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Nature and extent of intellectual disability nursing research in Ireland: a scoping review to inform health and health service research

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BMJ Open Nature and extent of intellectual disability nursing research in Ireland: a scoping review to inform health and health service research

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ABSTRACT

Objectives To capture the extent and nature of intellectual disability nursing publications in Ireland.

Design Scoping review using Arksey and O'Malley approach.

Data sources Six databases (PsycINFO, CINAHL, Medline, Academic Search Complete, Scopus, Embase) were searched along with a web-based search of the eight academic institutions delivering intellectual disability nurse education in Ireland for publications indexed from the earliest available date to the 31 December 2020.

Eligibility criteria Publications by an academic, practitioner or student working in intellectual disability practice or education in Ireland relating to intellectual disability nursing, care or education.

Data extraction and synthesis Data pertaining to type of paper/design, authors (academic/professional/student), year, collaboration (national/international), topic/content area and title were extracted from each paper. Data were analysed by two authors using Colorafi and Evans content analysis steps where data was tabulated, and a narrative synthesis undertaken.

Results The reporting of the review is in line with the Preferred Reporting Items for Systematic reviews and Meta-Analyses (PRISMA) and PRISMA extension for Scoping Reviews Checklist. Database and web-based searching resulting 245 articles meeting the criteria for this review. Through content analysis the 245 articles were mapped onto six themes: supporting inclusion, future planning, aspects of health, interventions, education, professional development and research, and personal and professional accounts of caring.

Conclusions This review highlights the extent and nature of intellectual disability publications by academic, practitioner or student working in intellectual disability nursing in Ireland together with opportunities for future growth and development. From the findings it is apparent that there is an ongoing need for intellectual disability nurses to define their role across the full trajectory of health provision and to make visible their role in person-family centred support, inclusion, and contributions in health education, health promotion and health management.

BACKGROUND

It has been previously suggested that there is a deficit in intellectual disability nursing

Strengths and limitations of this study

- This is the first scoping review to provide a comprehensive overview of Irish intellectual disability nursing research literature.
- This review was based on a comprehensive search of institutional websites and six databases.
- A formal quality appraisal process was not included in the review.
- Results from this review serve to advance the awareness of intellectual disability nursing research and provide guidance for future research.
- While a librarian was consulted regarding the search strategy, the services of a librarian were not included in this review.

research¹⁻⁴ which can be somewhat attributed to the low visibility of the intellectual disability nurse among the population of healthcare workers. Ireland and the UK remain the only countries providing a specialist undergraduate, direct entry intellectual/learning disability nurse education programme.⁵ Internationally different models of nurse education exist for intellectual disability such as generalist programmes with pockets of specialisation (eg, Netherlands) and inclusion in generalist programmes (eg, Australia, New Zealand, USA and Canada). In the USA, Canada and some parts of Europe a post-registration certificate and developmental disability nursing associations exist. In Ireland and the UK, students can complete a specialised preregistration branch programme in intellectual/learning disability and these programmes lead to the qualification and registration of intellectual/learning disability nurses with their national boards (Nursing and Midwifery Board of Ireland, Nursing and Midwifery Council). The debate surrounding the status of intellectual/learning disability nursing within the profession of nursing has long been argued.⁶ However, in the last 30

years, Ireland has witnessed many developments within the profession of intellectual disability nursing. One such development being undergraduate nurse education moving from the traditional hospital-based certificate apprenticeship model to third-level institutions providing diploma level in 1994 and moving to a 4-year degree level programme of study in 2002.⁷

From an Irish context the report of the Commission on Nursing⁸ recommended that earlier certificate and diploma educated nurses be supported to undertake post-registration education to support them to attain degree status and to preceptor future students. Building on from this report, the National Council for the Professional Development of Nursing and Midwifery (NCPDPM) was established in 1999. The NCPDPM oversaw the introduction of clinical nurse specialists (CNS) and advanced nurse practitioners posts in all areas of nursing in Ireland^{9–12} and the development of CNS in intellectual disability was described.¹³

Given the economic climate, and the focus on cost cutting measures and value for money, all agencies, services and provisions are under scrutiny and review. In Ireland a national review of undergraduate nurse education¹⁴ resulted in the development of national requirements and standards for undergraduate nursing which aligned to the Report of the Review of Undergraduate Nursing and Midwifery Programmes,¹⁵ European Union (EU) Nursing Competences¹⁶ and the continuation of the five-entry point to nursing (General, Mental Health, Children's, and Intellectual Disability) and Midwifery.

Internationally, recent published literature pertaining to intellectual disability nursing has focused on understanding the role,¹⁷ the uniqueness of the role,¹⁸ challenges,¹⁹ practice, policy and legislative issues²⁰ and the demographic profile of the intellectual disability nursing workforce.²¹ However, given the changing landscape of intellectual disability nursing, service delivery and education over the years in Ireland and the suggested lack of research, this paper aims to identify the existing landscape of intellectual disability nursing publications from Irish intellectual disability academic, practising nurses or student working in intellectual disability through a scoping review of the published literature.

METHODS

The methodologically approach proposed by Arksey and O'Malley²² for scoping reviews was chosen as it enables a comprehensive and systematic process to search the literature and to establish the full range and nature of the literature published on a particular topic. This involved a five-step process: (1) identifying the research question, (2) identifying relevant studies, (3) study choice, (4) plotting the data and (5) arranging, summarising and communicating the outcomes. This was an interactive process where each step was returned to and advanced during the review.

Identifying the research question

What is the nature and extent of intellectual disability nursing research in Ireland? This question was addressed by identifying the range and extent of Irish intellectual disability nursing publications by intellectual disability academic, practising nurses or student working in intellectual disability in Ireland.

Identifying relevant studies

The review search was conducted in 2021 across six databases: PsycINFO, CINAHL, Medline, Academic Search Complete, Scopus, Embase. Searches were conducted in title or abstract in each database using key words, truncation and Boolean methods. String one of the searches consisted of TI OR AB (intellectual disability OR mental retardation OR learning disability OR developmental disability). String two involved TI OR AB (nurs*) and string three composed of TI OR AB (Ireland OR Irish OR Republic of Ireland). Following which the three search strings were combined using the AND Boolean operator. The search process was piloted and agreed by all authors (OD, MEB and TH). Publications up to and including the 31 December 2020 were included in the review. No attempt was made to draw conclusions or make judgement on the quality of the literature as the focus of this review was on identifying, mapping and charting the nature and extent of the literature; critical appraisal and risk of bias assessments are not required in scoping reviews.

Study choice

All results retrieved from each database search (n=442) were exported to Endnote and screened for duplicates. In order to ensure relevant publications were not missed^{23 24} it was decided to conduct an additional search of the nursing schools/departments. The home pages of the eight academic institutions (four universities and four institutes of technology) that deliver intellectual disability nurse education in Ireland were searched. Each institution's Department/School of Nursing's webpage were searched for intellectual disability lecturers and their publication profile/listed publications were checked to identify any articles relating to intellectual disability nursing, care or education not already identified in the database search process. The web search identified an additional 169 results for inclusion which were combined with the results from the databases. The dual search method retrieved 611 results which were screened with 270 duplicates removed leaving 341 for screening. The next stage involved screening titles/abstracts and verifying authors were academic, practitioner or student working in intellectual disability in Ireland, as a result 69 papers were excluded. The remaining 272 went to a full-text review and 27 were excluded as they did not relate to intellectual disability nursing, care or education, with 245 meeting the criteria for this review. The screening process was conducted by paired reviewers (OD/MEB or OD/TH) and the search process and results are shown in figure 1 and the review was reported in line with the

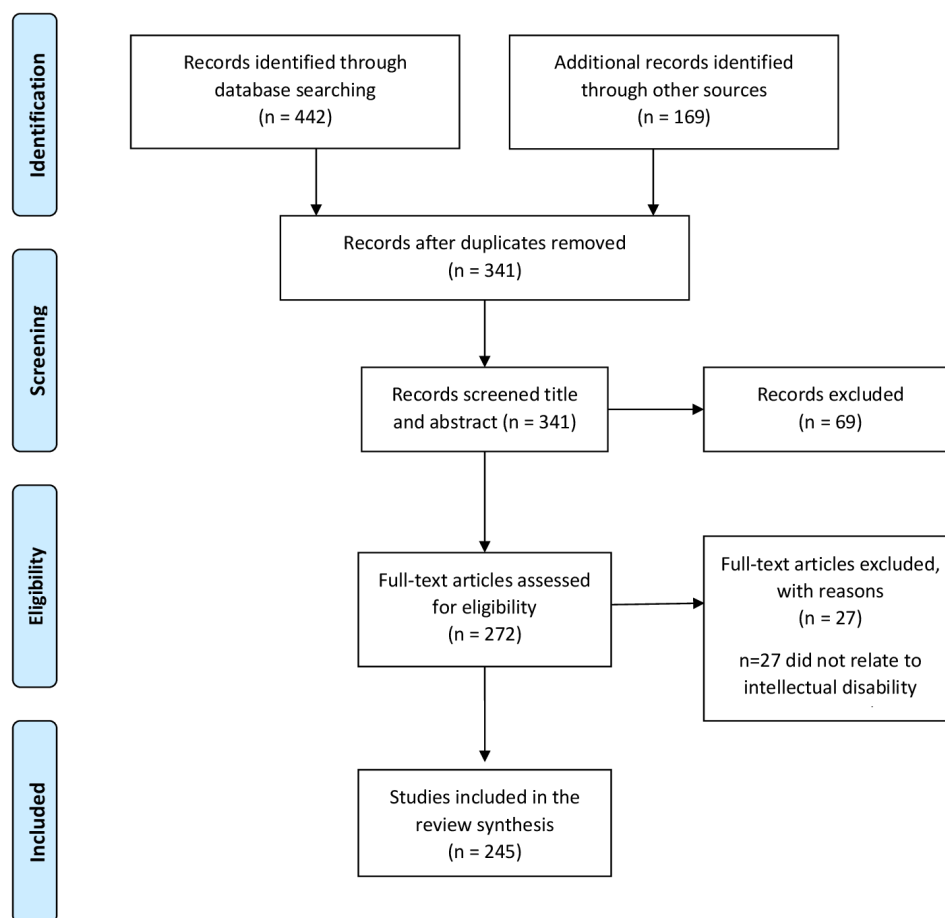


Figure 1 PRISMA flow diagram. PRISMA, Preferred Reporting Items for Systematic Reviews and Meta-Analyses.

Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews Checklist.²⁵

Plotting the data

Narrative, charts, tables and diagram illustrations were used to present the data from this review. To assist plotting the data, content analysis process was conducted following Colorafi and Evans²⁶ steps of (1) create a coding framework, (2) add codes and memos, (3) apply the first level of coding, (4) categorise codes and applying the second level of coding, (5) revise and redefine codes, (6) add memos, (7) visualise data and (8) represent the data. The data were coded by two reviewers (MEB/TH) and where disagreement occurred this was resolved by the third reviewer (OD).

Arranging, summarising and communicating the outcomes

The findings of this review were charted, collated, summarised and reported based on the researchers' analysis of the papers that met the review criteria. In coding of the data, it was acknowledged that the code could be included in multiple themes as overlap between themes is common.²⁷ Here a discussion took place between all

authors (OD/MEB/TH) and a consensus was reached. The researchers considered how the code sat within the overall theme and charting of the data in relation to the research questions. This flexible approach to analysis allowed for ordering, coding, categorising and summarising of data to present under six themes described below and make recommendations to inform health and health service research.

Patient and public involvement

Patients and/or the public were not involved in the design, or conduct, or reporting, or dissemination plans of this research.

RESULTS

In line with the aim and methodological process of this review, the results identify the study characteristics and six themes that were developed namely: supporting inclusion; future planning; aspects of health; interventions; education, professional development and research, and personal and professional accounts of caring.

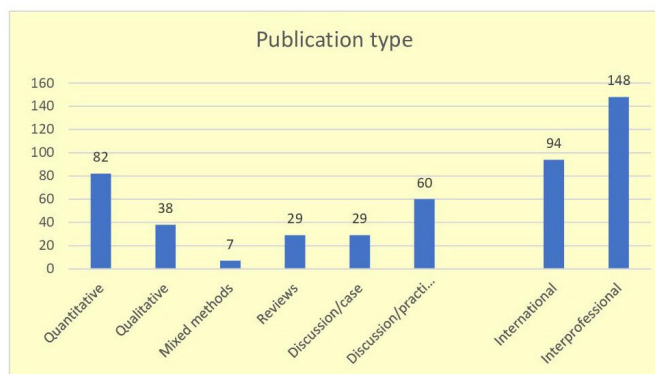


Figure 2 Type of publications.

Study characteristic

Within this scoping review 245 publications were identified (figure 2) and the top three types of published papers were quantitative research papers 82 (33.5%), discussion/practice papers 60 (24.5%) and qualitative research papers 38 (15.4%). Of note was that just over one third of papers (n=95, 38.5%) had international author representation and 148 papers (59.1%) were interprofessional authorship (figure 2).

A total of 33 academic authors were identified within the review (figure 3) and 22 authors from a professional nursing background contributed 42 publications (figure 4). The top three academic contributions were from McCarron (n=82, 33.2%), Doody (n=50, 20.2%) and Burke (n=25, 10.1%) accounting for a total of 63.6% (n=157) of the publications.

Within the papers reviewed there was one paper written by a mother in collaboration with a practising nurse and academic²⁸ and one paper written by a sibling in collaboration with a practising nurse and academic.²⁹ In addition, academics supported student publication papers

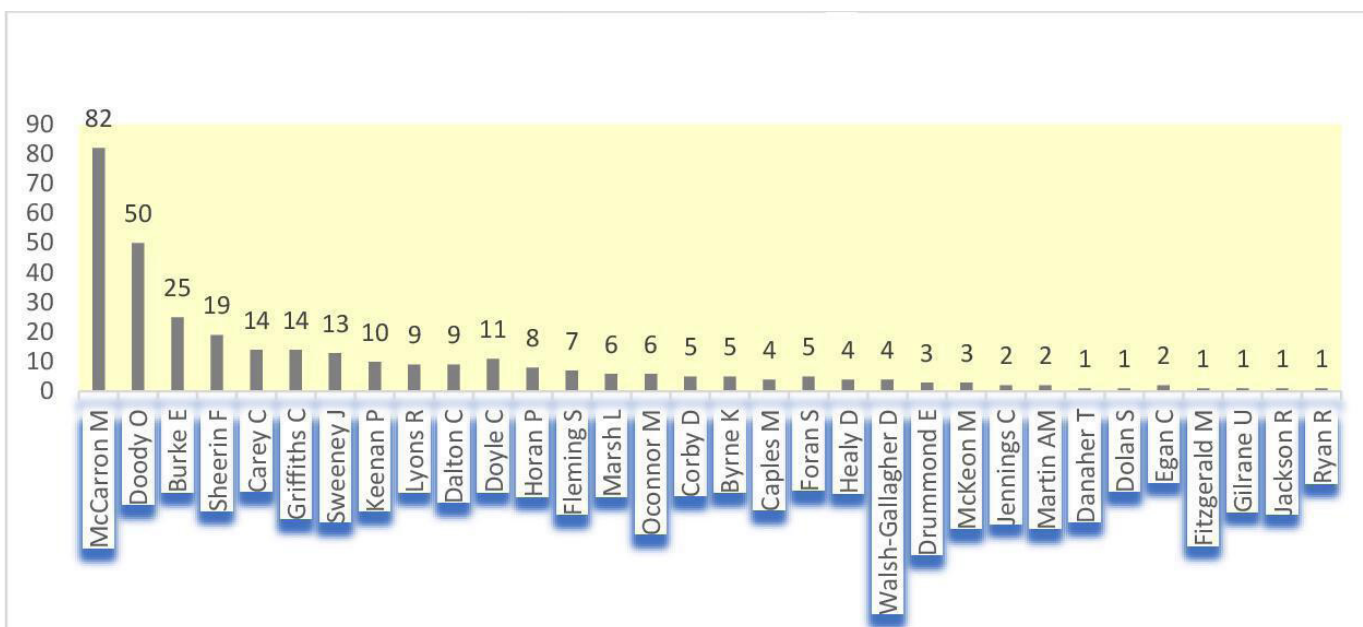


Figure 3 Academic authors.

with 13 students and 18 papers evident within the review (figure 5).

The growth of publication over the years is noted with the first publication evident from 1998 onwards and growing slowly in number during the early years with an average of three publications per year between 1998 and 2009 to a dramatic increase in the years between 2010 and 2020 with an average 18 papers per year (figure 6).

Theme 1: supporting inclusion

The first theme ‘supporting inclusion’ addressed topics affecting service user inclusion (n=19). The topics focused on marginalisation, human rights, community living, employment and decision making (table 1).

Theme 2: future planning

The second theme ‘future planning’ focused on the planning of care and direction of services (n=33) across the areas of ageing, dementia care, service delivery (table 2).

Theme 3: aspects of health

The third theme ‘aspects of health’ (n=36) encompassed mental health, dementia, emotional health, physical health and dental health (table 3).

Theme 4: interventions

The fourth theme ‘interventions’ (n=56) concerned direct involvement or contact with an individual with intellectual disability to manage a specific symptom/s or issue/s, pharmacological/non-pharmacological interventions and communication (table 4).

Theme 5: professional development, education and research

The fifth theme ‘professional development, education and research’ (n=57) concerned professional elements of the nursing role. The theme comprised professional

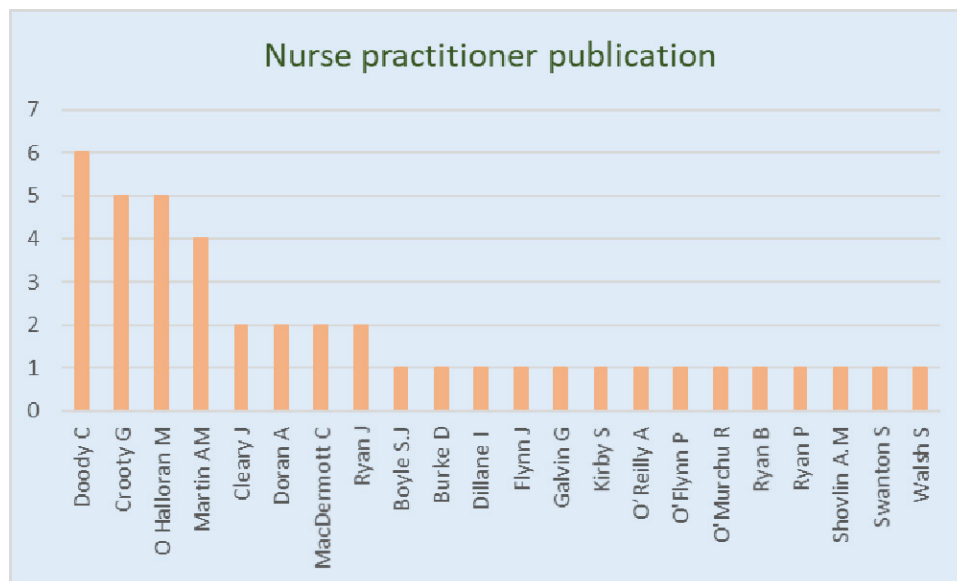


Figure 4 Publications by nurses in practice.

development, education and research informing practice (table 5).

Theme 6: personal and professional accounts of caring

The sixth theme 'personal and professional accounts of caring' (n=44) described experiences and perspectives of caring according to family, service user and nurses (table 6).

DISCUSSION

The aim of this paper was to identify the nature and extent of Irish published literature concerning intellectual disability nursing. It is evident from the findings of this review that intellectual disability nursing in Ireland is actively engaged in research and professional development. Thus, positively contributing to the individual,

family, community and international body of evidence supporting individualised care provision for persons with intellectual disability and their families. The depth and breadth of research in this area identified ranges across inclusion, planning, aspects of health, interventions, personal and professional development, education and research.

The concept of inclusion seems to be an increasing focus of research and the importance for the service user to have their voice heard in the development of inclusion and service provision in this area is unchallenged. The intellectual disability nurse is well positioned to advocate and address at local and national level the challenges that prevent this from being a reality and he/she can be the voice of the service user in service provision, service direction, research and policy.^{17 18} From this review, it is

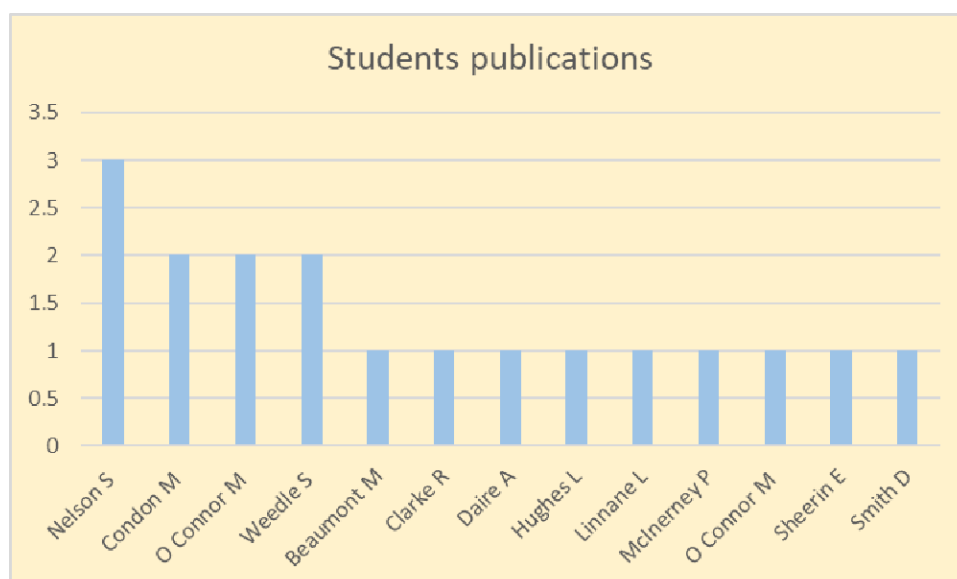


Figure 5 Student involvement in publications.

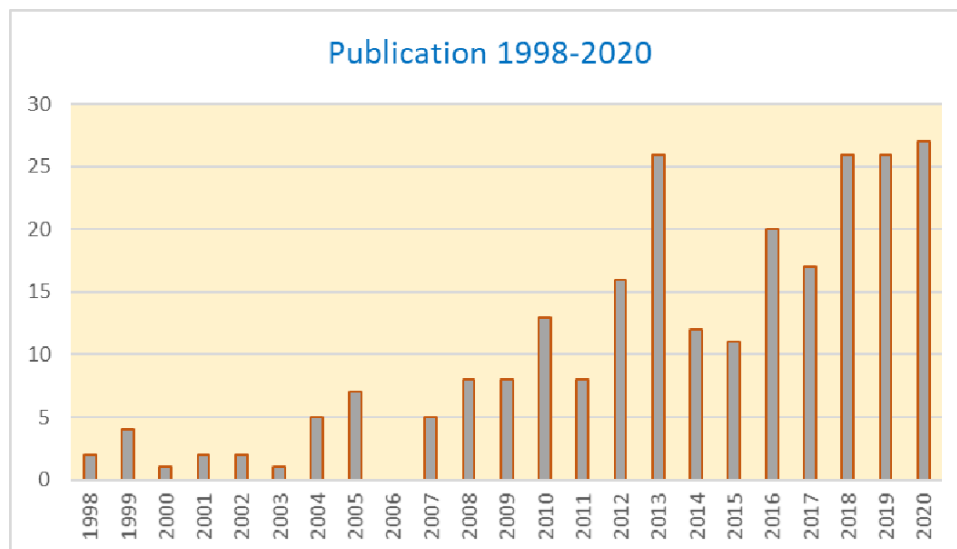


Figure 6 Publication span and volume.

evident that there is a breadth of literature concerning service planning. However, many of the papers identified provided a retrospective view and further research and publications are warranted as to what type of service and support people with intellectual disability and their families require into the future and what may be needed to enable the person to self-actualise.

Historically, young people have been cared for in residential congregated care settings, however, this is no longer the case as the current focus is care within the family.³⁰ In tandem with this intellectual disability nursing is evolving into the community and the family home, necessitating a need to focus on the future in line with service provision where the focus is no longer solely within congregated settings.⁷ This review highlights that the literature on the family experience of caring for and living with an individual with intellectual disability is scarce, only seven

papers in this review focus on the experience of caring in the family home from the perspective of family members. This is of concern given the changing landscape of care

Table 1 Supporting inclusion	
Subthemes	Article topic area
Marginalisation	Marginalisation and sexuality ⁵²
Human rights	Human rights and housing policy ⁵³ Human rights and citizenship of older adults ⁵⁴ Physical restraint interventions ⁵⁵
Community living	Transition to community ^{49 56 57} Public transport ⁵⁸ Community participation ⁵⁹ Deinstitutionalisation ⁶⁰ Place of residence ⁶¹
Employment	Employment and occupational outcomes ⁶² Employment issues ⁶³
Decision making	Parental decision making ⁶⁴ The right of choice ⁶⁵ Making choices ⁶⁶⁻⁶⁸ Measuring choice ⁶⁹

Table 2 Future planning

Subthemes	Article topic area
Ageing	Challenge of ageing ⁷⁰ A review on ageing ⁷¹ Needs of ageing people ⁷² Support the person who is frail ⁷³
Dementia care	Advance care planning for end of life ⁷⁴ Multidisciplinary specialist teams and dementia clinics ⁷⁵ Education ⁷⁶ Research investment to enable identification and quality care provision ⁷⁷ Developing a model of key indicators for future care ⁷⁸ Advanced dementia care ⁷⁹
Service delivery	Care /service delivery in relation to specific healthcare concerns Oral health ⁸⁰ Cancer information needs ⁸¹ Long-term care ⁸² Mental health care ⁸³ Challenging behaviours ⁸⁴ Delivery of healthcare Best practice ⁸⁵ Health, healthcare utilisation and access ⁸⁶⁻⁸⁸ Person-centred planning, health action planning ⁸⁹⁻⁹¹ Workforce planning ⁹² Health inequality ⁹³ Health information ⁹⁴⁻⁹⁶ Family support ⁹⁷ Development of nursing quality care process metrics and indicators ^{5 98 99} Staff support ¹⁰⁰ Early intervention access ¹⁰¹

Table 3 Aspects of health

Subthemes	Article topic area
Mental health	Mental health in people with an intellectual disability ¹⁰² Older adults the association of life events ¹⁰³ Biopsychosocial factors associated with depression and anxiety ¹⁰⁴
Dementia	Down syndrome ^{105–112} Patterns of multimorbidity in older persons ¹¹³
Emotional health	Self-determination and emotional well-being in older adults ¹¹⁴ Loneliness in older people ¹¹⁵ Problem behaviours among older adults ¹¹⁶ Determinants of aggression ¹¹⁷ Prevalence of aggressive behaviour ^{118 119}
Physical health	Bone health ^{120–122} Epilepsy ¹²³ Nutrition ¹²⁴ Physical activity ¹²⁵ Urinary continence ¹²⁶ Constipation ¹²⁷ Mortality rate ¹²⁸ Breast cancer and screening ^{129–131} Communication ¹³²
Dental health	Tooth loss and denture use ^{133–135} Cleaning and dental attendance ^{136 137}

for individuals with an intellectual disability from congregated settings to family-based/community-based care and the need for support.^{20 31} However, a prime opportunity exists for intellectual disability nursing to showcase and make visible their support and interventions with families who are constantly advocating for additional support and services in the community.^{18 32} This can be evidenced in practice-based publications and can be built on through research relating to nursing interventions.³³ Such

Table 4 Interventions

Subthemes	Articles
Interventions concerning direct involvement or contact with an individual with intellectual disability to manage a specific symptom/s or issue/s.	Assessment ^{138–142} Intervention of services ^{143–147} Symptom management ^{148–165}
Pharmacological interventions/ medication	General medication issues ^{166–168} Drug burden ^{169–172} Polypharmacy ¹⁷³
Non-pharmacological interventions	Alternative therapies ^{174 175}
Communication	Communication interventions ^{176–185} Interpersonal relationships ^{186–193}

Table 5 Professional development, education and research

Subthemes	Articles
Professional development	The historical development of intellectual disability nursing ^{6 194–199} The role of the nurse/nurse specialist ^{13 47 200–207} Clinical skills of the nurse ²⁰⁸ Networking with the profession ²⁰⁹
Education	Nurse registration policy ²¹⁰ Teaching strategies ^{211–213} <i>Undergraduate education papers</i> Clinical placement ²¹⁴ Preceptorship and competency assessment ^{215–217} Perceptions of nurse education ^{218–221} Transition from student to registered nurse ^{222 223} Undergraduate mature students ²²⁴ Transferable skills and knowledge ^{225 226} Student teacher reflection ²²⁷ <i>Postregistration education papers</i> Training needs analysis ²²⁸ Postgraduate education ²²⁹ Review of the impact of postgraduate education ²³⁰ Co-operative learning ²³¹
Research	Research addressing methodological issues ^{232–243} Research informing clinical practice ^{244–246}

endeavour would ensure an alignment with national policies including the development of graduate to advanced nursing and midwifery practice³⁴ and health service

Table 6 Personal and professional accounts of caring

Subthemes	Articles
Family experience	Adaptation and resilience ^{28 247} Respite ^{248 249} Living with a family member with intellectual disability ^{29 250} Caring ^{251 252}
Service user experience	Sex and sexuality ²⁵³ Parents with intellectual disability ^{254 255} Pregnancy ²⁵⁶ Growing older ²⁵⁷ Service delivery inclusion ²⁵⁸
Nurse experience and perspectives of caring	Experience of caring ^{259–269} Managerial support ²⁷⁰ Grieving ^{271 272} Family support ²⁷³ Transcultural care ^{274 275} Health promotion ²⁷⁶ Cocreated nursing process, ²⁷⁷ Supporting safe eating and drinking ²⁷⁸ Person-centred planning ^{279–281} Childbirth ²⁸² Care burden ²⁸³ Palliative care/end of life ^{284–288}



plans.^{35 36} In addition, such an approach facilitates the effective use of nursing resources, improving outcomes for services and service users and supports service redesign to be responsive and accessible to the population health needs of individuals with intellectual disability. Commencement of this was evident from this review highlighting that intellectual disability nursing research activity has begun to look to the future.

While physical health is of major importance and its interventions can be clearly articulated, mental health issues, though of equal import, are less easily identifiable but also less evident in the literature within this review. This might be due to the early development of health services and intellectual disability services in Ireland being predominantly religious based and operating on the fringes of the wider health service. However, within this transitioning background of service provision intellectual disability has become more integrated within the national health services and as a result it can be anticipated that greater collaboration, interventions, research and publications across all areas of healthcare will become increasingly evident. This is significant given the strong association between mental health and intellectual disability, it is widely accepted that dual diagnosis for mental health issues for example, anxiety and depression are common diagnoses within the sphere of intellectual disability and these individuals experience numerous barriers in accessing mental health care.^{37 38} In early 2021, Ireland launched a new service model³⁹ to address service development for people with intellectual disability experiencing mental health issues. This presents a clear opportunity for both intellectual disability and mental health nursing and other health services to engage in collaborative working across services to provide consistency, continuity and a seamless service in the overall improvement of service provision for people with intellectual disability and their family carers.³⁸

This review points to the direct involvement of intellectual disability nurses in interventions that support the health, well-being and enablement of people with intellectual disability. However, there is also evidence that opportunities exist to further investigate the role of the nurse in person-centred care, delivery of interventions, assessments, models of care and other areas of care including the effects of pharmacological and non-pharmacological interventions. This review also highlights the specific skill set of the intellectual disability nurse in communicating and supporting the person with intellectual disability and the multidisciplinary team (MDT) through design and delivery of communication interventions. The significant support and/or consultations afforded by intellectual disability nurses to other care professionals interacting and providing care to persons with intellectual disability was also in evidence in this review. Within the wider literature it is apparent that other healthcare professionals experience difficulties in working with individuals with intellectual disability as they often lack knowledge, communication skills, experience and confidence.^{40 41}

However, the expertise of the intellectual disability nurse is poorly championed and this needs to be addressed given the complex needs of people with intellectual disability.⁴²

The findings from this review highlight the paucity of studies that address and report on the actual role of intellectual disability nurses in their interactions with service users and their families in the community. This provides a clear scope for the leaders and practitioners in intellectual disability nursing to create opportunities to highlight their role and report their interventions.^{43 44} Given that this has not occurred to date, there may be a need to value such endeavours within practice and practice leadership and to collaborate with their intellectual disability counterparts in third level institutions. However, the current absence raises the question as to whether intellectual disability nurses have been undervalued or indeed have undervalued themselves and their role. A consequence of this may be the missed opportunities to be at the table where decisions are made⁴⁵ and effectively contribute to the direction and destiny of intellectual disability nursing and healthcare provision in Ireland.

As a nursing discipline, intellectual disability nursing is a small sub-group within healthcare provision. Thus, there is an onus on intellectual disability nurses to assume a leadership role⁷ and make their contribution visible.^{46 47} This has never been so important given the dramatic changes in service provision within the wider context of healthcare delivery.⁴⁸ Mindful of the size of the speciality of intellectual disability nursing (6.75%) within the overall branch of nursing and the fact that intellectual disability nurses are only in existence in Ireland since 1962, the transition of services from the fringes to mainstream healthcare⁴⁹ is ongoing. The nature, extent and base of intellectual disability nursing research in Ireland has developed especially in recent years illustrating that the profession has a central role in the education, promotion and management of the health and well-being of the intellectual disability community. However, the topics noted in this review, while diverse and worthwhile are generally descriptive or retrospective in nature. Thus, further research and publications are warranted regarding the interventions and evaluation of interventions delivered by intellectual disability nurses in the community.

To address this into the future, there is a need for the profession of intellectual disability nursing to engage in research be it, evaluations providing useful lessons for service development, qualitative inquiry to create insight and stimulate changes in practice, quantitative research such as pre-post measures or randomised controlled trials to indicate effectiveness of interventions. While the authors of this paper advocate for greater research it is important to acknowledge the challenges associated with research in this area including a lack of funding, absence of an intellectual disability arm in population studies and issues in researching vulnerable populations. However, these limitations need to be considered in terms of the debate concerning inclusion versus exclusion in research.⁵⁰

Overall, this review identifies a need for greater innovation and for intellectual disability nurses to carve out their role within the evolving healthcare environment of the intellectual disability community, highlighting their coordination, case manager and champion roles in supporting people with intellectual disability and their families. In addition, their therapeutic role and interventions within health and social care services in the primary, community, home, specialist or acute care setting needs to be emphasised, demonstrated and published to inform best practice as internationally there is a lack of a skilled educated workforce.⁵¹ It is evident from this review that the registered nurse in intellectual disability (RNID) has a wealth of knowledge and expertise that should not be lost or hidden. To underestimate and undervalue their role would be to the detriment of the health and well-being of the individuals with an intellectual disability, the communities in which they live and work and for the intellectual disability nursing profession.

The authors acknowledge that limitations to this review exist in the sense that it only aims to scope the extent and nature of the research in Ireland and that database searching only identified a limited number of results. This may be due to the search parameters or indexing issues. However, to counteract this limitation the websites of third level institutes providing intellectual disability nurse education were also searched. Within this search it was noted that on some of these website's the credentials of staff and/or publication lists were not always visible. In addition, while a librarian was consulted regarding the search strategy their services were not included in this review.

CONCLUSIONS

This review provides information as to the nature and extent of intellectual disability research in Ireland. In so doing, the review highlights a prime opportunity for intellectual disability nurses to define their role and contribution now and into the future in supporting people with an intellectual disability, their families and other healthcare professionals across the full extent of healthcare provision. This is key in a time of major change in service provision for people with intellectual disability in Ireland. The shift in healthcare service delivery places the intellectual disability nurse role within primary and community care teams. To define this changing role, the profession of intellectual disability nursing needs to focus on making their support and interventions around health education, health promotion and health management more visible. This increased visibility together with the intellectual disability nurses' empirical knowledge will ensure the profession's survival long into the future.

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