

Professional Association of Nurses in
Developmental Disability Australia Inc

Standards for Nursing Practice

2nd Edition



pandda
Professional Association of Nurses in
Developmental Disability Australia Inc

**The Professional Association of Nurses in Developmental Disability
Australia Inc. (PANDDA)**

Standards for Nursing Practice

Published by the Professional Association of Nurses in Developmental
Disability Australia Inc
PO Box 3633, Parramatta NSW 2124

First Edition published July 2002
2nd Edition published November 2020

Designed by John Thrift Publishing
Tel. 0408 639 263 | Website: www.jtp.net.au

Fineline Print & Copy Service NSW
Tel. 02 9519 0552 | Website: <https://finelinensw.com.au>

Copyright ©2020 All rights reserved. No part of this publication may be reproduced, stored in a retrieval system, or transmitted in any form or by any means, electronic, mechanical, photocopying, recording or otherwise, without the permission of the Professional Association of Nurses in Developmental Disability Australia Inc.

Contents

Foreword	2
Intellectual and Developmental Disability Nurses	3
Background	3
Acknowledgements	6
DOMAIN 1: A central dyadic relationship	8
Standard 1. Adopts a nurse-led, relationship-centred approach to care and support	8
DOMAIN 2: Fundamental knowledge and skills relevant to intellectual and developmental disability	9
Standard 2. Understands the nature and diversity of intellectual and developmental disability in the delivery of nursing care	9
Standard 3. Reflects on personal and professional development in I intellectual and developmental disability care and support	10
DOMAIN 3: Professional relationships, cognisant of ethical, legal and research-based practice relevant to intellectual and developmental disability	11
Standard 4. Practises within legal and ethical frameworks relevant to intellectual and developmental disability care and support	11
Standard 5. Engages in research-based practice with a focus on intellectual and developmental disability care and support	11
Standard 6. Facilitates intersectoral collaboration	12
Standard 7. Builds the capacity of colleagues to provide individualised care and support to people with intellectual and developmental disability	12
DOMAIN 4: Intellectual and developmental disability nursing as a specialty area of practice	13
Standard 8. Advocates for the specialty area of intellectual and developmental disability nursing within the profession and in the community	13
Glossary	14
Bibliography	15

Foreword

It is with much pleasure that the Professional Association of Nurses in Intellectual Developmental Disability Australia (PANDDA) Executive Committee present the *PANDDA Standards for Nursing Practice* (2nd edition) (hereafter referred to as the *PANDDA Standards*) on behalf of PANDDA Inc. A review of the 2002 PANDDA Standards was necessary to reflect current practice, in particular, following the introduction of the National Disability Insurance Scheme (NDIS). To ensure the revised practice standards were informed by research-based evidence, PANDDA Inc formed a partnership with a nurse academic research team from Western Sydney University to finance, research and develop new standards for practice.

The purpose of the revised standards for practice is to define the professional expectations of nurses working with people who have intellectual/developmental disability. These standards are underpinned by the values, knowledge, skills and attributes held by the discipline of nursing and further define the role of the intellectual/developmental disability nurse within the community. The standards reflect the interplay of social and health policy that informs and guides our practice. The standards also seek to provide and inform those outside the discipline of nursing of the vital role of nurses and nursing in the provision of services to people with intellectual/developmental disability and the broader community. The documenting and dissemination of these standards aims to enhance the health and well-being of people with intellectual/developmental disability and inform community expectations of this specialty area of nursing practice. This is a living document and offers a basis for discussion and debate within the discipline of nursing and the wider community.

The PANDDA Executive Committee
November 2020

Intellectual and Developmental Disability Nurses

An Intellectual and Developmental Disability (IDD) Nurse is a member of the general register of nurses administered by the Australian Health Practitioners Authority (AHPRA), and who cares for and supports individuals with intellectual and developmental disability, their families, caregivers and/or the community. IDD nurses practice in any context in which persons with intellectual and developmental disability are present. IDD Nurses are accountable for their own nursing practice. In the absence of any formal accreditation or distinctive domain of registration in Australia, the identity of an IDD nurse is available to anyone whose passion and major professional focus is the care of people with IDD.

Background

The *PANDDA Standards for Nursing Practice* (2nd edition) are a guide to the nursing profession, people with intellectual and developmental disability (IDD), their families, caregivers, support network, educators, industry, policy makers, and the public in general. The *PANDDA Standards* provide a framework for the knowledge and attributes required to provide relevant and appropriate nursing care and support to this vulnerable group of Australians. The *PANDDA Standards* are not a stand-alone set of guidelines. The purpose of the *PANDDA Standards* is to complement the Nursing and Midwifery Board of Australia (NMBA) Registered Nurse standards for practice by highlighting the additional knowledge and skills required to successfully promote positive health outcomes for people with IDD. Although we recognise the valuable contributions made by support workers, Assistance in Nursing (AINs) and Enrolled Nurses (ENs), the standards apply to Registered Nurses only.

The *PANDDA Standards* are based on the results of a 3-year research project funded by PANDDA Inc. A major finding of the research was that the nursing care and support of people with IDD is focused on a central dyadic relationship between the person and the nurse. We have called this 'nurse-led relationship centred care and support'. Our research indicates that this is the most important distinguishing feature of IDD nursing practice. Relationship-centred care and support that is definitive of IDD nursing does not dismiss the principles of person-centred care, rather it enhances person-centredness by

acknowledging the vital and meaningful interactions between all stakeholders that are inherent to nursing practice (Wilson et al., 2018). The published works specific to this body of research that have informed the *PANDDA Standards* (2nd edition) are available in the bibliography.

Broadly speaking, nurses who specialise in working with people with IDD value the unique dyadic and professional relationships that they develop with each individual. They base their practice on the best available evidence and, given the limitations of current research evidence, also seek to generate and disseminate a larger body of evidence for the future development of this specialty area of nursing. Integral to IDD nursing practice is the need to actively educate colleagues and the community in valuing people with IDD to minimise stereotypical attitudes leading to discriminatory practices. Essential to this is the need to develop a deep understanding of IDD to help minimise health inequities.

The *PANDDA Standards* are conceptualised in Figure 1 and consist of eight standards that are encompassed within four broad domains. These four domains are represented by concentric circles which illustrate both the inherent focus on the person with IDD at the core of all practice, and the need for nurses to be outward looking as they advocate for the specialty area of practice.

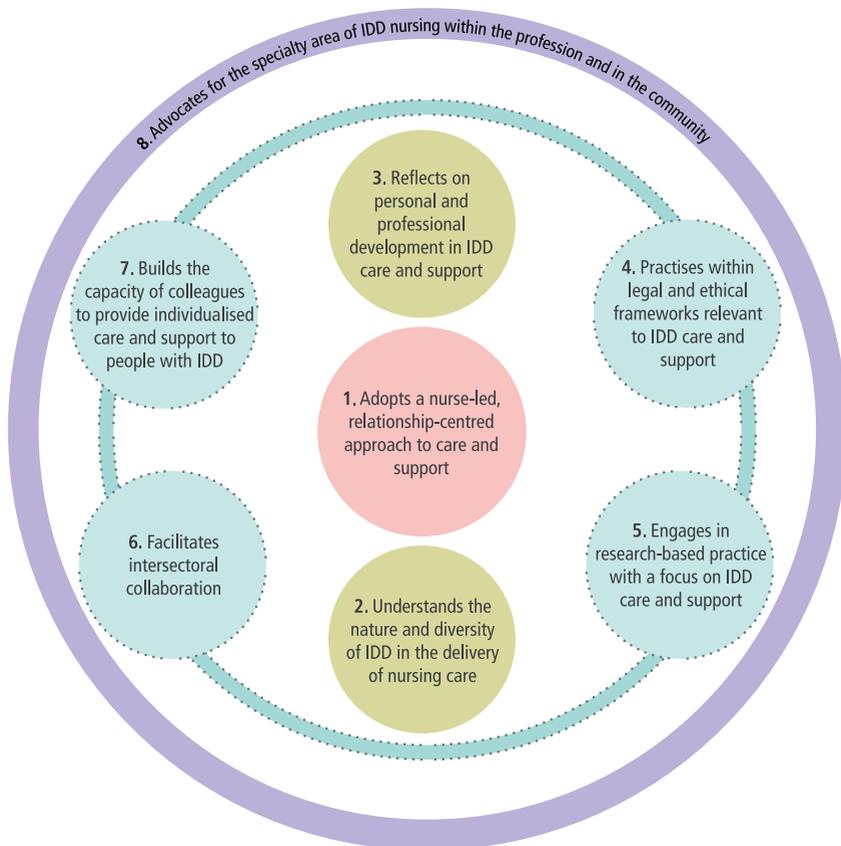


Figure 1. Conceptualised map of the PANDDA Standards.

- DOMAIN 1: A central dyadic relationship
- DOMAIN 2. Fundamental knowledge and skills relevant to intellectual and developmental disability
- DOMAIN 3. Professional relationships, cognisant of ethical, legal and research-based practice relevant to intellectual and developmental disability
- DOMAIN 4. Intellectual and developmental disability nursing as a specialty area of practice

Acknowledgements

The following people are acknowledged for their various contributions to the development of the PANDDA Standards:

The PANDDA Committee members for recognising the need for a review, and who put their trust in the research team.

Nathan Wilson for leadership in the research project that informed the 2nd edition as well as his leadership in developing and reviewing the PANDDA Standards.

Peter Lewis for significant contribution to the research project that informed the 2nd edition as well as his significant contribution to developing and reviewing the PANDDA Standards.

Virginia Howie for her contribution to the research project that informed the 2nd edition as well as the principle author of the PANDDA Standards (2nd edition).

Deb Denman for her expertise in overseeing the implementation of the Delphi Research Design.

All the researchers and nurses who were involved in, or contributed to, the 3-year program of research that informed these Standards.

Appreciation goes to the participants in the Delphi study who were PANDDA members, selected for their nursing expertise in caring and supporting people with IDD and for the contexts in which they practice. Their feedback was invaluable during the Delphi process.

Dr. Chris Atkins, RN, PhD, (retired), NSW

Mrs Rhonda Beggs, RN, MScAdvPrac, Disability Nurse Navigator, QLD

Brett Coleman, RN, NSW

Sue Easton, RN (retired), BN, Grad Dip (Developmental Dis), NSW

Mrs Paula Firmstone, RN, NSW

Louise Hedges, RN, CNS, NSW

Dr. Natasha Jojo, PhD (MH Nursing), Assistant Professor, University of Canberra, Bruce, ACT

Dr Penelope Kearney, RN (retired), PhD

Margaret Laing, RN, Health Care Team Leader, NSW

Maree McCulloch, RN, BAdult Voc Ed, Education manager, TasTAFE, Tas

Denise Robinson, RN, Support Coordinator, NSW

Gail Tomsic, RN, CNC, NSW

Bob Weaver, OAM, RN (retired), NSW

Recognition must also go to the many people with intellectual and developmental disabilities and their families and caregivers whose voices can be heard throughout the evidence which informed the research that went into the development of the *PANDDA Standards*, 2nd edition.

● DOMAIN 1

A central dyadic relationship

Standard 1. Adopts a nurse-led, relationship-centred approach to care and support

Develops a partnership between the nurse and person together with family and caregivers where:

- a) the dyadic relationship between the nurse and the person is mutual and forms the nucleus around which all other relationships interact.
- b) the nurse seeks to attain knowledge of the complexity and lifelong nature of each person's specific conditions, care and support needs.
- c) the relationship can take time to develop and can endure across parts of the person's life span.
- d) the dyadic relationship provides the focus of intersectoral collaboration between health care services, social services, and disability systems.
- e) the nurse, together with the person, involves families, caregivers, and support team in the planning of care within the context of the multidisciplinary team.
- f) the nurse recognises that people with IDD together with family and caregivers are experts in the experience of their own lives, including aspects of disability, spirituality, identity, cultural values, and beliefs.

● DOMAIN 2

Fundamental knowledge and skills relevant to intellectual and developmental disability

Standard 2. Understands the nature and diversity of intellectual and developmental disability in the delivery of nursing care

Develops a holistic understanding of the complex and individual approaches to IDD care, such as:

- a) gaining knowledge of IDD that includes awareness of the diverse nature of IDD, causes, likely associated co-morbidities, and presence of other disabilities (motor, social and/or sensory, mental health disorders).
- b) increasing communication ability by assessing for preferred communication method (e.g. eye gazing, communication board, pictures/images and/or sign language) and actively assess body language as a way of communication.
- c) recognising that both expressive and receptive communication barriers impact on information shared.
- d) understanding that behavioural manifestations are a way of communication and a change in behaviour may have significant meaning (e.g. experiencing pain).
- e) adopting positive behaviour support to minimise the risk of over-medication and negative and punitive responses related to behavioural management.
- f) consideration for personality and social supports that influences confidence, function, and coping abilities.
- g) focusing on functional ability with consideration for emotional intelligence, artistic ability, interests, and how the person engages with the world.
- h) supporting autonomy and enabling maximum levels of independence and functioning.
- i) recognising the importance of health literacy in managing self-care (e.g. healthy diet, lifestyle choices).
- j) awareness of economic issues that may impact on the person's ability to access health services and act on health advice.

Standard 3. Reflects on personal and professional development in intellectual and developmental disability care and support

Strives to develop a deep understanding of IDD to maximise practice opportunities by:

- a) meeting professional NMBA Registered nurse standards for practice.
- b) aiming to develop IDD nursing expertise through continuous practice in IDD care and support.
- c) using self-reflection in own practice with a view to optimising skills and knowledge in IDD care and support.
- d) engaging in IDD educational opportunities in consideration for lifelong learning.
- e) keeping abreast of government reforms to human service systems, demographic trends and changes within society relevant to IDD.

● DOMAIN 3

Professional relationships, cognisant of ethical, legal, and research-based practice relevant to intellectual and developmental disability

Standard 4. Practises within legal and ethical frameworks relevant to intellectual and developmental disability care and support

Attains knowledge of ethical and legal aspects specific to IDD care, such as:

- a) human rights for people with IDD that includes awareness of disability discrimination and equitable access to health care services.
- b) supporting a person's right to make their own decisions and/or participate in decision-making and to exercise their legal capacity, including the right to consent to treatment.
- c) supported decision-making includes the need for information presented in accessible format specific to their needs (e.g. Easy English).
- d) guardianship legalities relevant to the States and Territories in which the nurse works.
- e) dignity in care – respected as valued individuals so that the person feels safe and in control of their own planned care.

Standard 5. Engages in research-based practice with a focus on intellectual and developmental disability care and support

Practices in accordance with research-based evidence. The nurse:

- a) is a discerning consumer of research evidence related to IDD nursing care.
- b) actively participates in the generation of research evidence to support best practice.
- c) disseminates research findings and other evidence that supports the development of the specialist practice of IDD nursing.

Standard 6. Facilitates intersectoral collaboration

Facilitates access to services across all sectors: health care services, social services, and disability systems. The nurse maintains up-to-date knowledge of:

- a) the rationale/philosophy behind the National Disability Insurance Scheme (NDIS); pathways to access it; and processes within the NDIS.
- b) appropriate pathways across primary, secondary, and tertiary health care services to ensure continuity of care.
- c) available local community and social services for the person with IDD and their family and caregivers.

The nurse is an advocate for inclusive practices:

- d) to promote uptake of preventative programs (e.g. breast screening, annual health checks).
- e) by making reasonable adjustments to facilitate positive experiences for people with IDD, their families and caregivers (e.g. offering a first or last appointment, taking more time).

Standard 7. Builds the capacity of colleagues to provide individualised care and support to people with intellectual and developmental disability

Educates fellow health care professionals, disability support workers (DSWs) and members of the wider community to develop compassionate understanding of IDD by:

- a) identifying deficits in staff knowledge and actively seeking to educate colleagues in IDD care.
- b) developing educational opportunities and facilitating upskilling of DSWs in delivery of health-related care and support in the community.
- c) advocating for the person and their families/caregivers when negative staff and community attitudes are apparent.
- d) taking opportunities to promote the value of nursing contribution to the care of people with IDD amongst people with IDD and their families, the health and social service professionals, and the community.

● DOMAIN 4

Intellectual and developmental disability nursing as a specialty area of practice

Standard 8. Advocates for the specialty area of intellectual and developmental disability nursing within the profession and in the community

Demonstrates leadership skills relevant to IDD nursing practice by:

- a) engaging in and contributing to informed critique and exerting influence at the professional and systemic level of health and IDD care.
- b) taking opportunities to promote the value of nursing contribution to the care and support of people with IDD amongst people with IDD and their families, the health professions, health care services, social services, disability services, and the community.
- c) identifying systemic barriers and enablers to accessing quality health care and actively advocate to overcome identified barriers.
- d) planning and preparing for major incidents and public health events that are inclusive of people with IDD and their families and caregivers.

Glossary

Caregivers

A caregiver is an individual who provides ongoing care or assistance to a person with a disability. Caregivers can be paid or unpaid. Paid caregivers are those who work in disability services. Unpaid caregivers are usually family and friends who provide informal care.

Domain

A group of values.

Dyadic

Relating to the interaction between two people. Dyadic interactions can be very complex. A sociological significant relationship.

Intellectual and developmental disability

Characterised by significant limitations in intellectual functioning (learning, reasoning, problem-solving, judgement) and adaptive behaviour (everyday social and practical skills, activities of daily living, communication, independence). The condition occurs before the age of 18 and is lifelong. Sometimes further classified by clinicians into mild, moderate, severe (or profound), according to IQ level.

Intersectoral collaboration

Action that involves several sectors of society, for example, health, education, disability services and local government sectors to enhance community health.

Standards for nursing practice

A set of guidelines that represent the level of quality or attainment of practice that can be expected of a registered nurse. Standards provide a guide to the knowledge, skills, judgement, and attitudes that are needed to practice safely as a registered nurse. In this case, registered nurses who practice within the intellectual and developmental disability space.

Bibliography

- Cashin, A., Buckley, T., Donaghue, J., Heartfield, M., Bryce, J., Cox, D., Waters, D., Gosby, H., Kelly, J., & Dunn, S. (2015). Development of the Nurse Practitioner Standards for Practice Australia. *Policy, Politics, & Nursing Practice*, 16(1-2), 27-37. <https://doi.org/10.1177/1527154415584233>
- Jaques, H., Lewis, P., O'Reilly, K., Wiese, M., & Wilson, N.J. (2018). Understanding the contemporary role of the intellectual disability nurse: A review of the literature. *Journal of Clinical Nursing*, 27, 3858-3871. <https://doi.org/10.1111/jocn.14555>
- Lewis, P., Collison, J., Whitehead, L., Howie, V., Feighan, S., Wiese, M., O'Reilly, K., Jaques, H., & Wilson, N.J. (2020). Demographic profile of the intellectual disability nursing workforce in Australia: Findings from a national survey. *Journal of Intellectual & Developmental Disability*, 45(3), 24-268. <https://doi.org/10.3109/13668250.2019.1685478>
- Lewis, P., Gaffney, R. J. & Wilson, N. J. (2017). A narrative review of acute care nurses' experiences nursing patients with intellectual disability: Underprepared, communication barriers and ambiguity about the role of caregivers. *Journal of Clinical Nursing*, 26(11-12), 1473-1484. <https://doi.org/10.1111/jocn.13512>
- Lewis, P., Wilson, N.J., Jaques, H., O'Reilly, K. & Wiese, M. (2019). A qualitative study of nurses' perspectives of caring for children with intellectual disability and their families in a paediatric acute care setting. *Journal of Child Health Care*, 23(4), 639-651. <https://doi.org/10.1177/1367493519867234>
- O'Reilly, K., Lewis, P., Wiese, M., Goddard, L., Trip, H., Conder, J., Charnock, D., Lin, Z., Jaques, H., & Wilson, N.J. (2018). An exploration of the practice, policy and legislative issues of the specialist area of nursing people with intellectual disability: A scoping review. *Nursing Inquiry*, 25:e12258. <https://doi.org/10.1111/nin.12258>
- Professional Association for Nurses in Intellectual and Developmental Disability Australia (PANDDA). (2002). *Standards for Developmental Disability Nursing*. <http://www.pandda.net>

Wilson, N.J., Lewis, P., O'Reilly, K., Wiese, M., Lin, Z., Devine, L., Booley, R., Jaques, H., & Goddard, L. (2019). Reframing the role, identity, and standards for practice of registered nurses working in the speciality area of intellectual and developmental disability in Australia: The NDIS and beyond. *Collegian*, 26, 132-139. <https://doi.org/10.1016/j.colegn.2018.06.002>

Wilson, N.J., Wiese, M., Lewis, P., Jaques, H., & O'Reilly, K. (2019). Nurses working in intellectual disability-specific settings talk about their uniqueness of their role: A qualitative study. *Journal of Advanced Nursing*, 75(4), 1-11. <https://doi.org/10.1111/jan.13898>

Wilson, N.J., Collison, J., Feighan, S., Howie, V., Whitehead, L., Wiese, M., O'Reilly, K., Jaques, H., & Lewis, P. (2020). A national survey of nurses who care for people with intellectual and developmental disability. *Australian Journal of Advanced Nursing*, 37(3), 4-12. <https://doi.org/10.37464/2020.373.120>

