

Understanding the Contribution of Intellectual Disability Nurses:
Scoping Research

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Development of the Compendium of Intellectual Disability Nursing Interventions

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Introduction & Aim

- The RCN Foundation commissioned the University of West London and their collaborators to undertake a scoping research on understanding the contribution of nurses to improve the health and well-being of children, adults and older people with intellectual disabilities (ID), now and for the future.
- The aim of the research is to identify nursing led and/ or nursing care interventions that address the challenging and changing needs of people with ID.
- The research project report is in three volumes; Volume 1 of 3: Scoping literature review report; Volume 2 of 3: Scoping survey research report; and Volume 3 of 3: Compendium of intellectual disabilities nursing interventions.
- This poster presents Volume 3, a catalogue of these interventions as the 'Compendium of ID nursing interventions'

Review questions

The research sought to answer the following questions:

1. What nursing led / nursing centred interventions are in place to respond to the changing needs of people with ID?
2. Are there examples of service redesign to meet future needs?
3. How could ID nurses better contribute to these interventions?
4. Where in the UK are these interventions taking place?
5. In which settings (example: private, NHS, charity care settings)?

Background

- It is estimated that there are currently 1.5 million people with IDs in the UK and this population is changing and increasing, with approximately 2.16% of adults and 2.5% of children identified as having an ID (Mencap, 2020).
- Life expectancy of people living with IDs is increasing, as well as the complexity of the health and social care needs and conditions of this population (Truesdale and Brown, 2017).
- People with IDs are often or more likely to be dependent on others for their health and healthcare outcomes (Campbell and Martin, 2009), and that these outcomes could be improved through appropriate ID nursing interventions.
- A scoping literature review by Mafuba *et al.* (2020) categorised ID nursing interventions as effectuating nursing procedures, enhancing impact of services, and enhancing quality of life. The objective of this review was to produce a compendium of ID nursing interventions.
- There is a lack of definitive and up-to-date handbook or compendium of effective interventions that can be carried out by intellectual disabilities (ID) nurses.

Methods

- In Phase 1 of the project, we undertook a scoping literature review using the Joanna Briggs Institute's (JBI) scoping review protocols. We used a mixed methods approach to the review and synthesis. Thematic synthesis was used to generate analytical themes. Empirical (quantitative, qualitative, mixed methods) studies, synthesised evidence (literature reviews) and opinion papers, (n = 52) were included in the review (this is presented in Volume 1 of the report).
- In Phase 2 of the project, we undertook an online survey to collect quantitative and qualitative data. There were 230 participants from 7 countries.
- We used a scoping study questionnaire to identify ID nursing interventions, the impact of the interventions, and participants' understanding of their roles. The questionnaire was developed and pre-tested by four members of the scoping research team.
- Participants were ID nurses or other nurses registered with a nursing regulator who worked exclusively with people with intellectual disabilities. Participants were recruited through professional networks.
- We used a combination of voluntary response sampling (McCombes, 2020) and snowball sampling (Creswell and Plano Clark, 2017).
- We used thematic and content analyses to analyse qualitative data. We undertook descriptive and inferential analyses of quantitative data (this is presented in Volume 2 of the report).
- We merged interventions we identified in the scoping review with the interventions we found in the survey, removed

Results

- The interventions were undertaken in a wide range of settings and across the lifespan (maternity (4), children (156), adults (384), older adults (129), all age groups (393) and end of life (19), see Diagram 1 below.



Diagram 1a, left, showing distribution of interventions across the lifespan, Diagram 1b, right, showing distribution of interventions across the themes

- In Phase 1 we identified 154 ID nursing interventions, and in Phase 2 we identified 878 interventions from 7 countries. So, in total we identified 925 interventions after merging the interventions and removed duplicates.
- In Phase 2, these interventions were undertaken in a wide range of settings and across the lifespan.
- We categorised the interventions into five themes, see Diagram 1b:
 - effectuating nursing procedures,
 - enhancing impact of ID services,
 - enhancing impact of mainstream services,
 - enhancing quality of life, and
 - enhancing ID nursing practice

Discussion

- When we mapped ID nursing interventions to the stages of the lifespan and to the emerging themes, and what emerges is a very complex picture of ID nursing practice.
- The effectuating nursing procedures interventions are ID nursing activities that involve performing practical tasks with people with intellectual disabilities.
- The enhancing impact of ID services theme incorporates interventions directed at improving the work of organisations that specifically specialise on working with people with ID such as residential home services.
- The enhancing impact of mainstream services theme incorporates interventions directed at improving the work of mainstream healthcare organisations.
- The enhancing ID nursing practice (5%) theme incorporates activities undertaken by ID nurses to improve their own practice and the ID nursing profession.
- The enhancing quality of life theme incorporates interventions undertaken by ID nurses to promote the health and wellbeing of people with ID.
- We only identified a limited number of interventions undertaken by ID nurses relating to maternity. Maternity practice is outside the competence scope of ID nursing practice, so it is likely that ID nursing interventions in relation to women will always be limited.
- We identified 393 interventions which ID nurses were involved in across all the age groups. This represents 36% of interventions undertaken by the participants. The interventions related to all the five themes. A wide range of interventions across the lifespan and in a wide range of settings were in the effectuating nursing procedures theme.
- We identified interventions that ID nurses undertake when working with children, these include complex assessments, growth monitoring, clinical interventions, supporting families, and raising awareness on associated health risks amongst many others. These interventions illustrate the spectrum and complexity of the interventions undertaken by ID nurses when working with children.
- We identified an extensive array of assessment interventions undertaken by ID nurses when working with adults with diverse and complex needs. For example, assessing deterioration, mental capacity, mental health, and many more. These showed ID nurses required knowledge and competence to use a wide range of assessment tools, as well as knowledge of different and often unrelated health care needs.
- ID nurses are involved in working directly with older adults with ID reflecting that ID nurses are taking up new roles in dementia services and nursing homes where older adults with ID may reside. For those working in the community it reflects aging population.
- ID nurses ensured that people with ID of all ages experience good quality end of life care. The range of interventions in this psychologically difficult area illustrates the uniqueness of the knowledge and skills of ID nurses who work with people with ID across the lifespan.
- The research has identified a wide range of emerging interventions

that are implemented by ID nurses working in multi-disciplinary teams across a wide range of settings in the UK and other countries.

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Conclusions

- There is a wide range of interventions that ID nurses undertake in a complex sphere of practice. It is clear from the extent of these interventions that ID nurses need to constantly adapt and engage in a wide range of roles, and that they need to constantly assimilate emergent roles.
- The interventions undertaken by ID nurses need to be understood in the context of the complexity and changing needs of people with IDs, as well as the introduction of the new NMC standards for pre-registration nurse education in the UK.
- We have also identified possible gaps in the provision of care for individuals with intellectual disabilities. There are very limited interventions related to maternity and end of life care. It is likely that the limited involvement is reflective of the limited number of women with ID who choose to have children. The second significant gap relates to frailty and end of life care. Although people with ID are more likely to die in hospital settings, it is unclear why there is limited ID nurse involvement in this area given that it is likely that these people will be in receipt of health and social care support from health or social care services.
- What also emerges from this research are the complexities and changing needs of people with ID, the changing environments in which ID nurses are practising, and the increasing expectation for ID nurses to meet health, healthcare and social needs of people with ID across the lifespan.

Recommendations

- Given the complexity of health, 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 IDs, we recommend that more work be undertaken to further develop the compendium of ID nursing interventions. We recommend that further work focuses on developing guidance for implementing the interventions, linking each intervention to evidence and appropriate resources.

References

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