening (*Marriott et al., 2015)*, supporting women to self-examine breasts (Taggart *et al.,* 2011), providing behavioural advice (MacArthur *et al*., 2015), and monitoring and evaluating care interventions (Doody et al., 2017; Slevin and Sines, 2005). The roles of intellectual disability nurses in supporting assessments, educating others, developing appropriate guidelines, and supporting people with intellectual disabilities to effectively engage with other services cannot be over emphasised. For people with intellectual disabilities, these interventions may mean the difference between accessing appropriate services and support. As noted earlier, intellectual disability nurses' practice in complex environments which, are often

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multi-disciplinary and multiple-agency. To improve services and enhancing their impact and enhancing effectiveness, intellectual disability nurses need to work collaboratively to improve access to mainstream services. This will require them to engage in creative communication (Taua *et al.,* 2017) to enable things to happen (Llewellyn, 2005).

Other interventions identified include; encouraging clients to make their own decisions (Llewellyn, 2005), escalating treatment pathways (Marsham, 2012), facilitating self-management (Marsham, 2012; Doody *et al.,* 2019; Doody *et al.,* 2017; MacArthur *et al.,* 2015; Wagemans *et al.,* 2015; Morton-Nance, 2015; Bailey *et al.,* 2014; Brown *et al*., 2012; Marshall and Foster, 2002), match information with capacity to understand (Brown *et al.,* 2016), consult, refer, and make recommendations to other professionals relating to client care and client care issues (Doody, 2019), and record keeping (Lovell *et al*., 2014). Furthermore, Mafuba (2013) has noted the need for ID nurses to provide leadership in improving services, through influencing others (Brown *et al*., 2012). Brown *et al.* (2016) and Doody *et al.* (2019) have highlighted the importance of trouble shooting interventions that focus on improving the impact and effectiveness of other professionals and services.

Older adults

We found only one publication that considered intellectual disability nurse involvement with services for older adults. This is of significant concern given the growing population of older adults with intellectual disability, who often have complex and enduring healthcare needs which require accessing a multiplicity of services. These services are often in multiple agencies and are likely to be complex to navigate. Cleary and Doody, 2017; Bailey *et al.* (2014) identified the intellectual disability nurse role in coordinating services in order to improve healthcare service delivery to older adults. Given the complexity of the landscape services of services for older adults in the UK, this is a vital role. Navigating service accessibility for older adults is dependent on geographical location and the complexity of the person's morbidity. For intellectual disability nurses, matching services to the needs of the older adults they support indicate

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the need to undertake complex interventions involving other professionals and a wide range of agencies.

End of life care

The provision of end-of-life care for people with intellectual disabilities is complex (Morton-Nance and Schafer, 2012). The experience of end-of-life is a very individual and personal experience. Consequently, it could be argued that effective end of life care for people with intellectual disabilities necessitates the need for a person-centred approach. The intellectual disability nurse interventions identified in the literatures in this review, in some way, illustrate this necessity. The interventions undertaken by intellectual disability nurses in the literatures include; advance care planning (Wagemans *et al.,* 2015), coordinating services (Cleary and Doody, 2017; Bailey *et al.,* 2014), making referrals within the MDT (Bailey *et al.,* 2014), planning for end of life (Bailey *et al.,* 2014), shaping the nature of end-of-life care and influencing end-of-life decisions (Wagemans *et al.,* 2015), supporting relatives and helping medical staff to make person centred decisions (Wagemans *et al.,* 2015), and making and facilitating reasonable adjustments (Cope and Shaw, 2019; Mafuba *et al.,* 2018a; Northway *et al.,* 2017; Cleary and Doody, 2017; Drozd, and Clinch, 2016; MacArthur *et al.,* 2015; Marriott *et al.,* 2015; Morton-Nance, 2015)

Current palliative care services in the UK are fragmented (Dening *et al*., 2018). For people with intellectual disabilities, there is clearly a need for co-ordination of existing palliative care services for their needs to be met. Intellectual disability nurses need to undertake important interventions to address inequalities in care provision for people with intellectual disabilities who are at the end of their lives. These roles include facilitating collaborative working (Arrey, 2014), educating healthcare professionals about the needs of people with intellectual disabilities needing end of life care (Cleary and Doody, 2017; Morton-Nance, 2015; MacArthur *et al.,* 2015; Dalgarno and Riordan, 2014; Brown *et al.,* 2012; Slevin and Sines, 2005), finding resources for end of life care (Bailey *et al.,* 2014), sharing information with other professionals (Mafuba *et al.,* 2018a; Wagemans *et al.,* 2015), and liaising with health, social care, disability services and

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multi-disciplinary team in primary care and secondary care (McCarron *et al.,* 2018; Marshall and Foster, 2002).

Enhancing quality of life

In this theme we identified 41 (27%) interventions undertaken by intellectual disability nurses. The interventions in this theme relate to activities undertaken by intellectual disability nurses which, are focussed on addressing the determinants of health.

The RCN has argued that all nurses need to engage actively in 'upstream' public health which, focuses on preventative interventions (RCN, 2012). *Prevention is better than cure* (DoH and SC, 2018) has set out a vision for England which, puts preventative interventions at the centre of improving healthy lives. In addition, the *Future nurse: Standards of proficiency for registered nurses* (NMC, 2018) now require all nurses to have a wide range of knowledge and skills essential for promoting health and preventing ill health. This means that intellectual disability nurses in the UK are not only expected to, but are now required to undertake preventative interventions.

All age groups

For people with intellectual disabilities, improving the quality of their lives is essential for improving their quality of life, and their health and wellbeing. Mafuba *et al*., (2018a) have argued that intellectual disability nurses can contribute to this through enabling and supporting healthy lifestyle choices and by addressing determinants of health. It could be argued that maintaining people with intellectual disabilities in better health is an important intervention undertaken by intellectual disability nurses. This may mean that they need to engage in health improvement by supporting people with intellectual disabilities to develop skills to self-manage their conditions that may limit life. In the literatures under review such interventions undertaken by intellectual disability nurses include; addressing determinants of health and health inequalities (Cope and Shaw, 2019; Mafuba *et al*., 2018a; Sheerin, 2012), advocating for people with intellectual disabilities and / or their families (Cope and Shaw, 2019;

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McCarron *et al*., 2018; Ring *et al.*, 2018; Doody *et al.,* 2017; Brown *et al.,* 2016; Morton-Nance, 2015; Dalgarno and Riordan, 2014; Taua *et al.,* 2012; Brown *et al.,* 2012; Llewellyn and Northway, 2007; Llewellyn, 2005), enabling and empowering people with IDs to make their own informed choices (Sheerin, 2012), educating people with IDs and their carers about health and healthy lifestyles (Mafuba *et al.,* 2018a; Mafuba and Gates, 2013; Mafuba, 2013; Taggart *et al.,* 2011; Mafuba, 2009; Cleary and Doody, 2017; Morton-Nance, 2015; MacArthur *et al*., 2015; Dalgarno and Riordan, 2014; Northway *et al.,* 2017; Brown *et al.,* 2012; Slevin and Sines, 2005), promoting, enabling and supporting healthy lifestyle choices (Mafuba *et al.,* 2018a; Cope and Shaw, 2019; Doody *et al.,* 2019; McCarron *et al.,* 2018; Mafuba *et al.,* 2018b; Northway *et al.,* 2017; Adams and Shah, 2016; Nelson and Carey, 2016; Mafuban and Gates, 2013; Mafuba, 2013; Taua *et al.,* 2012; Sheerin, 2012; Taggart *et al.,* 2011; Mafuba, 2009; DoH, 2007; Marshall *et al.,* 2003), training and raising awareness (Oulton *et al.,* 2019; Doody *et al.,* 2019; Cleary and Doody, 2017; Marriott *et al.,* 2015; Morton-Nance, 2015; Arrey, 2014; Lovell *et al.,* 2014; Doody *et al.,* 2013; Taggart *et al.,* 2011; DoH, 2007), promoting human rights to healthy life (Cope and Shaw, 2019), providing support with the decision-making about healthy lifestyles (McCarron *et al.,* 2018), supporting social connectedness and community integration (McCarron *et al.,* 2018), supporting individuals to remain in their home (Northway *et al.,* 2017), supporting families (McCarron *et al.,* 2018; Cope and Shaw, 2019; Northway *et al.,* 2017; Bailey *et al.,* 2014), and safeguarding of children and adults (Northway *et al.,* 2017).

Children

We found only two publications that considered intellectual disability nurse involvement with addressing the determinants of health for children. This is of significant concern given the growing population of children with intellectual disabilities, who often have complex and enduring health needs which may impact on their ability to lead healthy and active lifestyles (Emerson *et al*., 2011). Intellectual disability nurses have an important role to play in mitigating the effects intellectual disabilities on children's health. However, in this review we only identified

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continence promotion (Marshall and Foster, 2002), and provision of informal support and advice (Oulton *et al.,* 2019) as the only interventions undertaken by intellectual disability nurses. The reason could be very well that school nursing services do not tent to normally employ intellectual disability nurses in the roles of school nurses.

Adults

Existing and longstanding studies have demonstrated that adults with intellectual disabilities amongst the most inactive and sedentary members of the population (Messent *et al.,* 1999). Many other barriers exist to limit the ability of adults with intellectual disabilities to live healthy active lifestyles. Current levels of service provision suggest that these barriers, their consequences on people with intellectual disability and healthcare costs are arguably poorly understood by policy makers, public health agencies, commissioners of health services, and healthcare providers. Consequently, people with intellectual disabilities are denied choices to live a physically active healthy lifestyles, and having to need the support of intellectual disability nurses to mitigate against the determinants of poor health. Given the aforementioned importance of preventative interventions, the limited number of publications is rather surprising. In these publications, a number of interventions that are relevant to improving the quality of life of people with intellectual disabilities have been identified and include; assessing people's understanding of their needs (Marsham, 2012), developing health education material (Taggart *et al.,* 2011), giving information and advice (Cope and Shaw, 2019; Mafuba *et al.,* 2018b; McCarron *et al.,* 2018; Northway *et al.,* 2017; Doody *et al.,* 2019; Doody *et al*., 2017; MacArthur *et al.,* 2015; Wagemans *et al.,* 2015; Morton-Nance, 2015; Bailey *et al.,* 2014; Brown *et al.,* 2012; Marshall and Foster, 2002), encouraging clients to make their own decisions about healthy living (Llewellyn, 2005), facilitating development of coping skills (Marsham, 2012), promoting amelioration of detrimental effects of challenging behaviour (Slevin and Sines, 2005), promoting employment (Northway *et al.,* 2017), promoting independence (Drozd and Clinch, 2016), promoting health checks and screening, personal and sexual relationships (Northway *et al.,* 2017),

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promoting resilience (Northway *et al.,* 2017; Dalgarno and Riordan, 2014), supporting people with IDs with a history of offending behaviour to develop appropriate relationships (Lovell and Bailey, 2016), and building therapeutic relationships (Lovell *et al.,* 2015; Arrey, 2014; Lee and Kiemle, 2014; Mason and Phipps, 2010).

Older adults

None of the publications we reviewed specifically identified interventions undertaken by intellectual disability nurses in addressing the determinants of health of older adults with intellectual disabilities. This is a major concern given the growing population of older adults with intellectual disabilities, who often have complex and enduring health needs which may impact on their ability to lead healthy and active lifestyles (Emerson *et al*., 2011).

End of life care

We found only two publications that considered intellectual disability nurse involvement in enhancing the quality of life of people with intellectual disabilities in palliative care. End of life experience is likely to be physically and emotionally debilitating. Intellectual disability nurses have an important role to play in meeting the palliative care needs of people with intellectual disabilities. However, in this review we only identified assessing changing health conditions and detecting deterioration (Ng, 2011; Wagemans *et al.,* 2015), advance care planning (Wagemans *et al.,* 2015), and supporting relatives and helping medical staff to make decisions (Wagemans *et al.,* 2015) as the only interventions undertaken by intellectual disability nurses with respect to Enhancing the quality of life of people with intellectual disabilities at the end of their lives.

Limitations

This scoping review has some limitations. Firstly, the terms of the review from the funding organisation were such that we included opinion publications. Consequently, our findings are not generalisable beyond the publications included in this review. Our results are only up to date as of

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31 May 2020. Covid-19 restrictions impacted on the process of literature search and retrieval of some publications from other libraries.

Conclusions

We have identified a wide range of interventions undertaken by intellectual disability nurses in meeting the healthcare needs of people with intellectual disabilities across the lifespan and in a variety of settings. However, the limited number of publications identifying the interventions undertaken by intellectual disability nurses in relation to maternity, children, older adults and end of life care presents a challenge for the profession. In addition, the lack of evidence to demonstrate the impact and effectiveness of interventions undertaken by intellectual disability nurses pose a challenge for intellectual disability nurses and the profession, whose wider contribution is ambiguous in wider health and social care practice. The aim of this scoping literature review was to identify intellectual disability nursing centered interventions in place to respond to the changing needs of people with intellectual disabilities, and their impact in order to inform further work for the overall project. The interventions identified sufficiently inform the wider project. In addition, although we are aware that that the detailed analysis we have undertaken is beyond normal expectations for a scoping review, the number of empirical studies included warranted a full mixed methods systematic literature review.

Although there is some evidence to support the emerging themes, the literature is limited in robustness and scope. Other than one study undertaken in the USA, we could not locate any studies that specifically investigated the impact or effectiveness of the many intellectual disability nursing interventions. This advocates for high quality research being essential in determining the impact and effectiveness of ID nursing interventions across the lifespan.

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 interventions undertaken by intellectual disability nurses in meeting

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the needs of people with intellectual disabilities. The interventions undertaken by intellectual disability nurses need to be understood in the context of the complexity and changing needs of people with intellectual disabilities, as well as the introduction of the new NMC standards for pre-registration nurse education.

Recommendations

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 intellectual disabilities, we recommend that urgent research is undertaken to further clarify ID nurse interventions, more specifically in relation to maternity, children, older adult, and end of life care. We would also recommend a systematic review be undertaken to focus more on the quality and validity of the studies included in this scoping review. We also recommend that research be undertaken focussing on the impact and effectiveness of the intellectual disability nursing interventions. Finally, we are aware of the disparate nature of geographical locations in which intellectual disability nurses' practice. For this, we recommend that a searchable online compendium of intellectual disability nurse interventions be established and regularly.

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References

Adams, D. and Shah, C. (2016) 'Prescribing of psychotropic medicines: the role of intellectual disability nurses'. *Learning Disability Practice,* 19(8), pp. 21-25. doi: 10.7748/ldp.2016.e1763.

Allerton, L., and Emerson, E. (2012). British adults with chronic health conditions or impairments face significant barriers to accessing health services. *Public Health,* 126(11), pp.920-927.

Arrey, S.K. (2014) *Lived experiences of registered learning disability nurses and palliative care professionals in caring for people with communication difficulties and a learning disability experiencing distress in palliative care settings: a hermeneutic phenomenological study.* ProQuest Dissertations Publishing. Available at: https://search.proquest.com/docview/1783893689 (Accessed: 24th May 2018).

Auberry, K. and Cullen, D. (2016) 'Implementation of an evidence-based seizure algorithm in intellectual disability nursing', *Journal of Intellectual Disabilities,* 20(1), pp. 55-64. doi: 10.1177/1744629515598216.

Backer, C., Chapman, M. and Mitchell, D. (2009) Access to secondary healthcare for people with intellectual disabilities: A review of the literature. *Journal of Applied Research in Intellectual Disabilities,* 22 (6), p.514-525.

Bailey, M., Doody, O. and Lyons, R. (2014). Surveying community nursing support for persons with an learning disability and palliative care needs. *British Journal of Learning Disabilities,* 44(1), pp.24-34. https://doi.org/10.1111/bld.12105.

Bakker-van Gijssel, E.J., Lucassen, P.L.B.J., Hartman, T., van Son, L., Assendelft, W.J.J., and van Schrojenstein Lantman-de Valk, H.M.J. (2017) Health assessment instruments for people with intellectual disabilities - A systematic review. *Research in Developmental Disabilities,* 64, pp.12-24.

Barr, O., Gilgunn, J., Kane, T. and Moore, G. (1999) 'Health screening for people with learning disabilities by a community learning l disability nursing service in Northern Ireland'. *Journal of Advanced Nursing,* 29(6), pp. 1482-1491. doi: 10.1046/j.1365-2648.1999.01036.x.

Blair, J. (2013) Everybody's life has worth – Getting it right in hospital for people with a learning disability and reducing clinical risks. *Journal of Patient Safety and Risk Management,* 19(3), pp. 58-63.

Braun, V., Clarke, V., Terry, G & Hayfield N. (2019). Thematic analysis. In Liamputtong, P. (Ed.), *Handbook of research methods in health and social sciences* (pp. 843-860). Singapore: Springer.

©UWL / RCN Foundation 2020

Brown, M., Chouliara, Z., MacArthur, J., McKechanie, A., Mack, S., Hayes, M., & Fletcher, J. (2016). The perspectives of stakeholders of learning disability liaison nurses: a model of compassionate, person-centred care. *Journal of Clinical Nursing,* 25(7-8), pp.972-982. doi:10.1111/jocn.13142.

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.

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 Intellectual Disability Research,* 56(12), pp. 1161-1174. doi: 10.1111/j.1365-2788.2011.01511.x.

Campbell, A.K. (2011). Nurses' experiences of working with adults who have an intellectual disability and challenging behaviour. *The British Journal of Developmental Disabilities,* 57(112), pp.41-51. DOI: 10.1179/096979511798967179.

Campbell, M. and Martin, M. (2009) Reducing health inequalities in Scotland: the involvement of people with intellectual disabilities as national health service reviewers. *British Journal of Learning Disabilities*, 38 (1), p.49–58.

Chapman, H.M. (2015). *The health consultation experience for people with intellectual disabilities: A constructivist grounded theory study based on symbolic interactionism.* Chester: University of Chester, Unpublished PhD Thesis.

Chauhan, U., Kontopantelis, E., Campbell, S., Jarrett, H. & Lester, H. (2010) Health checks in primary care for adults with intellectual disabilities: how extensive should they be? *Journal of Intellectual Disability Research,* 54 (6), p.479-486.

Cleary, J. and Doody, O. (2017) 'Nurses' experience of caring for people with intellectual disability and dementia'. *Journal of Clinical Nursing,* 26(5-6), pp. 620-631. doi: 10.1111/jocn.13431.

Cope, G. and Shaw, T. (2019). *Capturing the voices of learning disability nurses and people who use services.* London: Foundation of Nursing Studies.

Dahm M.F. and Wadwnsten, B. (2008) Nurses' experiences of and opinions about using standardised care plans in electronic health records – a questionnaire study. *Journal of Clinical Nursing,* 17(12), pp. 2137-2145. https://doi.org/10.1111/j.1365-2702.2008.02377.x.

Dalgarno, M.F. and Riordan, S.A. (2014). Forensic learning disability nursing: what's it really like? *Journal of Intellectual Disabilities and Offending*

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Behaviour, 5(4), pp.167-177. https://doi.org/10.1108/JIDOB-11-2014-0017.

Delahunty, L. (2017) 'Understanding the nurse's role in identifying children with intellectual disability', *Nursing Children and Young People,* 29(6), pp. 33-36. doi: 10.7748/ncyp.2017.e863.

Dening, K.H., Sates, C. and Lloyd-Williams, M. (2018) Palliative care in dementia: A fragmented pathway? *International Journal of Palliative Nursing,* 24(12), pp. 585-596. DOI: 10.12968/ijpn.2018.24.12.585.

DoH (2007). *Good practice in intellectual disability nursing.* London: Department of Health.

DoH & SC (2018) *Prevention is better than cure.* London: Department of Health and Social Care.

Doody, C., Markey, K. and Doody, O. (2013). Future need of ageing people with an intellectual disability in the Republic of Ireland: lessons learned from the literature. *British Journal of Learning Disabilities,* 41(1), pp. 13-21. https://doi.org/10.1111/j.1468-3156.2011.00716.x.

Doody, O., Slevin, E. and Taggart, L. (2019). A survey of nursing and multidisciplinary team members' perspectives on the perceived contribution of intellectual disability clinical nurse specialists. *Journal of Clinical Nursing,* 28(21-220, pp.3879-3889.

Doody, O., Slevin, E. and Taggart, L. (2017) 'Focus group interviews examining the contribution of intellectual disability clinical nurse specialists in Ireland'. *Journal of Clinical Nursing,* 26(19-20), pp. 2964-2975. doi: 10.1111/jocn.13636.

DRC (2006) *Equal treatment: Closing the gap.* Stratford Upon Avon: Disability Rights Commission.

Drozd, M. and Clinch, C. (2016). The experiences of orthopaedic and trauma nurses who have cared for adults with a learning disability. *International Journal of Orthopaedic Trauma Nursing,* 22, pp.13-23. doi: 10.1016/j.ijotn.2015.08.003.

Emerson, E. and Brigham, P. (2015). Exposure of children with developmental delay to social determinants of poor health: Cross-sectional case record review study*. Child Care, Health and Development,* 41(2), pp.249-257.

Emerson, E., Copeland, A. and Glover, G. (2011) *The uptake of health checks for adults with learning disabilities: 2008/9 to 2010/11.* (Online). Available at: http://www.karentysonspage.org/Emerson%202011%20Health%20Checks%20for%20People%20with%20Intellectual%20Disabilities%202008-9%20%202010-11.pdf (Accessed: 6 October 2020).

©UWL / RCN Foundation 2020

Emerson, E., Hatton, C., Baines, S. and Robertson, J. (2016a). The physical health of British adults with intellectual disability: Cross sectional study. *International Journal for Equity in Health,* 15(1), pp.1-9.

Emerson, E., Robertson, J., Baines, S. and Hatton, C. (2016b). Obesity in British children with and without intellectual disability: cohort study. *BMC Public Health,* 16(1), pp.1-10.

Hatton, C. and Emerson, E. (2015). Introduction: Health disparities, health inequity, and people with intellectual disabilities. *International Review of Research in Developmental Disabilities,* 48, pp.1-9.

Heslop, P., Blair, P.S., Fleming, P., Hoghton, M., Marriott, A., and Russ, L. (2014) The Confidential Inquiry into premature deaths of people with learning disabilities in the UK: a population-based study. *The Lancet,* 383(9920), pp. 889-895.

Heslop, P., Blair, P.S., Fleming, P., Hoghton, M., Marriott, A., and Russ, L. (2013) *Confidential Inquiry into premature deaths of people with learningl disabilities (CIPOLD)* - Final report. Bristol: Norah Fry Research Centre. https://doi.org/10.1111/jocn.14990.

Gates, B. and Mafuba, K. (2016) Use of the term "learning disabilities" in the United Kingdom: Issues for international researchers and practitioners. *Learning Disabilities: A Contemporary Journal*, 14(1), p.9-23.

Jenkins, R. (2012) 'Meeting the health needs of older people with intellectual disabilities'. *British Journal of Nursing,* 21(8), pp. 468-473. doi: 10.12968/bjon.2012.21.8.468.

Kavanagh, A., Aitken, Z., Emerson, E., Sahabandu, S., Milner, A., Bentley, R., LaMontagne, A., Pirkis, J. and Studdert, D. (2017). Inequalities in socio-economic characteristics and health and wellbeing of men with and without disabilities: a cross-sectional analysis of the baseline wave of the Australian Longitudinal Study on Male Health. *BMC Public Health,* 16(Supplement 3), pp.23-31.

Kerr, M. (2004) Improving the general health of people with learning disabilities. *Advances in Psychiatric Treatment,* 10, p.200-206.

LeDeR (2020). *The intellectual disability mortality review – Annual report.* Bristol: University of Bristol Norah Fry Centre for Disability Studies.

Lee, A. and Kiemle, G. (2014). 'It's one of the hardest jobs in the world': The experience and understanding of unqualified nurses who work with individuals diagnosed with both intellectual disability and personality disorder. *Journal of Applied Research in Intellectual Disabilities,* 28(3), pp238-248. https://doi.org/10.1111/jar.12125.

©UWL / RCN Foundation 2020

Llewellyn, G., Vaughan, C. and Emerson, E. (2015). Discrimination and the health of people with intellectual disabilities. *International Review of Research in Developmental Disabilities*, 48, pp.43-72.

Llewellyn, P. (2005) *An investigation into the advocacy role of the learning disability nurse.* Unpublished PhD thesis. University of Glamorgan, UK.

Llewellyn, P. and Northway, R. (2007) 'An investigation into the advocacy role of the learning disability nurse'. *Journal of Research in Nursing,* 12(2), pp. 147-161. doi: 10.1177/1744987106075626.

Lloyd, J.L. and Coulson, N.S. (2014) 'The role of intellectual disability nurses in promoting cervical screening uptake in women with intellectual disabilities'. *Journal of Intellectual Disabilities,* 18(2), pp. 129-145. doi: 10.1177/1744629514528829.

Lovell, A. and Bailey, J. (2016). Nurses' perceptions of personal attributes required when working with people with a learning disability and an offending background: a qualitative study. *Journal of Psychiatric and Mental Health Nursing*, 24(1), pp. 4-14. https://doi.org/10.1111/jpm.12326.

Lovell, A., Smith, D., and Johnson, P. (2015). A qualitative investigation into nurses' perceptions of factors influencing staff injuries sustained during physical interventions employed in response to service user violence within one secure learning disability service. *Journal of Clinical Nursing,* 24 (13-14), pp.1926-1935.

Lovell, A., Bailey, J., Kingdon, A. and Gentile, D. (2014). Working with people with learning disabilities in varying degrees of security: nurses' perceptions of competencies. *Journal of Advanced Nursing,* 70(9), pp. 2041-2050. https://doi.org/10.1111/jan.12362.

MacArthur, J., Brown, M., McKechanie, A., Mack, S., Hayes, M. and Fletcher, J. (2015) 'Making reasonable and achievable adjustments: the contributions of learning disability liaison nurses in 'Getting it right' for people with learning disabilities receiving general hospitals care'. *Journal of Advanced Nursing,* 71(7), pp. 1552-1563. doi: 10.1111/jan.12629.

Mafuba, K. (2009) 'The public health role of learning disability nurses: a review of the literature: Kay Mafuba explores how intellectual disability nurses contribute to the implementation of public health policy for people with learning disabilities'. Learning Disability *Practice,* 12(4), pp. 33-37.

Mafuba, K. (2013) *Public health: community intellectual disability nurses' perception and experience of their roles: an exploratory sequential multiple methods study.* ProQuest Dissertations Publishing. Available

©UWL / RCN Foundation 2020

at: https://search.proquest.com/docview/1937411950 (Accessed: 6 October 2020).

Mafuba, K. and Gates, B. (2015) 'An investigation into the public health roles of community learning disability nurses', *British Journal of Learning Disabilities,* 43(1), pp. 1-7. doi: 10.1111/bld.12071.

Gates, B. and Mafuba, K. (2016) Use of the term “learning disabilities” in the United Kingdom: Issues for international researchers and practitioners. *Learning Disabilities: A Contemporary Journal*, 14(1), p.9-23.

Mafuba, K., Forster, M., Kupara, D. and Gates, B. (2018a) *Mixed methods literature review on improving the health of people with a learning disability – a public health nursing approach. Final Report.* London: University of West London / Public Health England.

Mafuba, K., Gates, B. and Cozens, M. (2018b) 'Community learning disability nurses’ public health roles in the United Kingdom: An exploratory documentary analysis'. *British Journal of Learning Disabilities*, 22(1), pp.61-73. doi: 10.1177/1744629516678524.

Mallett, J and Dougherty, L. (2000) *The Royal Marsden Hospital Manual of Clinical Nursing Procedures, 5th Edition.* London: Wiley-Blackwell.

Marriott, A., Turner, S., Ashby, S. and Rees, D. (2015) 'Cancer screening for people with learning disabilities and the role of the screening liaison nurse'. *Tizard Learning Disability Review,* 20(4), pp. 239-246. doi: 10.1108/TLDR-07-2015-0027.

Marshall, D. and Foster, I. (2002) 'Providing a healthcare input to children in special schools'. *British Journal of Nursing,* 11(1), pp. 28-35. doi: 10.12968/bjon.2002.11.1.9320.

Marshall, D., McConkey, R. and Moore, G. (2003) 'Obesity in people with learning disabilities: the impact of nurse-led health screenings and health promotion activities'. *Journal of Advanced Nursing,* 41(2), pp. 147-153. doi: 10.1046/j.1365-2648.2003.02522.x.

Marsham, M. (2012) 'An exploration of community learning disability nurses’ therapeutic role'. *British Journal of Learning Disabilities,* 40(3), pp. 236-244. doi: 10.1111/j.1468-3156.2011.00702.x.

Mason, T. and Phipps, D. (2010). Forensic intellectual disability nursing skills and competencies: A study of forensic and non-forensic nurses. *Issues in Mental Health Nursing,* 31(11), pp.708-715.

McCarron, M., Sheerin, F., Roche, L., Ryan, AM., Griffiths, C., Keenan, P., Doody, O., D'Eath, M., Burke, E., McCallion, P. (2018) *Shaping the Future of Intellectual Disability Nursing in Ireland*. Dublin: Health Services Executive, Ireland.

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Mcilfatrick, S., Taggart, L. and Truesdale-Kennedy, M. (2011) Supporting women with intellectual disabilities to access breast cancer screening: a healthcare professional perspective. *European Journal of Cancer Care,* 20 (3), p.412-420.

McKeon, M. (2009) 'A survey of clinical nursing skills in intellectual disability nursing'. *Journal of Intellectual Disabilities,* 13(1), pp. 31-41. doi: 10.1177/1744629509103517.

Melville, C.A., Cooper S.A., Morrison I. J., Finlayson J., Allan, L., Robinson N., Burns E. and Martin, G. (2006) The outcomes of an intervention study to reduce the barriers experienced by people with intellectual disabilities accessing primary healthcare services. *Journal of Intellectual Disability Research,* 50 (1), p.11-17.

Mencap (2007) *Death by indifference. Following up the Treat me right report.* London: Mencap.

Mencap (2012) *Death by indifference: 74 deaths and counting.* London: Mencap.

Mencap (2020) Children – research statistics. Online. Available at: https://www.mencap.org.uk/intellectual-disability-explained/research-and-statistics/children-research-and-statistics (Accessed on: 06 October 2020).

Messent, P.R., Cooke, C.B. and Long, J. (1999). Primary and secondary barriers to physically active healthy lifestyles for adults with learning disabilities. *Disability and Rehabilitation,* 21(9), pp. 409-419. https://doi.org/10.1080/096382899297396.

Michael, J. (2008) *Healthcare for All: Report of the independent inquiry into access to healthcare for people with intellectual disabilities.* London: Department of Health.

Morton-Nance, S. (2015) 'Unique role of intellectual disability liaison nurses'. *Learning Disability Practice,* 18(7), pp. 30-34. doi: 10.7748/ldp.18.7.30.e1627.

Morton-Nance, S. and Schaler, T. (2012). End of life care for people with a learning disability. *Nursing Standard,* 27(10, pp 40-47. PMID: 23082363 DOI: 10.7748/ns2012.09.27.1.40.c9270.

Nelson, S. and Carey, E. (2016) The role of the nurse in assessing mobility decline in older people with learning disabilities. *Learning Disability Practice,* 19(9), pp. 19-24. doi: 10.7748/ldp.2016.e1776.

Ng, J. S. W. (2011) *Knowing the patient well: learning disability nurses' experiences of caring for terminally ill people with profound learning disabilities in residential care settings.* PhD thesis, University of Greenwich.

©UWL / RCN Foundation 2020

Northway, R., Cushing, K., Duffin, S., Payne, T., Price, P. and Sutherland, K. (2017) 'Supporting people across the lifespan: the role of intellectual disability nurses'. *Learning Disability Practice,* 20(3), pp. 22-27. doi: 10.7748/ldp.2017.e1841.

Oulton, J., Wray, Hassiotis, A., Kenten, C., Russell, J., Tuffrey-Wijne, I., Whiting, M., and Faith Gibson, F. (2019) Learning disability nurse provision in children's hospitals: hospital staff perceptions of whether it makes a difference. *BMC Pediatrics,* 19:192. https://doi.org/10.1186/s12887-019-1547-y.

Pennington, M., Ring, H., Howlett, J., Smith, C., Redley, M., Murphy, C., Hook, R., Platt, A., Gilbert, N., Jones, E., Kelly, J., Pullen, A., Mander, A., Donaldson, C., Rowe, S., Wason, J. and Irvine F. (2019). The impact of an epilepsy nurse competency framework on the costs of supporting adults with epilepsy and intellectual disability: findings from the EpAID study. *Journal of Intellectual Disability Research,* 63(12), pp. 1391-1400.

Peters, M., Godfrey, C.M., Khalil, H. and Mcinerney, P. (2017). Chapter 11: Scoping reviews. In: *2017 Guidance for the Conduct of JBI Scoping Reviews.* Adelaide: JBI.

Quinn, B.L., and Smolinski, M (2018). Improving school nurse pain assessment practices for students with intellectual disability. *The Journal of School Nursing,* 34(6), pp.480-488.

RCN (2012) *Going upstream: nursing's contribution to public health: Prevent, promote and protect - RCN guidance for nurses.* London: Royal College of Nursing.

Ring H., Howlett, J., Pennington, M., Smith, C., Redley, M., Murphy, C., Hook, R., Platt, A., Gilbert, N., Jones, E., Kelly, J., Pullen, A. Mander, A., Donaldson, C., Rowe, S., Wason, J. and Irvine, F. (2018). Training nurses in a competency framework tosupport adults with epilepsy and intellectual disability: the EpAID cluster RCT. *Health Technology Assessment,* 22(10). DOI: 10.3310/hta22100.

Robertson, J., Chadwick, D., Baines, S., Emerson, E., and Hatton, C. (2017). Prevalence of dysphagia in people with intellectual disability: A systematic review. *Intellectual and Developmental Disabilities*, 55(6), pp.377-391.

Robertson, J., Hatton C., Emerson, E. and Baines, S. (2014) The impact of health checks for people with learning disabilities: An updated systematic review of evidence. *Research in Developmental Disabilities,* 35(10), pp. 2450-2462.

©UWL / RCN Foundation 2020

Robertson, J., Hatton, C., Emerson, E. and Baines, S. (2015) Mortality in people with intellectual disabilities and epilepsy: A systematic review. *Seizure,* 29, pp.123-133. https://doi.org/10.1016/j.seizure.2015.04.004.

Sandelowski, M., Voils, C.I., Leeman, J. and Crandell, J. (2012) Mapping the mixed methods–mixed research synthesis terrain. *Journal of Mixed Methods Research,* 6(4), pp. 317–331. doi:10.1177/1558689811427913.

Savage, A., and Emerson, E. (2016). Overweight and obesity among children at risk of intellectual disability in 20 low- and middle-income countries. *Journal of Intellectual Disability Research*, 60(11), pp.1128-1135.

Sheerin, F.K. (2012) 'Learning disability nursing – responding to health inequity'. *British Journal of Learning Disabilities,* 40(4), pp. 266-271. doi: 10.1111/j.1468-3156.2011.00705.x.

Slevin, E. and Sines, D. (2005) 'The role of community nurses for people with learning disabilities: working with people who challenge'. *Journal of Nursing Studies*, 42, pp. 415-427.

Straetmans, J.M.J.A.A., van Schrojenstein Lantman-de Valk, H.M.J., Schellevis, F.G., and Dinant, G.J. (2007) Health problems of people with intellectual disabilities: The impact for general practice. *British Journal of General Practice,* 57(534), pp.64-66.

Taggart, L., Truesdale-Kennedy, M. and McIlfatrick, S. (2011) 'The role of community nurses and residential staff in supporting women with intellectual disability to access breast screening services'. *Journal of Intellectual Disability Research,* 55(1), pp. 41-52. doi: 10.1111/j.1365-2788.2010.01345.x.

Taua, C., Hepworth, J. and Neville, C. (2012) 'Nurses' role in caring for people with a comorbidity of mental illness and intellectual disability: A literature review'. *International Journal of Mental Health Nursing,* 21(2), pp. 163-174. doi: 10.1111/j.1447-0349.2011.00779.x.

Taua, C., Neville, C. and Scot, T. (2017). Appreciating the work of nurses caring for adults with intellectual disability and mental health issues. *International Journal of Mental Health Nursing,* 26(6), pp.629-638. https://doi.org/10.1111/inm.12291.

Timmins, F. and McCabe, C. (2005) How to conduct an effective literature search. *Nursing Standard*, 20(11), pp.41-47.

Tricco, A. C., Lillie, E., Zarin, W., *et al.* (2018). PRISMA Extension for Scoping Reviews (PRISMA-ScR): Checklist and Explanation. *Annals of Internal Medicine,* 169(7), pp.467-473. doi: 10.7326/M18-0850.

©UWL / RCN Foundation 2020

Truesdale, M. and Brown, M. (2017). *People with Learning Disabilities in Scotland: 2017 Health Needs Assessment Report.* Edinburgh: NHS Health Scotland.

Van Schrojenstein Lantman-de Valk H. M. J., Metsemakers J. F. M., Haveman M. J. and Crebolder, H. F. J. M. (2007) Health problems in people with intellectual disability in general practice: a comparative study. *Family Practice,* 17 (5), p.405-407.

Wagemans, A.M.A., van Schrojenstein Lantman-de Valk, H.M.J., Proot, I.M., *et al.* (2015). 'End-of-life decision-making for people with intellectual disability from the perspective of nurses. *Journal of Policy and Practice in Intellectual Disability,* 12(4), pp.294-302. doi: 10.1111/jppi.12140.

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Appendices

Appendix A: JBI Critical Appraisal of Evidence of Effectiveness

Reviewer…….Date:…….

Author:…….Year:…….Record Number:……

1. Was the assignment to treatment groups truly random?
   Yes No Not clear N/A

2. Were participants blinded to treatment allocations?
   Yes No Not clear N/A

3. Was allocation to treatment groups concealed from the allocator?
   Yes No Not clear N/A

4. Were the outcomes of people of people who withdrew described and included in the analysis?
   Yes No Not clear N/A

5. Was the assignment to treatment groups truly random?
   Yes No Not clear N/A

6. Were control and treatment groups comparable at entry?
   Yes No Not clear N/A

7. Were groups treated identically other than for the named interventions?
   Yes No Not clear N/A

8. Were outcomes measured in the same way for all groups?
   Yes No Not clear N/A

9. Were outcomes measured in a reliable way?
   Yes No Not clear N/A

10. Was appropriate statistical analysis used?
    Yes No Not clear N/A

Overall appraisal:		
Include	Exclude	Seek further information

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Comments (including reasons for exclusion):

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Appendix B: JBI Critical Appraisal Checklist for Qualitative Research

Reviewer_____Date_____

Author _____Year_____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?	□	□	□	□

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10. Do the conclusions drawn in the research report flow from the analysis, or interpretation, of the data?	□	□	□	□

Overall appraisal: Include □ Exclude □ Seek further info □

Comments (Including reason for exclusion)

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

Reviewer_____Date_____

Author _____Year_____Record Number _____

	Yes	No	Unclear	Not applicable
11. Is the review question clearly and explicitly stated?	□	□	□	□
12. Were the inclusion criteria appropriate for the review question?	□	□	□	□
13. Was the search strategy appropriate?	□	□	□	□
14. Were the sources and resources used to search for studies adequate?	□	□	□	□
15. Were the criteria for appraising studies appropriate?	□	□	□	□
16. Was critical appraisal conducted by two or more reviewers independently?	□	□	□	□
17. Were there methods to minimize errors in data extraction?	□	□	□	□
18. Were the methods used to combine studies appropriate?	□	□	□	□
19. Was the likelihood of publication bias assessed?	□	□	□	□
20. Were recommendations for policy and/or practice supported by the	□	□	□	□
21. Were the specific directives for new research appropriate?	□	□	□	□

Overall appraisal: Include □ Exclude □ Seek further info □

Comments (Including reason for exclusion)

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Appendix D: JBI Critical Appraisal Checklist for Text and Opinion Papers

Reviewer_____Date_____

Author _____Year_____Record Number _____

	Yes	No	Unclear	Not applicable
22. Is the source of the opinion clearly identified?	□	□	□	□
23. Does the source of opinion have standing in the field of expertise?	□	□	□	□
24. Are the interests of the relevant population the central focus of the opinion?	□	□	□	□
25. Is the stated position the result of an analytical process, and is there logic in the opinion expressed?	□	□	□	□
26. Is there reference to the extant literature?	□	□	□	□
27. Is any incongruence with the literature/sources logically defended?	□	□	□	□

Overall appraisal: Include □ Exclude □ Seek further info □

Comments (Including reason for exclusion)

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Appendix E: 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

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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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Appendix F: Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) Checklist

SECTION	ITEM	PRISMA-ScR CHECKLIST ITEM	REPORTED ON PAGE #
TITLE			
Title	1	Identify the report as a scoping review.	Click here to enter text.
ABSTRACT			
Structured summary	2	Provide a structured summary that includes (as applicable): background, objectives, eligibility criteria, sources of evidence, charting methods, results, and conclusions that relate to the review questions and objectives.	Click here to enter text.
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of what is already known. Explain why the review questions/objectives lend themselves to a scoping review approach.	Click here to enter text.
Objectives	4	Provide an explicit statement of the questions and objectives being addressed with reference to their key elements (e.g., population or participants, concepts, and context) or other relevant key elements used to conceptualize the review questions and/or objectives.	Click here to enter text.
METHODS			
Protocol and registration	5	Indicate whether a review protocol exists; state if and where it can be accessed (e.g., a Web address); and	Click here to enter text.

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SECTION	ITEM	PRISMA-ScR CHECKLIST ITEM	REPORTED ON PAGE #
		if available, provide registration information, including the registration number.	
Eligibility criteria	6	Specify characteristics of the sources of evidence used as eligibility criteria (e.g., years considered, language, and publication status), and provide a rationale.	Click here to enter text.
Information sources*	7	Describe all information sources in the search (e.g., databases with dates of coverage and contact with authors to identify additional sources), as well as the date the most recent search was executed.	Click here to enter text.
Search	8	Present the full electronic search strategy for at least 1 database, including any limits used, such that it could be repeated.	Click here to enter text.
Selection of sources of evidence†	9	State the process for selecting sources of evidence (i.e., screening and eligibility) included in the scoping review.	Click here to enter text.
Data charting process‡	10	Describe the methods of charting data from the included sources of evidence (e.g., calibrated forms or forms that have been tested by the team before their use, and whether data charting was done independently or in duplicate) and any processes for obtaining and confirming data from investigators.	Click here to enter text.

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SECTION	ITEM	PRISMA-ScR CHECKLIST ITEM	REPORTED ON PAGE #
Data items	11	List and define all variables for which data were sought and any assumptions and simplifications made.	Click here to enter text.
Critical appraisal of individual sources of evidence§	12	If done, provide a rationale for conducting a critical appraisal of included sources of evidence; describe the methods used and how this information was used in any data synthesis (if appropriate).	Click here to enter text.
Synthesis of results	13	Describe the methods of handling and summarizing the data that were charted.	Click here to enter text.
RESULTS			
Selection of sources of evidence	14		Click here to enter text.
Characteristics of sources of evidence	15	For each source of evidence, present characteristics for which data were charted and provide the citations.	Click here to enter text.
Critical appraisal within sources of evidence	16	If done, present data on critical appraisal of included sources of evidence (see item 12).	Click here to enter text.
Results of individual sources of evidence	17	For each included source of evidence, present the relevant data that were charted that relate to the review questions and objectives.	Click here to enter text.
Synthesis of results	18	Summarize and/or present the charting results as they relate to the review questions and objectives.	Click here to enter text.
DISCUSSION			

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SECTION	ITEM	PRISMA-ScR CHECKLIST ITEM	REPORTED ON PAGE #
Summary of evidence	19	Summarize the main results (including an overview of concepts, themes, and types of evidence available), link to the review questions and objectives, and consider the relevance to key groups.	Click here to enter text.
Limitations	20	Discuss the limitations of the scoping review process.	Click here to enter text.
Conclusions	21	Provide a general interpretation of the results with respect to the review questions and objectives, as well as potential implications and/or next steps.	Click here to enter text.
FUNDING			
Funding	22	Describe sources of funding for the included sources of evidence, as well as sources of funding for the scoping review. Describe the role of the funders of the scoping review.	Click here to enter text.

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