### Accepted Manuscript

Intellectual disability health content within nursing curriculum: an audit of what our future nurses are taught

Julian N. Trollor, Claire Eagleson, Beth Turner, Carmela Salomon, Andrew Cashin, Teresa Iacono, Linda Goddard, Nicholas Lennox

PII:	S0260-6917(16)30106-X
DOI:	doi: 10.1016/j.nedt.2016.06.011
Reference:	YNEDT 3319

To appear in: Nurse Education Today

Received date:18 February 2016Revised date:1 June 2016Accepted date:14 June 2016



Please cite this article as: Trollor, Julian N., Eagleson, Claire, Turner, Beth, Salomon, Carmela, Cashin, Andrew, Iacono, Teresa, Goddard, Linda, Lennox, Nicholas, Intellectual disability health content within nursing curriculum: an audit of what our future nurses are taught, *Nurse Education Today* (2016), doi: 10.1016/j.nedt.2016.06.011

This is a PDF file of an unedited manuscript that has been accepted for publication. As a service to our customers we are providing this early version of the manuscript. The manuscript will undergo copyediting, typesetting, and review of the resulting proof before it is published in its final form. Please note that during the production process errors may be discovered which could affect the content, and all legal disclaimers that apply to the journal pertain.

#### Running Head: NURSING CURRICULUM AND INTELLECTUAL DISABILITY

#### INTELLECTUAL DISABILITY HEALTH CONTENT WITHIN NURSING CURRICULUM: AN AUDIT OF WHAT

#### **OUR FUTURE NURSES ARE TAUGHT**

Julian N. Trollor<sup>a\*</sup>, Claire Eagleson<sup>a</sup>, Beth Turner<sup>a</sup>, Carmela Salomon<sup>a</sup>, Andrew Cashin<sup>b</sup>, Teresa Iacono<sup>c</sup>, Linda Goddard<sup>d</sup>, Nicholas Lennox<sup>e</sup>

\*Corresponding author

<sup>a</sup> Department of Developmental Disability Neuropsychiatry (3DN), School of Psychiatry, UNSW Australia. Mailing address: 34 Botany Street, UNSW NSW 2052, Australia

<sup>b</sup> School of Health and Human, Sciences Southern Cross University, PO Box 157, Lismore NSW 2480, Australia

<sup>c</sup> La Trobe Rural Health School, La Trobe University, PO Box 199, Bendigo VIC 3552, Australia

<sup>d</sup> Department of Mental Health and Learning Disabilities, London South Bank University, London, 103 Borough Road, London, SE1 0AA, United Kingdom

<sup>e</sup> Queensland Centre for Intellectual and Developmental Disability, Mater Research Institute/The University of Queensland, Mater Hospitals, Raymond Terrace, South Brisbane Qld 4101, Australia

Julian N. Trollor, MBBS(Hons), MD, FRANZCP, Chair Intellectual Disability Mental Health, Head of

Department of Developmental Disability Neuropsychiatry, j.trollor@unsw.edu.au, +61 2 9931 9160

Claire Eagleson, BPsych(Hons), MPsych(Clin), Project Officer, c.eagleson@unsw.edu.au, +61 2 9931

9140

Beth Turner, BSc Psychology (Hons), Project Officer, beth-turner@live.com, +61 2 9931 9160

**Carmela Salomon**, PhD, PDN(mental health), BNSc, Project Officer, c.salomon@unsw.edu.au, +61 2 9931 9160

Andrew Cashin, RN, MHN, NP, Dip App Sci, BHSC, GCert PTT, GCert HPOL, MN, PhD, FACNP,

FACMHN, FCN, Professor of Nursing, Andrew.cashin@scu.edu.au, +61 407052357

Teresa lacono, PhD, MAppSc, BAppSc (Spe Path), Professor of Rural and Regional Allied Health,

t.iacono@latrobe.edu.au, +61 3 5448 9110

Linda Goddard, RN., BSc(Nsg)., Med(SpEd), PhD, Associate Professor, goddarl3@lsbu.ac.uk, +44 20

7815 7010

Nicholas Lennox, MBBS, BMedSc, DipObs, FRACGP, PhD, Professor, n.lennox@uq.edu.au, +617

31632412

### Acknowledgements

The project was endorsed by the Professional Association of Nurses in Developmental Disability Australia, Charles Sturt University, La Trobe University, The University of Melbourne, The University of Queensland and Southern Cross University.

#### Funding

Funding for the study was provided by Ageing, Disability and Homecare (ADHC), New South Wales Government Department of Family and Community Services. ADHC had no role in the study design, collection, analysis or interpretation of data, writing the report, or the decision to submit it for publication.

### **Conflicts of interest**

None

Word count: 5396

#### Abstract

<u>Background</u> – Individuals with intellectual disability experience chronic and complex health issues, but face considerable barriers to healthcare. One such barrier is inadequate education of healthcare professionals.

<u>Objective</u> – To establish the quantity and nature of intellectual disability content offered within Australian nursing degree curricula.

<u>Design</u> – A two-phase national audit of nursing curriculum content was conducted using an interview and online survey.

<u>Setting</u> – Australian nursing schools offering pre-registration courses.

<u>Participants</u> – Pre-registration course coordinators from 31 universities completed the Phase 1 interview on course structure. Unit coordinators and teaching staff from 15 universities in which intellectual disability content was identified completed the Phase 2 online survey.

<u>Methods</u> – Quantity of compulsory and elective intellectual disability content offered (units and teaching time) and the nature of the content (broad categories, specific topics, and inclusive teaching) was audited using an online survey.

<u>Results</u> – Over half (52%) of the schools offered no intellectual disability content. For units of study that contained some auditable intellectual disability content, the area was taught on average for 3.6 hours per unit of study. Units were evenly distributed across the three years of study. Just three participating schools offered 50% of all units audited. Clinical assessment skills, and ethics and legal issues were most frequently taught, while human rights issues and preventative health were poorly represented. Only one nursing school involved a person with intellectual disability in content development or delivery.

<u>Conclusion</u> – Despite significant unmet health needs of people with intellectual disability, there is considerable variability in the teaching of key intellectual disability content, with many gaps evident. Equipping nursing students with skills in this area is vital to building workforce capacity.

### **Keywords**

Intellectual disability

Nursing education

Curriculum

Health inequalities

SCRACH MANNES

#### BACKGROUND

People with intellectual disability (ID) constitute 1% to 3% of the population globally (Maulik et al., 2011). Compared to the general population, this group experiences chronic and complex health issues, with poorer physical health (Beange et al., 1995), mental health (Einfeld et al., 2006) and health outcomes (Emerson et al., 2012; WHO and World Bank Group, 2011). The unmet health needs of people with ID are substantial (Robertson et al., 2015). Health inequalities for people with ID are evidenced by higher mortality rates, including premature death from preventable causes (Heslop et al., 2014; Trollor et al., 2015), with health conditions often undiagnosed or inappropriately treated (Iacono and Davis, 2003).

Despite substantial reforms in the disability sector, and an expectation that this group will benefit from access to *mainstream* health services, the health needs of people with ID continue to be poorly met, with preventive healthcare, health promotion and general healthcare being inadequately addressed (Iacono and Davis, 2003; Rimmer and Braddock, 2002; Webb and Rogers, 1999). However, there have been some positive developments, such as the Comprehensive Health Assessment Program (CHAP) which has increased health promotion, disease prevention and casefinding activity for individuals with an ID (Lennox et al., 2007; Lennox et al., 2010).

Multiple barriers to accessing quality healthcare are experienced by this population. These include inadequate education of health professionals, with health-related undergraduate programs rarely addressing the needs of people with disability, rendering graduates ill-prepared for clinical practice in this area (Costello et al., 2007; WHO and World Bank Group, 2011). Australian research points to a lack of quality care received by people with ID, especially in acute care settings (Iacono and Davis, 2003; Webber et al., 2010). A systematic review of hospital experiences encountered by people with an ID revealed that hospital staff often lacked appropriate knowledge and skills about ID, failed to provide adequate care or reasonable adjustments, and displayed negative attitudes (Iacono et al., 2014). Ineffectual collaboration between health and disability services has also been

found to pose a substantial barrier (Lawrence, 2006). However, hospital policies and systems relating specifically to ID, and the presence of a hospital liaison person, was found to enhance care (lacono et al., 2014). A number of comprehensive approaches to adapting clinical practice in response to research on this population's healthcare needs have been outlined in *The Guide: Accessible Mental Health Services for People with an Intellectual Disability*, and in the *Intellectual Disability Mental Health Core Competency Framework: A Manual for Mental Health Professionals*, including the importance of adapting communication and being aware of how to manage challenging behaviours (Department of Developmental Disability Neuropsychiatry, 2014, 2016). An awareness of the complex legal and ethical considerations, especially around consent, is also important for nurses (Arscott et al., 1999; Phillips et al., 2004).

As a signatory to the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) (UN General Assembly, 2006), Australia has committed to ensure that persons with an ID have the highest attainable standard of health. Taken together with Australia's Disability Discrimination Act (Commonwealth Government Australia, 1992), the government is responsible for ensuring equity of access. To realise this currently unmet goal, definitive action must be made by health services and practitioners. However unless properly educated, practitioners (including nurses) may lack the knowledge, skills, confidence and attitudes required to identify the needs of people with an ID and make reasonable adjustments to meet their needs (Tuffrey-Wijne et al., 2014).

Australia's National Disability Strategy (Commonwealth of Australia, 2011) clearly prioritises the highest possible health and well-being outcomes for people with disabilities through the universal equipping of health practitioners and services. Sector developments in Australia, such as the National Disability Insurance Scheme (NDIS), offer a renewed focus on the interface between health and disability services, including through the education of health professionals (Disability Reform Council, 2015). It is thus timely to review the extent to which the education of nurses equips them to address the health needs of people with ID.

As the largest health professional group in Australia, nurses play a key role in delivering healthcare services to people with ID, including treatment, health promotion and disease detection (Australian Institute of Health and Welfare, 2010; Heath, 2002; Thomas and Chaperon, 2011). Until the late 1980s, nurses were the primary care providers for this group, particularly in institutions (Goddard et al., 2008). Following the closure of institutions for people with ID, there was a subsequent decline in nurses caring for this population exclusively. Once nursing education moved to universities (from 1984 to 1993), six specialised programs (including one in ID) were combined on the basis that a single comprehensive course would cover all areas. In practice, both these changes, combined with the shift in funding of disability services from health to other government departments from 1989, resulted in a decrease in the prominence of ID in registered nursing curricula (The NSW Council for Intellectual Disability, 2005). See Figure 1. for a timeline of these changes.

### Insert Figure 1. about here

Various models of nursing education exist globally, determining if and when ID education is provided. In the UK, students can complete a specialised pre-registration branch program in ID; in parts of the Netherlands, students can specialise in ID in the latter parts of their 4-year generic degree; and in the US and Canada a post-registration certificate now exists. In Australia and New Zealand, the move from direct entry training for ID to a generic 3-year degree has seen a loss of specialised nursing knowledge and skills (Robinson and Griffiths, 2007). The accreditation standards for Australian pre-registration nursing courses do not specify that ID or developmental disability must be taught (Australian Nursing and Midwifery Accreditation Council, 2012). The competency standards for registered nurses (Nursing and Midwifery Board Australia, 2010) mention disability only in general in the description of the registered nurse's role. There are no longer any postgraduate nursing courses specialising in ID in Australia. In New Zealand, preparing students to care for people with a disability is not a required unit in undergraduate nursing curricula (Seccombe,

2007). While they may not learn disability content, students are expected to undertake a placement in "continuing care settings including rehabilitation/disability care settings" (but not necessarily ID specific) before registration (Nursing Council of New Zealand, 2015). Robinson and Griffiths (2007) suggest that the UK education model may be the best to enhance service delivery.

Evidence suggests that tertiary education is the best time to influence the knowledge, skills and attitudes of future health professionals (Campbell, 2009). A lack of exposure to specialty areas during undergraduate education has been associated with fewer graduates choosing to work in that area (Happell, 2010). Further, a lack of experience with ID has been associated with low levels of confidence and negative attitudes towards people with ID (Thompson et al., 2003). Following a recent literature review and survey of all UK education institutions that offer pre-registration nursing courses, Beacock et al. (2015) recommended nursing curricula should include the following to meet the healthcare needs of people with ID: communication, attitudes, capacity/consent, equality/reasonable adjustments, role of carers and ID nurses/teams, health issues, and challenging behaviour.

There is a scarcity of research on what ID content is taught in Australian university nursing curricula, so the preparedness of graduates to deliver quality care to people with an ID is not known. Internationally, a student survey of disability education in a UK nursing pre-registration curriculum showed that the content dealt with the classification, causes and prevention of ID, with an emphasis on special needs and rights. Skills, such as communicating with people with a cognitive or sensory impairment, were not included (Scullion, 1999). A survey of nursing colleges in the United States revealed a lack of ID education in curricula, with reported barriers including a lack of time and faculty expertise (Smeltzer et al., 2005). For countries with generic courses, Robinson and Griffiths (2007) found there is little focus on ID in undergraduate programmes.

Research on the role of clinical nurse specialists in ID in Ireland and the UK highlights their importance in client care, education and advocacy (National Council for the Professional

Development of Nursing and Midwifery, 2004). Their education and health promotion role helps to maintain quality standards of care, and they serve as role models for other nurses (Begley et al., 2010). In a hospital environment, intellectual disability liaison nurses identified and implemented reasonable adjustments to practice, ensuring patient needs were met (MacArthur et al., 2015).

The potential for Australian nursing students to receive education and the opportunity to interact with people with ID through appropriate curricula content is unknown. We conducted the first national audit of Australian pre-registration nursing course curricula to evaluate content about ID. Here we report on what and how much is taught about ID health to nursing students. The audit was the first component of a multi-phase strategy to build health workforce capacity in Australia by renewing nursing and medical ID curricula.

#### <u>METHOD</u>

A two phase national audit of nursing curriculum content was conducted. Figure 2 shows details of the recruitment and data collection procedures. The Deans/Heads of School of 34 Nursing schools delivering Australian Nursing and Midwifery Accreditation Council (ANMAC) registered nursing degrees at the time of the study were approached via email and invited to participate. Once permission was provided, an invitation was emailed to the pre-registration course coordinator to complete Phase 1, which consisted of an interview on the registered nursing course structure. If ID content was identified in Phase 1, an invitation was emailed to unit coordinators and teaching staff to complete Phase 2, which consisted of a survey regarding ID content. A protocol of three telephone calls and/or email reminders and an additional telephone call at each phase was followed. Institutions were coded to preserve anonymity during analysis and reporting of data.

Insert Figure 2. about here

The measures were developed from those created by Lennox and Diggens (1999) for a medical curriculum audit of ID content. This design was used in the current study as it could capture the amount and type of ID content taught even when nursing curricula were structured differently across universities. Table 1 includes details about question domains and categories within the measures. In Phase 1, 11 interview questions on course structure were answered by telephone or email (see Appendix A). In Phase 2, 16 questions on specific ID content were answered by telephone or via a website link (see Appendix B for survey tool).

#### Insert Table 1. about here

#### Ethical considerations

Approval for the study was obtained from the UNSW Australia Human Research Ethics Advisory Panel (Approval No. 2013-7-04), and all author universities.

#### **RESULTS**

#### Participation rates

As Figure 2 shows, of the 34 nursing schools approached, 31 (91%) participated in the audit. Of participating nursing schools, for 16 (52%), no ID content in their course was reported, and for 15 (48%) nursing schools for which ID content was identified, detailed information was then collected.

#### Course programmes and length

Figure 3 displays the number of different types of pre-registration nursing degrees offered by how many schools (e.g. 9 schools offered 2 degrees). At the time of the audit, 30 participating schools (97%) offered Bachelor of Nursing (BN) programmes and one (3%) offered a Bachelor of Science (BSc) programme as basic pre-registration registered nursing course options. All but one course was three years in duration (the BSc course was 3.5 years). The participating schools offered

alternate pathways in which a registered nursing degree was attainable, such as the Bachelor of Nursing/Bachelor of Midwifery programme (range = 1-5.5 years duration). Total students enrolled varied across institutions (range = 60-700, M=300).

Insert Figure 3. about here

### Intellectual disability units

The term *intellectual disability (ID) unit* refers to discrete teaching components containing some auditable content specific to ID (e.g. a subject on mental health and illness that contains education on ID). The number of hours of ID content per unit differed. The number of ID units offered by how many participating nursing schools is presented in Figure 4. The 31 participating schools offered a total of 34 ID units. Three participating schools offered 50% of the units (17 units). Fourteen schools (45%) offered compulsory ID units (33 units in total). The total time dedicated to teaching ID content in compulsory units varied (range = 10 min-12 h; M = 3.6 h). For universities that offered ID education, the average number of hours of compulsory content was 8.85. One participating nursing school (3%) offered an elective ID unit, in which just one student was enrolled in 2014, with 9 hours of ID content.

#### Insert Figure 4. about here

Figure 5 displays the distribution of ID units across the years of study, which were evenly distributed with no year having notably more ID units (data from three units was missing). For four schools (13%) units were taught in two or more years of study.

#### Insert Figure 5. about here

Less than a third of participating nursing schools (9, 29%) provided compulsory ID content that covered the broad topic areas of physical health and mental health. Two schools (6%) offered

compulsory ID content that covered only physical health, whilst one school (3%) provided content that covered only mental health.

Table 2 Provides details of specific topic areas included within compulsory ID units: clinical assessment skills, and ethics and legal issues were most frequent. The topics covered with least frequency were human rights issues and preventative health. Twelve participating schools (38%) offered compulsory ID content, including two or more topic areas. Data for three units (two participating schools) was missing.

#### Insert Table 2. about here

The elective ID content offered by one school covered both ID physical and mental health, and included every specific topic area listed in Table 2.

#### Inclusive practice

Five schools (16%) offered compulsory ID units involving direct contact with people with an ID (such as during a clinical placement). One participating school (3%) offered compulsory ID content that involved people with ID in its development or delivery. As part of this course, a person with ID participated in role plays portraying a patient to help students practice their communication skills. The elective unit offered did not involve direct contact with people with ID, nor involve this population in the development and delivery of the content.

#### DISCUSSION

It was evident from the curricula audit that there was substantial variability across schools in the amount of ID content taught. Less than half of the audited schools offered some compulsory ID content, with one school offering content as part of an elective course only. Ten percent of the schools offered 50% of the units. The time spent on compulsory ID education varied from 10 minutes

to 12 hours, with an average of just 3.6 hours per unit. The distribution of content was evenly spread across the three years of study.

The potential healthcare implications of the across-school variability in the amount and nature of ID content taught are substantial. Given that over half of the audited schools offered no ID content, it is very likely that the majority of Australian nursing students are emerging from their preregistration studies with little to no knowledge of the needs of people with ID. This situation is likely to contribute to the poor practices in hospitals that people with ID often experience (Iacono et al., 2014).

It is possible that nursing students graduating from the small number of schools with a large amount of ID content may be well equipped to meet the needs of this population. However the potential to ameliorate the poor healthcare experiences of people with ID may be diluted as these nurses move into work settings in which there are few colleagues with similar educational backgrounds. A consistent across-school education standard pertaining to the amount of ID content taught appears to be greatly lacking at present, but is much needed. As nurses are the largest body of healthcare professionals in Australia and play key health roles (Australian Institute of Health and Welfare, 2010; Heath, 2002; Thomas and Chaperon, 2011), the inclusion of ID specific education in nursing curricula has serious implications for the quality of healthcare people with ID receive.

Identified through the curricula were worrying inconsistencies and gaps in the type of ID content taught across schools, especially considering the areas Beacock et al. (2015) suggested should be covered in nursing education. Despite the substantially higher rates of both mental and physical co-morbidities and poor health outcomes in people with ID (Beange et al., 1995; Emerson et al., 2012; WHO and World Bank Group, 2011), less than a third of schools covered both physical and mental health issues as a part of their compulsory content.

Despite evidence that health providers are often concerned about legal and ethical issues (Phillips et al., 2004), again less than a third of schools included content in this area. This area is highly relevant for people with ID as ethical considerations, including the ability to give informed consent, can be more complex than for the general population (Arscott et al., 1999). Most frequently covered were clinical assessment skills (by two thirds of schools), perhaps because assessment skills form the basis on which other competencies are built (Gibbons et al., 2002). However, less than a quarter of schools offered content in clinical management skills, which is concerning given the need for effective management of behavioural difficulties and the adaptation of management techniques such as presenting concepts in novel ways (Department of Developmental Disability Neuropsychiatry, 2014, 2016).

One particular barrier to treatment for people with ID is ineffective collaboration between multiple health and disability agencies (Lawrence, 2006). This is vital given the high incidence of chronic and complex health needs in this population. Even though there has been a recent focus on interdisciplinary team work, including in relation to ID (Iacono et al., 2011), and increasing concern about chronic and complex health issues (Ageing Disability and Home Care, 2014), these areas received attention by only a few schools.

Less than a quarter of schools covered preventative health measures, despite the high mortality and morbidity rates in people with ID being partially attributable to preventable causes (Heslop et al., 2014; Trollor et al., 2015). Similarly, in only a small percentage of schools was content found on human rights issues, and disability and healthcare systems, despite the findings that this group have significant unmet health needs (Robertson et al., 2015) and greater health disadvantage (Emerson et al., 2012). Further, the inclusion of people with ID in the development and delivery of teaching and research is a requirement of human rights legislation (Commonwealth Government Australia, 1992; UN General Assembly, 2006). These findings are in contrast to the curriculum audited in Scullion (1999), in which there was an emphasis on the rights of people with an ID.

Research suggests contact with people with ID during education fosters more positive attitudes (Seccombe, 2007). Therefore, neither legislation nor research evidence appears to have provided a sufficient driver for direct contact with people with ID or their involvement in content planning. Overall, the current study reflects findings from the small number of international studies which have found an absence of ID education in pre-registration nursing courses (Robinson and Griffiths, 2007; Smeltzer et al., 2005). Findings from the current audit reflect those reported by Lennox and Diggens (1999) of inconsistencies in the ID content taught across *medical* schools in Australia.

There is evidence, both in Australia (Webber et al., 2010) and internationally (Tuffrey-Wijne et al., 2014), that if nurses lack ID knowledge and experience, they may fail to reasonably adjust practice to meet the needs of people with ID, likely contributing to the high rate of undiagnosed conditions in this population (Iacono and Davis, 2003), their poor health outcomes (including premature death), and negative experiences of health services (Beange et al., 1995; Einfeld et al., 2006). Conversely, if nurses develop skills and knowledge to modify their assessment and treatment practices, and to manage challenging behaviour, post-registration they will be more likely to detect physical and mental health conditions in this population, deliver more effective treatments, and provide more positive healthcare experiences. In short they will be in a better position to help address these inequalities (Hahn, 2003).

The results of the current study should be interpreted with some key limitations in mind. Firstly, the researchers cannot be certain that the ID content figures were not inflated, or that the information and details that were provided were complete. Secondly, almost all of the data was collected via email, with the aim of reducing burden on participants. However, this strategy may have reduced participant engagement due to survey fatigue. Lastly, there was inconsistency in course type and structure, and variable definitions of study, which made it challenging to directly compare the proportion of the curriculum dedicated to ID content across nursing schools.

This audit is the first stage in a project which aims to develop, evaluate and implement a national tertiary educational framework and implementation toolkit for nursing schools in the area of ID physical and mental health. This framework will offer the potential to assist nurse educators across the higher education sector to incorporate evidence-based, up-to-date teaching materials and resources into existing curricula. Curricula development may also be informed by UK intellectual disability nursing courses. Taking into account the significant health needs of people with ID and human rights legislation, it is recommended that Australian and international nursing schools respond by reviewing their curricula to ensure nurses receive education that covers all of the major topic areas mentioned above, and content that is consistent and principle based.

#### **Conclusions**

This study provided the first comprehensive national audit of ID teaching in nursing curricula to be conducted in Australia. It was evident there is much variability in ID content taught across schools, and gaps in key areas. Implementing a renewed curriculum around ID in nursing in Australia (and indeed internationally) would help to build workforce capacity to improve the provision of care for people with ID. It would also address a key objective of the NDIS which is to strengthen mainstream healthcare systems to meet the needs of people with disability (NDIS, 2015). Equipping nursing students with these skills during their pre-registration education is vital to build confidence and encourage positive attitudes. This will lead to productive partnerships between nurses and people with ID and their families, and a workforce that can reduce the barriers to care and improve the health outcomes for people with ID.

#### REFERENCES

- Ageing Disability and Home Care, 2014. Leading Clinical Practice and Supporting Individuals with Complex Support Needs in an NDIS Environment. Options and Considerations for New South Wales. NSW Health, Sydney.
- Arscott, K., Dagnan, D., Stenfert Kroese, B., 1999. Assessing the ability of people with a learning disability to give informed consent to treatment. Psychological Medicine 29 (06), 1367-1375.10.1017/S0033291799008715.
- Australian Institute of Health and Welfare, 2010. Nursing and midwifery labour force 2008. Australian Institute of Health and Welfare Canberra.
- Australian Nursing and Midwifery Accreditation Council, 2012. Registered Nurse Accreditation Standards. ANMAC, Canberra.
- Beacock, S., Borthwick, R., Kelly, J., Craine, R., Jelfs, E., 2015. Learning Disabilities: Meeting Education Needs of Nursing Students. LINDAN and CoDH, London.
- Beange, H., McElduff, A., Baker, W., 1995. Medical disorders of adults with mental retardation: A population study. American Journal on Mental Retardation 99 (6), 595-604.
- Begley, C., Murphy, K., Higgins, A., Elliott, N., Lalor, J., Sheerin, F., Coyne, I., Comiskey, C., Normand,
  C., Casey, C., Dowling, M., Devane, D., Cooney, A., Farrelly, F., Brennan, M., Meskell, P.,
  MacNeela, P., 2010. An Evaluation of Clinical Nurse and Midwife Specialist and Advanced
  Nurse and Midwife Practitioner Roles in Ireland (SCAPE). National Council for the
  Professional Development of Nursing and Midwifery in Ireland, Dublin.
- Campbell, F.K., 2009. Medical education and disability studies. Journal of Medical Humanities 30 (4), 221-235.10.1007/s10912-009-9088-2.
- Commonwealth Government Australia, 1986. Disability Services Act. Office of Parliamentary Counsel, Canberra.
- Commonwealth Government Australia, 1992. Disability Discrimination Act. Attorney-General's Department, Canberra.

- Commonwealth of Australia, 2011. 2010-2020 National Disability Strategy: An initiative of the Council of Australian Governments. Commonwealth of Australia, Canberra.
- Costello, H., Bouras, N., Davis, H., 2007. The role of training in improving community care staff awareness of mental health problems in people with intellectual disabilities. Journal of Applied Research in Intellectual Disabilities 20 (3), 228-235.10.1111/j.1468-3148.2006.00320.x.
- Department of Developmental Disability Neuropsychiatry, 2014. Accessible Mental Health Services for People with an Intellectual Disability: A Guide for Providers. 3DN, Sydney.
- Department of Developmental Disability Neuropsychiatry, 2016. Intellectual Disability Mental Health Core Competency Framework: A Manual for Mental Health Professionals. NSW Ministry of Health, Sydney.
- Disability Reform Council, 2015. National Disability Insurance Scheme: Integrated Market, Sector and Workforce Strategy. Disability Reform Council, Canberra.
- Einfeld, S.L., Piccinin, A.M., Mackinnon, A., Hofer, S.M., Taffe, J., Gray, K.M., Bontempo, D.E., Hoffman, L.R., Parmenter, T., Tonge, B.J., 2006. Psychopathology in young people with intellectual disability. Journal of the American Medical Association 296 (16), 1981-1989.10.1001/jama.296.16.1981.
- Emerson, E., Baines, S., Allerton, L., Welch, V., 2012. Health inequalities and people with learning disabilities in the UK: 2012. Durham: Improving Health & Lives: Learning Disabilities Observatory.
- Gibbons, S.W., Adamo, G., Padden, D., Ricciardi, R., Graziano, M., Levine, E., Hawkins, R., 2002.
   Clinical evaluation in advanced practice nursing education: Using standardized patients in health assessment. Journal of Nursing Education 41 (5), 215-221.
- Goddard, L., Davidson, P.M., Daly, J., Mackey, S., 2008. People with an intellectual disability in the discourse of chronic and complex conditions: an invisible group? Australian Health Review 32 (3), 405-414.10.1071/AH080405.

- Hahn, J.E., 2003. Addressing the need for education: curriculum development for nurses about
   intellectual and developmental disabilities. Nursing Clinics of North America 38 (2), 185-204.
   10.1016/S0029-6465(02)00103-2
- Happell, B., 2010. Moving in circles: A brief history of reports and inquiries relating to mental health content in undergraduate nursing curricula. Nurse Education Today 30 (7), 643-648.10.1016/j.nedt.2009.12.018.

Heath, P., 2002. National review of nursing education 2002. Commonwealth of Australia, Canberra.

- Heslop, P., Blair, P.S., Fleming, P., Hoghton, M., Marriott, A., Russ, L., 2014. The Confidential Inquiry into premature deaths of people with intellectual disabilities in the UK: a population-based study. The Lancet 383 (9920), 889-895.10.1016/S0140-6736(13)62026-7.
- Iacono, T., Bigby, C., Unsworth, C., Douglas, J., Fitzpatrick, P., 2014. A systematic review of hospital experiences of people with intellectual disability. BMC Health Services Research 14 (1), 505.10.1186/s12913-014-0505-5.
- Iacono, T., Davis, R., 2003. The experiences of people with developmental disability in emergency departments and hospital wards. Research in Developmental Disabilities 24 (4), 247-264.10.1186/s12913-014-0505-5.
- Iacono, T., Lewis, B., Tracy, J., Hicks, S., Morgan, P., Récoché, K., McDonald, R., 2011. DVD-based stories of people with developmental disabilities as resources for inter-professional education. Disability and Rehabilitation 33 (12), 1010-1021.10.3109/09638288.2010.520802.
- Lawrence, F., 2006. Models of service and indicators of organisational effectiveness in the specialist field of dual disability. A comparative review between the Victorian Dual Disability Service and selected services in Canada and the USA. Victorian Dual Disability Service, Melbourne.
- Lennox, N., Bain, C., Rey-Conde, T., Purdie, D., Bush, R., Pandeya, N., 2007. Effects of a comprehensive health assessment programme for Australian adults with intellectual disability: a cluster randomized trial. International Journal of Epidemiology 36 (1), 139-146.10.1093/ije/dyl254.

- Lennox, N., Bain, C., Rey-Conde, T., Taylor, M., Boyle, F.M., Purdie, D.M., Ware, R.S., 2010. Cluster Randomized-Controlled Trial of Interventions to Improve Health for Adults with Intellectual Disability Who Live in Private Dwellings. Journal of Applied Research in Intellectual Disabilities 23 (4), 303-311.10.1111/j.1468-3148.2009.00533.x.
- Lennox, N., Diggens, J., 1999. Medical education and intellectual disability: A survey of Australian medical schools. Journal of Intellectual and Developmental Disability 24 (4), 333-340.10.1080/13668259900034091.
- MacArthur, J., Brown, M., McKechanie, A., Mack, S., Hayes, M., Fletcher, J., 2015. Making reasonable and achievable adjustments: the contributions of learning disability liaison nurses in 'Getting it right' for people with learning disabilities receiving general hospitals care. Journal of Advanced Nursing 71 (7), 1552-1563.10.1111/jan.12629.
- Maulik, P.K., Mascarenhas, M.N., Mathers, C.D., Dua, T., Saxena, S., 2011. Prevalence of intellectual disability: a meta-analysis of population-based studies. Research in Developmental Disabilities 32 (2), 419-436.10.1016/j.ridd.2010.12.018.
- National Council for the Professional Development of Nursing and Midwifery, 2004. An Evaluation of the Effectiveness of the Role of the Clinical Nurse/Midwife Specialist. National Council for the Professional Development of Nursing and Midwifery, Dublin.
- NDIS, 2015. National Disability Insurance Scheme: A Framework for Information, Linkages and Capacity Building (Draft). NDIS, Canberra.
- Nursing and Midwifery Board Australia, 2010. National Competency Standards for the Registered Nurse. Nursing and Midwifery Board Australia, Melbourne.
- Nursing Council of New Zealand, 2015. Education programme standards for the registered nurse scope of practice. Nursing Council of New Zealand, Wellington.
- Phillips, A., Morrison, J., Davis, R., 2004. General practitioners' educational needs in intellectual disability health. Journal of Intellectual Disability Research 48 (2), 142-149.10.1111/j.1365-2788.2004.00503.x.

- Richmond, D.T., 1983. Inquiry Into Health Services for the Psychiatrically III and Developmentally Disabled: Report Recommendations Summary. Department of Health, NSW, Division of Planning and Research.
- Rimmer, J.H., Braddock, D., 2002. Health promotion for people with physical, cognitive, and sensory disabilities: an emerging national priority. American Journal of Health Promotion 16 (4), 220-224.10.4278/0890-1171-16.4.220.
- Robertson, J., Hatton, C., Baines, S., Emerson, E., 2015. Systematic Reviews of the Health or Health care of People with Intellectual Disabilities: A Systematic Review to Identify Gaps in the Evidence Base. Journal of Applied Research in Intellectual Disabilities 28 (6), 455– 523.10.1111/jar.12149.
- Robinson, S., Griffiths, P.D., 2007. Approaches to specialist training at pre-registration level: an international comparison. National Nursing Research Unit King's College London, London.
- Scullion, P.A., 1999. 'Disability' in a Nursing Curriculum. Disability & Society 14 (4), 539-559.10.1080/09687599926118.
- Seccombe, J.A., 2007. Attitudes towards disability in an undergraduate nursing curriculum: The effects of a curriculum change. Nurse Education Today 27 (5), 445-

451.10.1016/j.nedt.2006.08.003.

- Smeltzer, S.C., Dolen, M.A., Robinson-Smith, G., Zimmerman, V., 2005. Integration of disabilityrelated content in nursing curricula. Nursing Education Perspectives 26(4), 210-216.
- The NSW Council for Intellectual Disability, 2005. Submission to the Productivity Commission on the Health Workforce. NSW CID, Sydney.
- Thomas, L., Chaperon, Y., 2011. Comments to the Australian Government in response to the Discussion Paper on Connecting Health Services with the Future: Modernising Medicare by providing Rebates for Online Consultations. Australian Nursing Federation, Canberra.

- Thompson, T.L.C., Emrich, K., Moore, G., 2003. The effect of curriculum on the attitudes of nursing students toward disability. Rehabilitation Nursing 28 (1), 27-35.10.1002/j.2048-7940.2003.tb01718.x.
- Trollor, J., Srasuebkul, P., Xu, H., Howlett, S., 2015. Mortality Rates and Cause of Death Highlight Major Health Inequalities for People with Intellectual Disability. Submitted.
- Tuffrey-Wijne, I., Goulding, L., Giatras, N., Abraham, E., Gillard, S., White, S., Edwards, C., Hollins, S., 2014. The barriers to and enablers of providing reasonably adjusted health services to people with intellectual disabilities in acute hospitals: evidence from a mixed-methods study. BMJ Open 4 (4), e004606.10.1136/bmjopen-2013-004606.
- UN General Assembly, 2006. United Nations Convention on the Rights of Persons with Disabilities, 13 December 2006, A/RES/61/106, Annex I. UN General Assembly, New York.
- Webb, O., Rogers, L., 1999. Health screening for people with intellectual disability: the New Zealand experience. Journal of Intellectual Disability Research 43 (6), 497-503.10.1046/j.1365-2788.1999.00233.x.
- Webber, R., Bowers, B., Bigby, C., 2010. Hospital experiences of older people with intellectual disability: Responses of group home staff and family members. Journal of Intellectual and Developmental Disability 35 (3), 155-164.10.3109/13668250.2010.491071.

WHO and World Bank Group, 2011. World report on disability. World Health Organisation, Geneva.

### Appendix A.

Phase 1: Interview Schedule- relating to the overall structure of the course

1) What is the name of your University?

2) What is your current position within the University?

3) How many pre-registration nursing degrees do you currently offer?

4) What is the duration of the degree(s) for a full-time student (in years)?

5) How many students graduated from the degree(s) in the last academic year?

6) Approximately what percentage of students' time during the degree involves direct patient contact?

7) In total, how many subjects/units of study (including both non-clinical and clinical units) are

provided as part of this degree?

8) Of the total subjects/units of study in the degree:

- a. How many are compulsory subjects/units of study?
- b. How many are elective subjects/units of study?
  - i. Of the elective subjects/units of study do any of them have an intellectual disability component?
  - ii. If yes, approximately what proportion of students choose this ID component?

9) How many subjects/units of study (including both non-clinical and clinical units) in this degree contain at least some formal teaching content in intellectual disability physical health and/or intellectual disability mental health?

10) Could you please provide a copy of your course outline?

- 11) How many staff within the nursing school:
  - a. Specialise in the area of intellectual disability physical health and/or intellectual disability mental health?
  - b. Have a demonstrated interest in the area of intellectual disability physical health and/or intellectual disability mental health?
  - c. Currently provide teaching within the curriculum specifically in the area of intellectual disability physical health and/or intellectual disability mental health?

### Appendix B.

Phase 2: Survey Schedule- relating to specific unit of study

- 1. What is the name of the programme this unit of study is offered in?
- 2. What year of the degree is this unit of study offered?
- 3. Please provide an overall description of the intellectual disability physical health content and/or intellectual disability mental health content delivered in this unit of study:
- 4. Is this subject/unit of study compulsory or elective?
  - a. If elective, how many students are enrolled in this subject/unit?
- 5. How many hours of either direct teaching or clinical placement time are involved in this unit of study?
- 6. Does the intellectual disability content in this unit of study include:
  - a. Intellectual disability physical health
    - i. If yes, approximately how many hours are provided in this unit of study?
  - b. Intellectual disability mental health
    - i. If yes, approximately how many hours are provided in this unit of study?
- 7. Does this unit of study involve direct patient contact with people with an intellectual disability?
- 8. Which of the following is covered within the intellectual disability content in this unit of study?
  - a. Clinical assessment skills
  - b. Clinical management skills
  - c. Ethics and legal issues
  - d. Preventative health
  - e. Disability and healthcare service systems
  - f. Interdisciplinary team work
  - g. Human rights issues in disability
  - h. Chronic and complex health issues
- 9. What is the mode of delivery?
  - a. Lecture
  - b. Tutorial
  - c. Workshop
  - d. Other\_\_\_\_\_
- 10. Is it in a clinical setting?

11. Do any of the assessments or exams for this unit include intellectual disability specific content?

### 12. Does this unit of study use problem-based or enquiry-based learning?

- a. Problem-based learning
- b. Enquiry based learning
- 13. Are people with an intellectual disability involved in the development and/or delivery of this unit of study?
  - a. If yes, how are they involved?
- 14. Reflecting on your experiences within your university's nursing program:
  - a. What has supported the inclusion of intellectual disability physical health and/or intellectual disability mental health content in your program?
  - b. What have been the most significant barriers for the inclusion of intellectual disability physical health and/or intellectual disability mental health content in your program?
- 15. Would you like to make any further comments regarding barriers and enablers for the inclusion of intellectual disability content in your program?
- 16. In relation to the delivery of intellectual disability physical health and/or intellectual disability mental health content, are there any examples of good educational practice that you would be willing to share?

#### Figure names

- Figure 1. Timeline illustrating the decline of specialist intellectual disability nursing in Australia
- Figure 2. Recruitment and data collection procedure
- Figure 3. Total number of pre-registration nursing degrees offered by participating schools
- Figure 4. Total number of intellectual disability units offered by nursing schools
- Figure 5. Distribution of compulsory and elective intellectual disability content in nursing courses

A CLO MAN

#### Figure 1



Figure 2



Figure 3



Figure 4







A CLANK

	Domain	Question category		
Phase 1	Course structure	Program type; total units; entry level; duration; number of students; contact hours; number of compulsory units; number of elective units; number of units containing intellectual disability specific content.		
	School staff profile	Total staff specialising in intellectual disability; total staff with a demonstrated interest in intellectual disability; total staff who teach intellectual disability content.		
Phase 2	Unit details	Year of course; compulsory or elective enrolment; total number of students enrolled.		
	Intellectual disability content	Total intellectual disability teaching time; type of intellectual disability content; topics covered; direct clinical contact.		
	Teaching style	Teaching mode; inclusion of people with intellectual disability in the development or delivery of content; assessments; learning style.		
	A CY			

### Table 1. Question domains and categories within measures

Topic area	Schools N	Proportion of participating schools %	Units N	Proportion of total units %
Clinical assessment skills	10	32	19	56
Ethics and legal issues	9	29	20	59
Interdisciplinary team work	9	29	11	32
Chronic and complex health issues	9	29	10	29
Clinical management skills	7	23	9	26
Disability and health care systems	5	16	10	29
Human rights issues	5	16	7	21
Preventative health	5	16	5	15
R Cli				

Table 2. Specific topic areas included within compulsory intellectual disability units.

### Highlights

- Less than half of schools audited offered intellectual disability content
- Where intellectual disability education was included, average was 3.6 h per unit
- Quantity and type of intellectual disability content taught varied substantially
- Clinical assessment skills most commonly taught, preventative health least common
- Only one school included a person with intellectual disability in content delivery

A CERTING