



**Educating the future nursing workforce to
meet the health needs of people with
intellectual and developmental disability:
Submission to the Independent Review of
Nursing Education**

Project Team:

Dr Nathan J Wilson, PANDDA President, Associate Professor, School of Nursing and Midwifery, Western Sydney University

Ms Virginia Howie, PANDDA Committee Member, Lecturer, School of Nursing, Midwifery and Social Sciences, Central Queensland University

Dr Chris Atkins, PANDDA past President and Founding Member

Endorsed by the PANDDA Executive Committee, 7th June, 2019

Contact: Professional Association of Nurses in Developmental Disability Australia Inc.
PO Box 3633, Parramatta NSW 2124, W: <http://www.pandda.net/index.html>

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Focus of Submission

The purpose of this submission is to make a series of recommendations specific to the Review's Terms of Reference with respect to the: "*educational preparation required for nurses to meet future health, aged care and disability needs of the Australian community including clinical training*".

About PANDDA

PANDDA is the only Australian association representing the professional interests of nurses who work with and care for people with intellectual and developmental disability (IDD). Many of PANDDA's members work within disability-specific services, however a growing number work in primary health roles, specialist assessment clinics, community health teams, private consultancy, and in academic/research institutes. PANDDA has published a series of position statements and practice standards for its members and also the wider public that are freely available for download from the PANDDA website: <http://www.pandda.net/index.html>

Background

The UN *Convention on the Rights of People with Disabilities* (CRPD) directs that a person has a right to life and right to attain the highest attainable standard of health without discrimination on the basis of disability. Following ratification of the CRPD in 2008, the Australian government sought a national approach to disability reform in order to improve the lives of people with disability, their families and carers (DSS, 2011). This resulted in the National Disability Strategy (2010-2020) that guides policy across States and Territories and aims to improve the interface between disability services and health services (DSS, 2011). Governments are also guided by the Disability Discrimination Act (1992) (DDA) that protects people with IDD from discrimination which includes equitable access to healthcare (AHRC, 2014). However, it is apparent that health disparities and inequitable access to quality health care still exist for people with IDD.

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Key Issues

Demographic overview and definition. People with IDD have both a *cognitive and an adaptive behaviour disability* originating before the age of 18 years (Schalock et al., 2010). Therefore, people with IDD find understanding and learning a challenge in addition to having a reduced ability to independently manage their lives. Approximately 3% of the Australian population has IDD; in 2012, this represented about 668,100 Australians (AIHW, 2012). People with IDD are a diverse group with varying intellectual capacity, from those with mild IDD who live independently, to those with severe to profound IDD who often require full-time supported accommodation. Further, many people with IDD also require daily support with decision making, personal hygiene, mouth care, medication administration, appropriate clothing, nutrition, and personal safety (McKeon, 2009).

Health disparity and inequality of access. People with IDD have very poor mental health outcomes, reduced physical health status and experience major barriers accessing mainstream health services when compared to the general population (Wilson & Charnock, 2017). Higher rates of morbidity and mortality compared to the general population are evident. A recent Australian study that focussed on cause of death demonstrated that the deaths of 38% of people with IDD over a period of six years (2005-2011) were potentially avoidable compared to 17% of a matched cohort from the general population (Trollor, Srasuebku, Xu & Howlett, 2017). The study found that the average life expectancy of people with IDD was 54 years; a 26-year gap with the general population. Similar findings were reported in a Queensland study on deaths in care (Office of the Public Advocate (Qld), 2016). The reasons for such disparity are multi-faceted. People with IDD are at higher risk than the general population for developing heart disease, high blood pressure, obesity, poor oral health and respiratory disease. However, due to poor health literacy associated with IDD, adopting healthy lifestyle behaviours are not so achievable. There is also a failure of healthcare services to address these unmet needs. People with IDD have a poor uptake of screening and preventative services, are often misdiagnosed or inadequately treated, and are subject to poor attitudes by healthcare staff. Discrimination, prejudice, indifference, intolerance, stigma, and uncaring attitudes have been described in the literature (ABS, 2016; Trollor et al., 2017), making this an extremely vulnerable group. The post-institutionalisation ideal that people with IDD would be able to access the mainstream health system has not been realised.

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Complex health support needs. People with IDD require varying levels of care and support and in a variety of contexts according to an individual's needs across the lifespan. A considerable number of this vulnerable population group have complex support needs, for example one Australian study reported an average of 5.4 medical disorders per person with IDD (Beange, McElduff & Baker, 1995). Complex support needs include co-occurring problems such as mental illness, chronic and complex health needs, complex communication difficulties, maladaptive behaviours, homelessness, and interactions with the criminal justice system (Dowse, Dew & Sewell, 2019). People with IDD and complex support needs have multiple service involvement, experience both a breadth and depth of needs, face barriers accessing and receiving effective service responses, and the cyclical complexity of their needs alters over time and at different life stages. Nurses have a vital role to play in supporting, in particular, people with IDD with complex health needs. The four key domains of nursing practice for all people with IDD are: 1) direct health care and support, 2) teaching and coaching of others about complex health needs, 3) advocacy and case coordination, and 4) using education, research and evaluation to ensure evidence-based practice (FaCS, 2014).

Communication and consent. Communication difficulties are also well-recognised as many individuals struggle to be included in conversations, or may struggle to express their healthcare needs. Some individuals are non-verbal, requiring technology to facilitate communication. In acute care settings, consent to medical treatment is complicated by literacy problems, communication problems and unsubstantiated assumptions by health professionals (University of Hertfordshire [UH], 2018). For example, some staff incorrectly assume the patient is unable to comprehend and fail to provide them with information, and in other instances, patients who lack the capacity to understand are given information and treatment options. In the first instance this could be considered neglect, and in the latter case, this would be considered assault. Capacity to consent is a problem faced by most people with IDD and an area for which nurses working within the mainstream health system struggle (Lewis, Gaffney & Wilson, 2017). That is, these nurses feel under-prepared, face challenges communicating with people with IDD, and are often unclear about the role that caregivers play in the provision of care, which includes the complex issues surrounding consent. Diagnostic overshadowing and/or acquiescence – major causes of misdiagnosis and adverse events – are common when nurses and other health professionals have limited insight into the communication issues facing people with IDD (Mason & Scior, 2004). Finally, the role of families and

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carers as advocates for people with IDD is an integral part of IDD care as they often know the person with IDD best. Yet, nurses, as well as other health professionals, fail to understand and make use of them as a means to enhance communication about needs and, therefore, better outcomes.

Changing population profile. There is also a significant change to the demographics of Australians with IDD. In addition to early onset of age-related health issues, there is also an increase to the ageing population of people with IDD meaning that age-related health issues are becoming more prominent. Early onset dementia in people with Down syndrome is a prominent case example. There is also an increase in the survival rate of many babies, children and young adults with IDD due to advances in medical and nursing interventions during peri-natal care. That is, the range of health needs is increasing and the breadth of nursing skills and interventions required to support these needs is likewise increasing.

The knowledge gap. In the past, Mental Retardation nursing was a separate registration or within the specialty of Mental Health nursing. When nurse education transitioned to higher education in the late 1980's to 1990's IDD content was to be embedded within the new curriculum. However, it is now evident that IDD specific content has been eroded over time. In a recent national audit of nursing curriculum content of 31 universities, Trollor et al., (2016) found considerable variability in key IDD content with many gaps evident.

The authors recommended that nursing curriculum be reviewed to include IDD content to boost confidence and encourage positive attitudes that would reduce barriers and improve health outcomes for people with IDD.

Building workforce capacity is even more critical, given that those nurses who were trained in IDD care prior to the 1990's are now retired or retiring, leaving a perceived void in the knowledge, skills and experience of IDD care in the nursing workforce. This is especially concerning, given that lack of training and education is the main contributor to a self-perceived lack of confidence and knowledge by health care staff (Iacono et al., 2014).

Every nurse, no matter the context of their role, will encounter people with IDD. This includes, but is not limited to, maternity, paediatric, community, adult, mental health and aged care settings. Nurses need to know *how* to care for

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people with IDD. As it stands, virtually every nurse that graduates from an Australian nursing school misses out on education about the disparate health issues facing people with IDD (Trollor et al., 2016). Given the inequality and disparate outcomes faced by this group of Australians, this is less than satisfactory. Nurses need to know about the causes, health risks, health screening, and health promotion needs of people with IDD. Insights into how to adapt their communication and modify their nursing interventions are crucial. Further, recent Australia research has not only described the cyclical complexity of the nurse/patient dyad, but has also started to conceptualise the reality that nurses vitally work in partnership with the person with IDD, the family, key supports, as well as the health and disability service systems (Wilson et al., 2019). Undergraduate students require exposure to such insights in addition to learning effective strategies to practice what has been referred to as *nurse-led, relationship-centred* care alongside people with IDD and their families.

Dedicated curriculum content. Many researchers recommend curricular changes to enhance nursing students' awareness and increase knowledge of people with IDD (Temple & Murdoch, 2012; Trollor et al., 2016). Essential topics for inclusion in nurse curriculum have been explored including: what is IDD, communication, capacity and consent, health of people with IDD, reasonable adjustments, medication, enabling independence and inclusion, expressing distress, health promotion, working with families, and others, profound IDD, and a lifespan approach to care (RCN, 2017). In addition, including people with IDD in curriculum content development is essential. Allowing people with IDD to have a voice empowers them by acknowledging their unique insights and perspectives and ensures curriculum content is responsive to the needs and goals of those people who use healthcare services. Developing socially inclusive awareness in nursing students by including IDD specific content with input by IDD self-advocates will create graduate nurses who are well-prepared for the workplace (Heidke, Howie & Ferdous, 2018).

There is an urgent need to educate pre-registration and post-registration nurses in IDD care so that nurses gain confidence and skills required in order to provide the appropriate nursing care and reduce health inequalities for people with IDD across the lifespan.

Case studies - avoidable deaths due to knowledge deficits of healthcare professionals when caring for someone with IDD

Michelle died from meningitis caused by an ear infection. Despite crying and moaning, health staff at Bankstown Hospital overlooked the possibility that something serious was wrong with Michelle and put her unusual behaviour down to her having intellectual disability

<https://www.abc.net.au/news/2017-02-08/study-finds-intellectually-disabled-two-times-preventable-death/8248772>

Giuseppe had a fall and was admitted to hospital; he died after going 10 days without food as he could not tolerate a naso-gastric tube and was not able to communicate or care for himself: <https://www.standard.co.uk/news/uk/man-with-downs-syndrome-died-after-10-days-without-food-in-hospital-a4101371.html>

Policy considerations

The aim of policy should be to teach students how to recognise IDD in order to flag and alert others so that reasonable adjustments can be made to care and in planning treatment options. Training should be mandatory so that people with IDD receive the same health care as everyone else in accordance with the UN CRPD and the DDA (1992); this is a human rights issue.

In the UK, the government is currently holding a national consultation on the future mandatory training for all nurses and medical staff about working with people with IDD:

<https://www.mencap.org.uk/get-involved/campaign-mencap/current-campaigns/treat-me-well/consultation-learning-disability>

This is in response to the same issues raised here in Australia where disability advocates are already starting to lobby for an inquiry into the health of people with IDD which will focus on nurse training:

<http://www.nswcid.org.au/our-health-counts.html>

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In addition to the increased and changing demographic of people with IDD, the advent of the NDIS means that more opportunities will be available to nurses to specialise in this area in the future. For example, the NDIS has schedules for nurses to conduct individual assessments, train families and carers in health-related procedures, as well as provide mental health and continence assessments/interventions.

Recommendations

- 1. Dedicated content within the national undergraduate nursing curricula either in the form of a standalone unit of study, or embedded within a unit (e.g. chronic illness and disability). This content should be informed by the inclusion of people with IDD; various reported methods from the UK offer ways that this can be undertaken very effectively. *Outcome: increased knowledge and competence about working with a sub-group of Australians with very poor health outcomes.***
- 2. IDD care embedded in the NMBA RN Standards of practice. *Outcome: people with IDD receive the same health care as everyone else.***
- 3. Clinical placement opportunities where student nurses will meet and care for people with IDD. *Outcomes: increased competence and confidence in how to care for, communicate with and adjust nursing interventions for people with IDD.***
- 4. The development of a 4th year embedded honours component, for interested and capable students, who can combine a small research study with their new graduate year. *Outcomes: enhance the research literacy of nurses, build the evidence base for the role of nurses who care for people with IDD.***

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