

The Nursing and Midwifery Board of Australia
Via email to: mbafeedback@ahpra.gov.au

Monday 24 June 2019

To Whom it May Concern

Thankyou for the opportunity to provide feedback in relation to the Proposed Decision-Making framework for nurses and midwives. I am writing from the ACT Disability, Aged and Carer Advocacy Service (ADACAS), we provide free individual advocacy, information and advice to people with a disability, people experiencing mental ill health, older people and carers.

In addition, ADACAS' Policy and Projects team has been working on supported decision making (SDM) projects for the past 8 years aiming to enable and empower more people to participate actively in decisions about their life. Our current projects include SDM as a tool for equitable access to healthcare, how SDM and advocacy can be used as tools to prevent the abuse of older people and the implementation of SDM at a systemic level in response to proposed changes in legislation. (Project team lead: Helen Connolly, team members Sarah Sowry, Ivette Gonzalez, Barbara Fisher, Damien Venner).

As part of these projects we have developed a suite of resources to provide information, tips and tools to help people use supported decision making. These resources have been developed in consultation with people who require support to make decisions, carers, health professionals and service providers and can be found at www.support-my-decision.org.au.

In the next month we are also launching *the Decision Support Toolkit* app that is particularly designed for service providers and carers who may be supporting people to make decisions. The app provides information about supported decision making, managing risks and planning for the future, and includes a toolkit to document and support people through the decision making process.

Through this submission we seek to highlight the issues that our clients have raised with us, and our learnings from 8 years of decision making research. We value the opportunity to provide this feedback and would also greatly appreciate the opportunity to talk or meet with you to discuss the proposed DMF.

ADACAS acknowledges the Ngunnawal people as the traditional owners of the land on which we work, and pay our respects to their Elders, and to all Aboriginal and Torres Strait Islanders in our community.

Principles of Decision Making

Given ADACAS's focus on supported decision making (SDM) in healthcare we were excited to see the comment on your consultation website: www.nursingmidwiferyboard.gov.au/News/Current-Consulations.aspx that the proposed framework is focused on '*strengthening the involvement of the person receiving care in the decision making*'.

The importance of supported decision making (SDM) is highlighted in the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD)¹ and the Australian Law Reform Commission's decision making principles (<https://www.alrc.gov.au/publications/national-decision-making-principles>). SDM is a way to uphold rights and to enable people to actively participate in decisions about their life and receive equitable access to healthcare.

A key way of further highlighting this commitment would be to include supported decision making and person led decisions in the Principles of Decision Making.

Recommendation 1: that the Principles of decision-making be updated to include person-led decisions and supported decision-making.

Does the proposed Decision Making Framework adequately include the person/woman receiving care in the decision making?

It is evident in the proposed DMF that there is a renewed emphasis on partnership and collaboration with the person receiving care. This is a positive inclusion in the DMF however the actions in the DMF appear at present to be more in line with shared decision making principles rather than supported decision making. ADACAS believes that the DMF should instead explicitly articulate an expectation of person-led* decisions around treatment and care (with support as required). (*The person referenced being the person receiving the treatment).

For person centred care to fully uphold decision making rights, the person receiving care should lead the decision and determine the support they require to make that decision. The support required may be adapting communication and information to better facilitate understanding, or may involve receiving support from someone in their support network. The person receiving care should lead the decision about the source and means of their support as it may change dependent on the decision being made². For further information, refer to <https://support-my-decision.org.au/>

Recommendation 2: The DMF should be updated to reflect supported decision-making principles.

¹UN General Assembly, *Convention on the Rights of Persons with Disabilities : resolution / adopted by the General Assembly, 24 January 2007, A/RES/61/106*, available at: <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/article-12-equal-recognition-before-the-law.html>) [accessed 24 June 2019]

² Rae, K, and May, F. (2013), *Spectrums of Support* report, accessed via: <http://www.adacas.org.au/media/1083/spectrums-of-support-final-20130911.pdf>

This partnership and collaboration with a person's support network that is included as a key action in the guide for nurses should also be extended into the guide for midwives (it is not currently present). There is clear recognition of the woman's role in decision making but it is not articulated that she has the right to lead the decisions about her care and receive support where and when she needs it. The source of the required support may be the multidisciplinary team but may also be someone in her support network.

Recommendation 3: The DMF should highlight the person's right to elect both who supports them and also what that support looks like for them, as a key action for both nurses and midwives alike.

One of the key actions in both the nursing and midwifery guides is the assessment and management of potential risks. At present, decisions around risks and safeguards appear in the DMF as decisions made by the treating team without explicit commitment to including the person receiving care in the decision making process.

People receiving care should be supported to identify and understand potential risks associated with a decision and should be actively involved in decisions about how to manage the risks. It is important to recognize that everyone has the right to take risks as they may represent an opportunity to achieve a goal or learn from mistakes. It is essential to safeguard risks as much as possible without removing them, and the person's decision making rights, all together. This action point should be amended to fit within a supported decision making model where people receiving care are supported to go through the decision making process, including decisions that may involve risk.

Recommendation 4: DMF should be updated to ensure people receiving care, and their chosen supports, are actively involved in decisions about potential risks and risk management.

In light of our research focus, as mentioned above, we would greatly appreciate the opportunity to talk or meet with you to discuss the proposed DMF, and would also be happy to discuss and answer any questions that you may have regarding this submission.

Kind regards,

Sarah Sowry
Supported Decision Making Team
(On behalf of Helen Connolly, Projects and Research Coordinator)
ADACAS