Review Paper

Understanding the contribution of intellectual disabilities nurses. Paper 1 of 4 -Scoping literature review

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Abstract

The objective of this scoping review was to summarise evidence on the contribution of intellectual disabilities nurses to improve the health and well-being of children, adults and older people with intellectual disability, now and for the future. The Preferred Reporting Items for Systematic Reviews and Meta-Analysis (for Scoping Reviews) (PRISMA-ScR) process and Joanna Briggs Institute (JBI) guidance was used. We included 54 publications. We identified 154 interventions undertaken by intellectual disability nurses. We categorised the intellectual disability nursing interventions into three themes: effectuating nursing procedures, enhancing impact of services, and enhancing quality of life. Findings point to 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 updated. This will provide opportunities to engage more effectively in evidence-based practice.

Keywords

intellectual disability, effectuating nursing procedures, enhancing impact, enhancing quality of life, nursing procedures

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Data Availability Statement included at the end of the article

Introduction

This is the first of a series of 4 papers of a 3-phase study undertaken between 1 February 2020 and 31 March 2021. The overall aim of the research was to identify nursing led interventions that are in place to address the challenging and changing needs of people with intellectual disability. This paper reports the findings from the scoping literature review phase of the study. The *a priori* literature search was undertaken between 1 February 2020 and 31 May 2020, and subsequent *ad hoc* literature search was undertaken during the duration of the project. A re-run of the literature search was undertaken in September 2023 to identify any new studies. We identified one new study. However, no new themes or interventions emerged from this study. The objective of this phase of the study was to identify interventions undertaken or that could be undertaken by intellectual disability nurses working directly with people with intellectual disabilities, and their impact on the health and wellbeing of people with intellectual disabilities. Paper 2 reports the findings from an online cross-sectional survey of intellectual disability nurses that identified 5 major themes of nursing interventions: effectuating nursing procedures, enhancing impact of intellectuality disability services, enhancing impact of mainstream services, enhancing quality of life, and enhancing intellectual disability nursing practice. Paper 3 reports the findings from evaluation questions of an online survey of intellectual disability and other nurses working with people with intellectual disabilities understood these interventions. Paper 4 reports the impacts and case examples of intellectual disability nursing interventions from an online survey of intellectual disability nurses and other nurses working predominantly with people with intellectual disabilities.

There is a lack of clarity on effective interventions that can be carried out by intellectual disability nurses. By interventions we mean any evidence-based actions, procedures, or treatments undertaken by the nurses (Hogston and Simpson, 2002). Intellectual disability nurse role expectations vary across countries. Lack of clarity on effective intellectual disability nursing interventions can result in confused and ambiguous expectations among healthcare professionals. This may result in reduced quality of health and healthcare experiences for people with intellectual disability. Clarity of role expectations for intellectual disabilities nurses is beneficial because it may improve communication, flexibility, and responsiveness at every level of health policy implementation for people with intellectual disability.

The Nursing and Midwifery Council of the United Kingdom and the Nursing and Midwifery Board of Ireland offer pre-registration intellectual disability nursing programmes and in the Netherlands students can choose to specialise in intellectual disability in the 4th year of a generic programme (Robinson et al.,2017). In other countries such as Australia, New Zealand and United States of America (USA) pre-registration nursing programmes have intellectual disability (Trollor et al., 2016). In countries like the USA and Canada, there are post-registration courses for nurses working with people with intellectual disability. Internationally, the role of intellectual disability nursing varies significantly but it is evident that the specialist knowledge and skills are essential in enhancing the delivery of person-centred care that improve health outcomes for people with intellectual disability (Brown et al., 2016).

The provision of health and healthcare services to people with intellectual disability is opportunistic. This is despite evidence that point to a need for specific and targeted interventions to achieve better outcomes (McIlfatrick et al., 2011; Chauhan et al., 2010; Robertson et. al., 2014), despite evidence demonstrating that preventative nursing interventions are effective in identifying the health needs of people with intellectual disability (Emerson et al., 2011; Robertson et. al., 2014). These nurses need to deliver effective nursing care to people with intellectual disability in challenging circumstances . This is also contrary to the the United Nations Convention on the Rights of

Persons with Disability (Melville et al., 2006), which stipulates that people with intellectual disability have the right to the highest attainable standard of health.

The scoping literature review sought to answer the following question;

> What intellectual disability nursing interventions are in place to respond to the changing needs of people with intellectual disability, and what is the impact of these interventions?

There are estimated 1.5 million people (approximately 2.16% of adults and 2.5% of children) with intellectual disability in the UK, this is changing and increasing (Mencap, 2012, Mencap, 2020). People with intellectual disability are high and frequent users of all health services, including primary care, child health services, acute healthcare services and specialist intellectual disability services. There is increasing complexity of the health and social care needs and conditions of this population (Truesdale and Brown, 2017). They are known to have much greater health needs than those of comparable age groups (Backer et al., 2009; Kerr, 2004; Straetmans, et al., 2007; Hatton and Emerson, 2015; Kavanagh et al., 2017; LeDer, 2020; Robertson et al., 2017; Savage and Emerson, 2016; Emerson et al., 2016a; Emerson et al., 2016b), and experience preventable higher mortality rates (Mencap 2007; Heslop et al., 2013; Heslop et al., 2014; Robertson et al., 2015; Bakker-van Gijssel et al., 2017; LeDeR, 2020). These health problems are commonly, and widely undiagnosed, misdiagnosed, and untreated (Llewellyn et al., 2015; Emerson and Brigham, 2015). People with intellectual disability are more likely to be dependent on others for their health and healthcare outcomes (Campbell and Martin, 2009).

Poor uptake of health services amongst the population of people with intellectual disability is a longstanding issue (Allerton and Emerson, 2012; Robertson et al., 2014). People with intellectual disability are likely to be passive participants in their health and healthcare and are dependent on others for their health and healthcare outcomes (Campbell and Martin, 2009). The provision of health services for people with intellectual disability appear opportunistic, despite the need for targeted interventions (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 disability (Emerson et al., 2011; Robertson et. al., 2014).

The lack of role clarity of the professionals working with people with intellectual disability has been consistently identified as one of the most common barriers to better health outcomes for people with intellectual disability (Mafuba, 2009, 2013; Mafuba and Gates, 2015; Mafuba, Gates and Cozens, 2018b). These outcomes could be improved through appropriate intellectual disability nursing interventions. It is therefore important to clarify the interventions intellectual disability nurses can play to minimise the potential consequences of the risks the result in the preventable premature death of people with intellectual disability. Lack of clarity on effective nursing interventions can result in confused and ambiguous expectations among healthcare professionals, as well as reduced quality of health and healthcare experiences for people with intellectual disability. It is important to establish the evidence base for the most effective interventions to delivering nursing care to people with intellectual disability.

Methods

The Preferred Reporting Items for Systematic Reiviews Meta-Analyses for Scoping Reviews (PRISMA-ScR) process and Joanna Briggs Institute (JBI) guidance were used to select the literature for review and to present the findings (Trico et al., 2018; Peters et al., 2017). We adopted a mixed methods approach to the review and synthesis due to the heterogeneous nature of the literature. JBI

tools were used to pool findings and rate them for quality. Thematic synthesis (Braun et al., 2019) was used to generate analytical themes.

Eligibility criteria

Inclusion and exclusion criteria. Sources were included if they were published before commencement of this review and were published in English, or subsequently translated into English. Peer reviewed journal articles, unpublished studies (e.g., theses) were considered for review if they included references to intellectual disability nursing interventions.

Types of studies. Qualitative, quantitative and mixed method studies published in peer-reviewed journals, opinion papers, and literature reviews were included.

Types of phenomena of interest. Intellectual disability nurse interventions that focused on improving the health and well-being of pregnant women with intellectual disabilities, children, adults, and older people with intellectual disability.

Types of participants. Intellectual disability nurses and other nurses that exclusively worked with people with intellectual disability across the lifespan, people with intellectual disability, and carers of people with intellectual disability. We included literature reviews, and opinion papers that focussed on interventions undertaken by intellectual disability nurses even though they had no participants.

Search terms. Search terms were organised into 3 domains, then the overall domains were combined using AND, with domains 1 and 2 searched for in Title only (see Table 1).

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

Table 1 shows the search terms that were used, how they were combined, and how databases were searched. We also searched the reference and citation lists of the review papers for additional literature.

Selection of sources of evidence

Documents were assessed by three reviewers for methodological validity and relevance. We used the JBI Checklist for analytical cross-sectional studies (JBI, 2020a), the JBI Checklist for qualitative research (JBI, 2020b), the JBI Checklist for randomised controlled trials (JBI, 2020c), the JBI Checklist for systematic reviews and research syntheses (JBI, 2020d), and the JBI Checklist for text and opinion (JBI, 2020e) to appraise literatures.

Table 1. Search terms.

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* OR "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 OR "Role" OR "Intervention"
Limited to English; -2020; Research Studies:

Data charting process

Three reviewers independently carried out data extraction using a data extraction form based on Timmins and McCabe (2005). 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: author(s) details, 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 the JBI levels of evidence: Levels of evidence for effectiveness (JBI, 2013) to rate papers.

Synthesis

We adopted a narrative approach to synthesis because of the heterogeneous and disparate in nature of the literature. The inclusion of diverse forms of evidence was important for broadening the evidence base to inform the review (Sandelowski et al., 2012). We used the Braun et al.'s (2019) approach to thematic analysis to generate analytical themes. Three members of the research team of six undertook data synthesis, with the remaining three members making a review panel that reviewed and agreed the emerging themes.

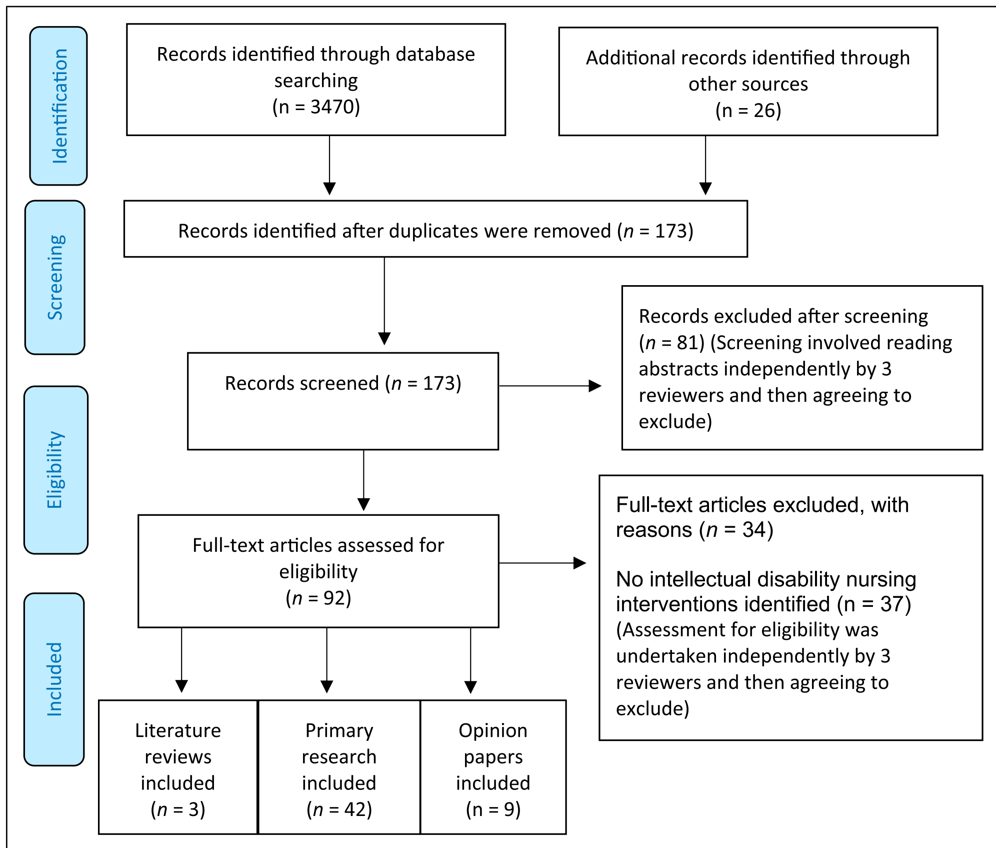

Figure 1. Literature appraisal and selection flow diagram.

We identified 154 interventions undertaken by intellectual disability 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). Out of the 154 interventions only 2 were underpinned by some evidence of effectiveness.

Results

Selection of literatures

We included 3 literature reviews, 42 primary research papers, and 9 opinion and text papers in the review. Figure 1

Critical appraisal within sources of evidence

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

Results and characteristics of sources of evidence

Table 2. Results and characteristics of sources of evidence.

Authors / Country / JBI Level of Evidence	Aims	Methods	Findings / Interventions
Literature reviews			
1. Mafuba et al. (2018a) / UK / 4a	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
2. Taua et al. (2012)/ Australia / 4a	Examined literature on the role of the nurse caring for people with a dual disability of intellectual disability and mental illness.	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
3. Mafuba (2009) / UK / 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
Primary research			
1. Wilson et al. (2020) / Australia / 4b	Described the roles that Australian nurses play, the breadth of skills that they deploy, and the range of contexts in which they practice.	Descriptive survey. N = 101 nurses working with people with intellectual disabilities	1. Direct assessment and care 2. Supervision of support workers 3. Staff management within the service 4. Education 5. Specialist consultation 6. Advocacy
2. Oulton et al. (2019) / UK / 4b	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 17. Engaging senior managers

(continued)

Table 2. (continued)

Authors / Country / JBI Level of Evidence	Aims	Methods	Findings / Interventions
3. Doody et al. (2019)/ Ireland / 4b	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.
4. Pennington et al. (2019)/ UK / 1c	This was part of a wider study on the development of a nurse-led approach to managing epilepsy in adults with an intellectual disability. This paper 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
5. Mafuba et al. (2018b) / UK / 4b	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.
6. Ring et al. (2018) / UK / 1c	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.	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 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.	1. Patient assessment 2. Medication management 3. Ordering and interpreting investigations 4. Providing education 5. Support and counselling to patients and families
7. Quinn & Smolinski (2018) / USA / 4b	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%)

(continued)

Table 2. (continued)

Authors / Country / JBI Level of Evidence	Aims	Methods	Findings / Interventions
8. Taua et al. (2017)/ New Zealand / 4b	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. Multicohort study: (i) people with intellectual disability and mental health issues; (ii) their usual carers (from community settings); and (iii) nurses in inpatient settings. This paper presents only the findings from group 3 (nurses, *n* = 13).	1. Focussed assessment to avoid diagnostic overshadowing. 2. Enabling creative communication. 3. Modifying mental health interventions to suit people with intellectual disabilities.
9. Doody et al. (2017) / Ireland / 4b	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, (1991)) 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
10. Cleary & Doody (2017)/ Ireland / 4b	The study aimed to explore nurses' experiences of caring for older persons with intellectual disability and dementia.	Husserlian phenomenology 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).	1. Caregiving at mid-stage (eating and drinking) and at end stage (toileting and incontinence). 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.
11. Auberry & Cullen (2016) / USA / 4b	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 (AANN) Seizure Algorithm during telephone triage.	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
12. Drozd and Clinch (2016)/ UK / 4b	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 a intellectual disability in an orthopaedic or trauma hospital setting in England (*n* = 13).	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
13. Lovell & Bailey (2016)/ UK / 4b	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.
14. Brown et al. (2016) / UK /4b	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, person-centred care.	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 and 11 within focus groups.	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

(continued)

Table 2. (continued)

Authors / Country / JBI Level of Evidence	Aims	Methods	Findings / Interventions
15. Lovell et al. (2015)/ UK / 4b	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.
16. MacArthur et al. (2015) / UK / 4b	To examine 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.	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), general hospital (*n* = 19) and intellectual disability liaison nurses (*n* = 6).	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. 7. Providing carer educational support. 8. Undertaking pre-morbid baseline assessments. 9. Providing eating and drinking advice and guidelines. 10. Providing diagnostic advice
17. Chapman (2015) / UK (PhD Thesis) / 4b	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
18. Marriott et al. (2015) / UK / 4b	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.
19. Wagemans et al (2015) / Netherlands / 4b	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.
20. Lloyd & Coulson 2014) / UK / 4b	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
21. Arrey (2014) / UK PhD Thesis / 3e	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 disability in palliative care settings.	Hermeneutic phenomenology incorporating a constructivist perspective was used. Purposive sampling. Semi structured interviews. Thematic analysis. 13 participants (intellectual disability nurses – (*n* = 8) + 5 palliative care professionals).	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 6. Facilitating collaborative working.

(continued)

Table 2. (continued)

Authors / Country / JBI Level of Evidence	Aims	Methods	Findings / Interventions
22. Lee & Kiemle (2014) / UK / 4b	The research investigated the experiences of nurses supporting individuals diagnosed with ID and personality disorder.	In-depth, semi-structured interviews were used with (n = 9) intellectual disabilities nurses working with clients with a forensic history and intellectual disabilities. Interpretative phenomenological analysis (IPA) was used.	1. Building therapeutic relationships with people with intellectual disabilities and personality disorder. 2. Providing emotional support.
23. Bailey et al. (2014)/ Ireland / 4b	Described the provision of community nursing support for persons with an intellectual disability and palliative/end-of-life care needs in one HSE region in Ireland.	Mixed methods study - exploratory descriptive survey utilising a cross-sectional self-reporting questionnaire. 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).	1. Providing information 2. Support the family 3. Supporting and advising staff 4. Coordinating services 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
24. Dalgarno & Riordan (2014) / UK / 4b	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) intellectual disability 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.
25. Lovell et al. (2014) / UK / 4b	Identified and discussed 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
26. Mafuba & Gates (2015) / UK / 3e	This paper reports 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 disabilities.	A 9-item online questionnaire survey of community intellectual disability nurses (UK-wide) (n = 171) (band 5: *n* = 19; band 6: *n* = 67; band 7: *n* = 59; band 8: *n* = 26). Non-proportional quota sampling.	1. Promoting health 2. Facilitating access to health services 3. Providing health education 4. Undertaking health prevention, health protection and health surveillance.
27. Mafuba (2013) / UK. PhD Thesis / 3e	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
28. Doody et al. (2013) / Ireland / 4b	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). Purposive sample of intellectual disability nurses (*n* = 7).	1. Preparing other nursing specialisms to care holistically for people with intellectual disabilities.

(continued)

Table 2. (continued)

Authors / Country / JBI Level of Evidence	Aims	Methods	Findings / Interventions
29. Brown et al. (2012) / UK /4b	Examined 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
30. Jenkins (2012) / UK / 4b	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
31. Marsham (2012) / UK / 4b	Explored 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 managing an adult caseload (n = 7).	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. 7. Assessing people's understanding of their needs.
32. Taggart et al. (2011) / UK / 4b	Examined 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
33. Campbell (2011) / New Zealand / 4b	Described nurses' emotional response to violent incidents and explored the support they require in dealing with constant exposure to workplace violence the purpose of this study.	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.
34. Ng (2011) / UK PhD Thesis / 4b	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.
35. Mason & Phipps (2010)/ UK / 4b	Identified the main skills and competencies of forensic intellectual disability nurses; to establish if these perceived main skills and competencies differ between forensic and non-forensic intellectual disability nurses and identified 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.

(continued)

Table 2. (continued)

Authors / Country / JBI Level of Evidence	Aims	Methods	Findings / Interventions
36. McKeon (2009) / Ireland / 4b	Provided 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.	Questionnaire survey (questionnaire used a nursing skills list from The Royal Marsden Hospital Manual of Clinical Effectuating nursing procedures (Mallett and Dougherty, 2000)). 26 questionnaires were completed, 18 from a residential setting and 8 from a community living setting.	1. Violence prevention 2. Needs assessment
37. Llewellyn & Northway (2007) / UK / 4b	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
38. Slevin & Sines (2005) / UK / 4b	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 4. Monitoring and evaluating care interventions
39. Llewellyn (2005) / UK / 4b	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
40. Marshall et al. (2003) / UK / 4c	Followed up people identified as overweight and obese following special health screening clinics and to determine the actions taken. Evaluated the impact of health promotion classes on participants' weight loss.	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
41. Marshall & Foster (2002) / UK / 4b	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
42. Barr et al. (1999) / UK / 4b	Introduced 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
Opinion papers			
1. Cope & Shaw (2019) / UK / 5c	Report 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 11. Supporting admissions and outpatients

(continued)

Table 2. (continued)

Authors / Country / JBI Level of Evidence	Aims	Methods	Findings / Interventions
2. McCarron et al. (2018) / Ireland / 4b	The project determined 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 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.
3. Delahunty (2017) / UK / 5c	The 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 identify children who should be formally assessed for intellectual disability.	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.
4. Northway et al. (2017) / UK / 5b	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). Thematic analysis was used.	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 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

(continued)

Table 2. (continued)

Authors / Country / JBI Level of Evidence	Aims	Methods	Findings / Interventions
5. Nelson & Carey (2016) / Ireland / 5c	Highlights the importance of the 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.	Opinion paper.	1. Promotion of the health and well-being 2. Assessment of mobility decline in older people with intellectual disabilities. 3. Supporting maintenance of optimal health.
6. Adams & Shah (2016) / UK / 5b	Examined 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.	Opinion paper.	1. Reviewing and assisting with the withdrawal of antipsychotic medication 2. Reducing prescribing of antipsychotic medicines 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.
7. Morton-Nance (2015) / UK / 5c	Explored 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, 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
8. Sheerin (2012) / Ireland / 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
9. DoH (2007) / England, UK / 5c	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

Discussion

What is clear from this scoping review is the wide range of interventions that intellectual disability nurses undertake in a complex sphere of practice. The sheer extent of these interventions signifies that intellectual disability nurses need to constantly adapt and engage in a wide range of roles, as well as constantly assimilating emergent roles (Northway et. al., 2017). The literature also documents the complexity and changing nature of care and care needs of people with intellectual disability, the changing environments in which intellectual disability nurses are practising, and the increasing expectation for intellectual disability nurses to meet the health needs of people across the lifespan.

In the *effectuating nursing procedures* theme, we identified a wide range of nursing procedures that intellectual disability nurses currently undertake. In *enhancing the impact of services* theme the need for intellectual disability nurses to engage in inter-professional working cannot be over-emphasised – their input is often essential in ensuring care is co-ordinated, integrated, and meets the needs of the individual and their support network. 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 disability.

Effectuating nursing procedures

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

Maternity. The review by McCarron et al., (2018) highlighted the need for intellectual disability nurses to work with people with access pre-natal screening services but a very limted number of studies identified interventions undertaken by intellectual disability nurses in this area. Providing support in this area is important because without such support it is likely that pregnant women with intellectual disability may be unable to access appropriate maternity care. The lack of any evidence of intellectual disability nurse interventions in this area may be indicative of the fact that maternity practice is outside the competence scope of nursing practice in general, so it is likely that intellectual disability nursing interventions in relation to women will always be limited. However, it could be argued that the need for intellectual disability nurses to work with women with intellectual disabilities to access maternity and pre-natal screening services is important (McCarron et al., 2018). Expectant mothers with intellectual disabilities may face child protection issues and intellectual disability nurses can undertake important interventions to support them through these processes. It could be argued that intellectual disabilities nurses are well placed to work directly with pregnant women with intellectual disabilities through supporting them psychologically, as well as supporting them to access appropriate maternity services.

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 (Quinn and Smolinski, 2018). Complex and changing needs require continuous assessment to maintain and improve the health and wellbeing of people with intellectual disability. Evidence-based needs assessment is more likely to result in the development and implementation of effective interventions (McCarron et al., 2018); Quinn and Smolinski, 2018; Doody, Slevin and Taggart, 2017; Delahunty, 2017; Sutherland, 2017; Nelson and Carey, 2016).

Evidence demonstrates that intellectual disability nurses undertake health screening (McCarron et al., 2018); 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 carried out by intellectual disability nurses and has potential to reduce the consequences of undiagnosed health needs that are prevalent in the population of people with intellectual disability.

Another significant intervention undertaken by intellectual disability nurses across the lifespan is care planning (Taua, Hepworth and Neville, 2012). In addition, Dahm and Wadwnsten (2008) have highlighted the importance of care planning to the delivery of effective nursing interventions. It is surprising that only two studies (Taua et al., 2012; Dahm and Wadwnsten, 2008) in this review

identified and described care planning as an important intervention as an important role undertaken by intellectual disability nurses.

Other essential nursing procedures identified in the literatures are nutrition and dysphagia management (Northway et al., 2017), managing violence and challenging behaviour (Campbell, 2011), 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 interventions undertaken by intellectual disability nurses across the lifespan. This complexity requires intellectual disability nurses to be adaptable to deliver effective care to people with intellectual disability.

Several studies have 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 (Taua et al., 2012; Wagemans et al., 2015). 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 communication (Wagemans et al., 2015). It can be argued that effective communication is an important intervention in intellectual disability nursing practice because it underpins effective delivery of healthcare to people with intellectual disability.

Children. Intellectual disability nurses also to have skills to assess a wide range of the needs of children with intellectual disability and Northway et al. (2017) have highlighted the need for intellectual disability nurses to be involved in developmental assessments (Northway et al*.,* 2017; Delahunty, 2017). However, this review has identified a limited range of interventions undertaken by intellectual disability nurses in this area. 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.

Interventions reported in some studies in this review include 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 (Lovell et al., 2015). These interventions illustrate the complexity of the roles of intellectual disability nurses. However, what is not clear from these studies is the evidence-base to support these interventions, and robust evidence to demonstrate their effectiveness and impact.

Adults. Undertaking nursing procedures is fundamental to the role of intellectual disability nurses when working with adults in a wide range of settings. The literature included in this review shows that intellectual disability nurses undertake a wide range of assessment activities when working with adults including; assessing risk (Pennington et al., 2019), direct assessment (Wilson et al., 2020) undertaking focused assessment in order to avoid diagnostic overshadowing (Taua et al*.,* 2017), receiving and assessing referrals from other services and agencies (Doody et al., 2019), undertaking pain assessments (Quinn and Smolinski, 2018), and assessing and preparing patients with intellectual disability for surgery (Drozd and Clinch, 2016). This demonstrates that intellectual disability nurses work with adults with intellectual disability who have diverse and complex needs. It is more likely that intellectual disability 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 nurses work with 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), medication (Ring et al., 2018), self-harm (Mason and Phipps, 2010), family therapy and support (Mason and Phipps, 2010), psychological interventions (Mason and Phipps, 2010), behavioural interventions and support (Cleary and Doody, 2017), and building therapeutic relationships (Lovell et al., 2015). What is evident here is that intellectual disability nurses have a wide range of skills required to directly manage a wide range of complex 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 literature suggests that intellectual disability nurses may have to switch between a wide range of activities in a day's work and are likely to require advanced multi-tasking and critical thinking skills.

Older adults. We identified a limited number of nursing procedures undertaken by intellectual disability nurses in this area, which include undertaking clinical diagnosis (Drozd and Clinch, 2016), providing environmental supports and staff training in the principles of person-centred dementia (Cleary and Doody, 2017), diagnosing mental health problems (Jenkins, 2012), undertaking assessments of mobility decline (Nelson and Carey, 2016), and undertaking dementia assessments (Northway et al., 2017). Factors such as limited employment of specialist intellectual disability nurses in older people's care homes, along with reduced life expectancy for people with intellectual disability may contribute to this limited involvement.

End of life care. We unearthed a limited number of papers identifying interventions undertaken by intellectual disability nurses in this vital area of practice (Ng, 2011; Keenan et al., 2018; Wagemans et al., 2015). This is concerning, given the impact of bereavement on emotional and psychological wellbeing. Interventions include assessing changing health conditions and detecting deterioration (Ng, 2011), completing hospital or hospice referrals (Bailey et al., 2014), managing end of life care (Bailey et al., 2014), pressure relief and skin care (Bailey et al., 2014), bereavement counselling (McCarron et al., 2018), and facilitating communication (Oulton et al., 2019). 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 disability across the lifespan with diverse backgrounds and needs.

Enhancing impact of services

In this theme we identified 73 (47%) interventions. The interventions relate to activities where intellectual disability nurses work with other professionals and organisations, facilitating others to provide better care to people with intellectual disability.

Maternity. Only two publication identified intellectual disability nursing roles that focused on enhancing the impact and or effectiveness of maternity services (Northway et al., 2017; McCarron et al., 2018). The dearth of literature 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 to improve access to maternity services by women with intellectual disability. 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 roles that focus on ensuring that other professionals and services effectively support people with intellectual disability across the lifespan. The interventions we identified include; assessing effectiveness of interventions (Mafuba et al., 2018a), 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, 2018b); Mafuba and Gates, 2015; Mafuba, 2013; Brown et al., 2012), facilitating the making of and implementation of reasonable adjustments (Cope and Shaw, 2019; (Mafuba et al., 2018b; 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, 2015; Mafuba, 2013), health protection (Mafuba and Gates, 2015; Mafuba, 2013) and health surveillance (Mafuba et al., 2018a; Mafuba and Gates, 2015; Mafuba, 2013; Sheerin, 2012). It is evident from these literatures that intellectual disability nurses play a significant role in enhancing the effectiveness of preventative interventions implemented by other organisations and professionals. To enhance their own effectiveness, intellectual disability nurses need to work collaboratively in improving access to mainstream services.

To further enhance the impact and effectiveness of other healthcare professionals and agencies intellectual disability nurses need to be involved in information sharing, liaise with other professionals and agencies, make, and facilitate reasonable adjustments, provide support in primary care, raise awareness on intellectual disability, and support families. This is important because intellectual disability nurses need to ensure that other professionals and healthcare agencies effectively meet the needs of people with intellectual disability. Intellectual disability nurses, therefore, they need to engage with all stakeholders at individual, community, and population levels.

Children. We found only three publications that explicitly identified roles and interventions undertaken by intellectual disability nurses to improve mainstream services for children (Marshall and Foster, 2002; Delahunty, 2017; Oulton et al., 2019). As in other areas of intellectual disability nursing practice noted earlier, the limited number studies that 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 in this area 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 children and adult 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 disability.

Adults. The publications included in this review identified a wide range of interventions undertaken by intellectual disability nurses in a wide range of services. 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), 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), and providing leadership in improving services (Mafuba, 2013).

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 multi-disciplinary and multiple agencies. To improve services and enhance 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).

Older adults. We found only two publications that considered intellectual disability nurse involvement with the impact of 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 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 multi-disciplinary team in primary care and secondary care (McCarron et al., 2018; Marshall and Foster, 2002). For people with intellectual disability, 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 disability who are at the end of their lives.

Enhancing quality of life

In this theme we identified 41 (27%) interventions. The interventions are focused on addressing the determinants of health.

All age groups. In the literatures under review the interventions we identified 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; 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 intellectual disabilities to make their own informed choices (Sheerin, 2012), educating people with intellectual disabilities and their carers about health and healthy lifestyles (Mafuba et al., 2018b; Mafuba and Gates, 2015; 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; Northway et al., 2017; Adams and Shah, 2016; Nelson and Carey, 2016; Mafuba and Gates, 2015; 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).

For people with intellectual disability, improving the quality of their lives is essential for their health and wellbeing. 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 disability 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 disability to develop skills to self-manage their conditions that may limit life.

Children. We found only three publications that considered intellectual disability nurse involvement with addressing the determinants of health for children (Emerson et al., 2011; Marshall and Foster, 2002; Oulton et al., 2019). This is of significant concern given the growing population of children with intellectual disability, 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 disability on children's health. However, in this review we only identified 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. Adults with intellectual disability are known to be inactive and lead sedentary lives (Messent et al., 1999). The number of interventions that are relevant to improving the quality of life of people with intellectual disabilities we have identified 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., 2018a; 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), 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).

Intellectual disability nurses play important roles in assessing people's understanding of their needs, developing health education material, giving information and advice, encouraging people with intellectual disability to make their own decisions about healthy living, promoting employment, promoting health checks, and screening. Intellectual disability nurses play important roles in supporting adults with intellectual disabilities to live a physically active and healthy lives.

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 disability. This is a significant concern given the growing population of older adults with intellectual disability, 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 minimal 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.

Intellectual disability nurses have an important role to play in meeting the palliative care needs of people with intellectual disability.

Limitations

The terms of the review from the funding organisation were such that we included opinion publications. Covid-19 restrictions at the time of literature search restricted our ability to physically access some libraries. The research was concluded in March 2021 and we acknowledge that other studies may have been published since then that may add to the body of evidence in this area

Conclusions

Although there is some evidence to support the emerging themes, the literature is limited in robustness and scope. High quality research is essential in determining the impact and effectiveness of intellectual disability nursing interventions across the lifespan. 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 the wider health and social care sphere practice.

While we are conscious of the narrative nature of our review, we conclude that important lessons can be learnt to further develop and clarify the interventions undertaken by intellectual disability nurses in meeting the needs of people with intellectual disability. The interventions undertaken by intellectual disability nurses need to be understood in the context of the complexity and changing needs of people with intellectual disability, as well as the introduction of the new NMC (2018) standards for pre-registration nurse education in the UK.

Recommendations for research. 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 disability, research to further clarify intellectual disability nurse interventions, more specifically in relation to maternity, children, older adult, and end of life care is needed. Research need to be undertaken focusing on the impact and effectiveness of intellectual disability nursing interventions.

Recommendations for practice. Intellectual disability nurses undertake a wide range of interventions in a complex sphere of practice. Intellectual disability nurses need to develop skills to constantly adapt to meet the changing needs of people with intellectual disabilities.

Recommendations for education. There appears to be a variation within some countries and between countries as the interventions intellectual are trained to undertake. Nurse educators need to be more collaborative nationally and internationally to develop learning opportunities for intellectual disability nurses to improve their knowledge and skills as they take on new roles that involve complex interventions.

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Ethical statement

Ethical approval

We confirm that Ethical Committee approval was sought from the University of West London (Approval No: 01032) and is acknowledged within the text of the submitted manuscript.

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Data Availability Statement

Raw data were generated at the University of West London. Data supporting the findings of this study are available from the corresponding author Professor Kay Mafuba (kay.mafuba@uwl.ac.uk) on request. Data will be retained for at least 5 years.

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Appendix

Appendix 1: JBI Levels of evidence for effectiveness

Level 1 – Experimental Designs.

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

Level 2 – Quasi-experimental Designs.

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

Level 3 – Observational – Analytic Designs.

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

Level 4 – Observational –Descriptive Studies.

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

Level 5 – Expert Opinion and Bench Research.

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