



**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**

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Educating the future nursing workforce to meet the health needs of people with intellectual and developmental disability

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.

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.

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

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

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>

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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20 June 2019

The Secretariat
Educating the Nurse of the Future

Dear Sir or Madam,

Re: Support for the Professional Association of Nurses in Developmental Disability Australia Inc's (PANDDA) submission to the Independent Review of Nursing Education 2019

I am writing in support of PANDDA's submission to the Independent Review of Nursing Education in Australia, which recommends future nursing curricula that include mandatory content about the health of people with intellectual and developmental disability (IDD), and how to adapt nursing care to better accommodate their needs.

As the Public Advocate for Queensland I am appointed under the *Guardianship and Administration Act 2000* (Qld) to undertake systemic advocacy on behalf of people with impaired decision-making capacity. My primary role is to promote and protect the rights and interests of Queenslanders with impaired capacity and to support their autonomy and participation in all aspects of community life.

Appropriate access to health care is a fundamental and basic human right that a significant proportion of people with IDD cannot realise.

Over 400,000 Australian residents have intellectual disability, and the health inequalities they experience are of grave concern. People with intellectual disability experience, in comparison with the general population:

- Over twice the rate of avoidable deaths
- Twice the rate of emergency hospital admissions
- Hospital admissions that cost twice as much
- Higher rates of physical and mental health conditions
- Lower rates of preventative health care.¹

In 2016, my office undertook a review of the deaths in care of people with disability in Queensland.² This review investigated the deaths of 73 people, and found that more than half of the deaths were potentially avoidable.

The review also highlighted the multiple and complex health needs of people with disability that are often exacerbated by barriers preventing access to appropriate and responsive health care and disability supports, as well as by poverty and social exclusion.

¹ NSW Council for Intellectual Disability, Inclusion Australia (NCID), *The Health of People with Intellectual Disability, Budget and Federal election 2019, Commitments sought from Australian political parties*, NSW Council for Intellectual Disability, Sydney NSW, February 2019

² Office of the Public Advocate (Qld), *Upholding the right to life and health; A review of the deaths in care of people with disability in Queensland*, Brisbane 2016.

Recommendations from the review covered a broad spectrum, particularly highlighting the need for enhanced training and education of health professionals to better support people with disability, with the development of:

- A multi-faceted education and information strategy to respond to identified gaps in knowledge in respect of providing health care support for people with disability.
- A multi-layered strategy for the training of health professionals, inclusive of that provided by tertiary institutions as well as that which is provided 'on the ground' in Health and Hospital Services.

The recommendations included by PANDDA in its submission, address these issues directly, proposing that;

- there be dedicated content included in the national undergraduate nursing curricula;
- IDD care be embedded into the Nursing and Midwifery Board of Australia's (NMBA) Registered Nurse (RN) standards of practice;
- clinical placement opportunities be provided that allow student nurses to meet and care for people with IDD; and
- the inclusion of a 4th year honours component in the nursing curricula, that will allow for the completion of research studies by students that will contribute to the development of the evidence base for the role of nurses who care for people with IDD.

The difference these programs would make to the lives and health outcomes of people with IDD would be immense. Problems associated with communication and the diagnosis of health conditions for people with IDD due to a lack of education and training for medical and health staff mean that medical conditions can go undiagnosed, leading to poor health outcomes including avoidable deaths.

In the longer term, the programs would also save Government money, via savings associated with reduced hospital room emergency presentations, the proactive treatment of avoidable chronic and acute conditions resulting in fewer hospitalisations, reduced support needs under the National Disability Insurance Scheme, and the increased participation of people with intellectual disability and their families and carers in the Australian community and economy.

It is simply unacceptable for Australia to continue to operate a health system that is not accessible or responsive to people with IDD.

I urge the Secretariat to include the proposals developed by PANDDA as a recommendation of the review, to ensure that health professionals are adequately educated and trained to provide appropriate standards of care to some of the most vulnerable people in our community.

Yours sincerely



Mary Burgess

Public Advocate (Queensland)

Educating the Nurse of the Future

nursingreview@health.gov.au

Inclusion Australia lends its strong support to the Professional Association of Nurses in Developmental Disability Australia's (PANDDA) submission to the Independent Review of Nursing Education.

Inclusion Australia has campaigned for action on education for health care providers, including nurses for some time. As discussed in PANDDA's submission, compared with the general population, people with intellectual disability experience poor health outcomes including over twice the rate of avoidable deaths, higher rates of hospital admissions and physical and mental health conditions and lower rates of preventative healthcare.

Health professionals face challenges communicating with people with intellectual disability, dealing with issues of consent, distinguishing health problems from the disability, and diagnosing complex health conditions. They generally have minimal training in intellectual disability health care, as there is currently no curriculum content in the majority of nursing degrees.

Dedicated curriculum content is critical in addressing the poor and costly health outcomes for people with intellectual disability and their families. Training in intellectual disability should be mandatory for all nursing professionals.

Hearing directly from people with lived experience is essential; students and professionals seeing people with intellectual disability as authoritative sources of information and knowledge is a powerful learning experience in itself. We strongly support PANDDA's position that curriculum enhancement must involve co-design with people with intellectual disability to ensure the curriculum is informed and effective.

Yours sincerely

Justine O'Neill

Justine O'Neill

CEO, NSW Council for Intellectual Disability

For Inclusion Australia

21 June 2019

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21st June, 2019

To the Advisory group, Independent Review of Nursing Education,

Please accept this letter of support for the submission to the review by PANDDA.

PANDDA provides an essential voice within the nursing profession with an active membership that gives voice both to those within the nursing profession who work with people with developmental disability, and through them, those they care for.

The Centre for Disability Research and Policy conducts world- leading research into the lives, experiences and needs of people with disability and we have a strong focus on developmental and intellectual disability. Our aim is to transfer these research findings to the practice and policy sector so that we can bring about positive change for people with disability, their families, carers and communities.

This submission by PANDDA is an important one because it reminds us of the need to specifically educate nurses in relation to developmental and intellectual disability. If we do not do this then the nursing workforce is underprepared for the needs of people and lacks 'disability confidence' to go into roles where they come into contact with people with developmental and intellectual disability. This creates poor practice and leads to workforce gaps in this important area.

While all of the PANDDA submission is important and should be considered in relation to the future of nursing education, I would like to highlight the following parts of the submission:

- Complexity. Complexity of needs in this group means that their needs often fall across multiple health contexts and into social care. In response the PANDDA submission endorses education around the following key domains:
 - “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. This is essential and very relevant given the current Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability. Nursing education needs to proactively respond to this.
- Including detailed information about people with intellectual and developmental disability in the curriculum, but also including incidental information, so that the nurses of the future are intrinsically oriented towards inclusion.
- Understanding of the human-rights context of care for people with intellectual and developmental disability. This includes taking a partnership approach with individuals in their own care.

For these reasons I believe that it is essential that nursing education include specific content related to intellectual and developmental disability. I have no hesitation in endorsing the submission by PANDDA.

Yours sincerely,

A handwritten signature in black ink, appearing to read 'Jennifer Smith-Merry'.

Associate Professor Jennifer Smith-Merry Director,

Centre for Disability Research and Policy