COGNITIVE DECLINE PARTNERSHIP CENTRE

Cognitive Decline Partnership Centre Activity 24 Project Team

Submission to the NSW Law Reform Commission Inquiry into the Guardianship Act 1987 – Draft Proposal

Dear Commissioner

Thank you for the opportunity to make a submission to this Inquiry. We write in our capacity as a team of academic researchers, practitioners and consumer representatives involved in a Cognitive Decline Partnership Centre funded research project. This research team includes members with consumer experience in dementia care, and professional expertise in law, medicine, psychology, aged care service provision, and policy development. The project is investigating community and professional views on supported decision-making, as a potential way of facilitating greater involvement in decision-making and advance care planning by people with dementia and their care-partners.

Terms of Reference:

Considering the scope of this research project, we limit our submission to the context of people living with dementia, and within the following Terms of Reference:

- The Report of the 2014 ALRC Equality, Capacity and Disability in Commonwealth Laws;
- The UN Convention on the Rights of Persons with Disabilities;
- The demographics of NSW and, in particular, the increase in the ageing population.

We have responded to those elements of the proposed 'Assisted Decision-Making Act' ('the new Act') that are most relevant to our current research.

1.1 A new Act

We agree with the streamlining of the *Guardianship Act 1987* (NSW) and the enduring power of attorney provisions in the *Powers of Attorney Act 2003* (NSW), within a single form of supported and representative decision-making. Given that there are no substantial differences in the principles by which supported or representative decision-making is to occur across the financial and personal domains, this streamlining will simplify the provisions. Implementation will require significant training, and ongoing vigilance to ensure that the use of the term 'Representation Order' or 'Enduring Representation Agreement' does not become synonymous with "substitute decision-making powers in all domains/areas". Practitioners and the public will require training in order to focus in on the relevant domains of decision-making, and may require guidance regarding the borders between certain decision domains (e.g. healthcare versus lifestyle or lifestyle versus financial), which can be unclear in some situations.

1.8 Statutory Objects

We agree with the inclusion of Statutory Objects to outline the duty of everyone exercising functions under the Act, and broadly agree with the principles in respect of people in need of decision-making assistance.

1.9 General principles

While we broadly agree with the General Principles in respect of people in need of decision-making assistance, we feel, however, that principle (c) "Their personal and social wellbeing should be maintained" is liable to misinterpretation, and may give the impression that 'stasis' in personal and social wellbeing is condoned, or encouraged, within the Act. The primary definition of 'maintain' is "cause or enable (a condition or situation) to continue".[1] While such wording may be suitable for situations in which a person's wellbeing is currently at an acceptable state, in many cases those who are in need of decision-making assistance will not be in this situation. We suggest that the wording could be adjusted to say (c) "Their personal and social wellbeing should be promoted". We do not argue for including "to the greatest extent possible" as this may be read as overriding some of the other potentially conflicting principles (e.g. principle (m) "Their rights and autonomy should be restricted as little as possible).

1.11 Determining a person's will and preference

We agree with the shift from a 'best interests' or 'welfare and interests' standard of substitute decision-making towards the concept of 'giving effect to a person's will and preference. We also support the inclusion of guidance on determining a person's will and preference when applying the first of the general principles.

1.12 Definition of decision-making ability

We agree with providing a statutory definition of decision-making ability, which applies across all areas (6.2 and 6.4).

1.13 Presumption of decision-making ability

We agree with the inclusion of a new statutory presumption of decision-making ability

[1] Oxford Dictionary. Accessed 4/2/2018 from https://en.oxforddictionaries.com/definition/maintain

1.14 Assessing decision-making ability

We agree with the inclusion of guidance on assessing decision-making ability, particularly given the explicit requirement of witnesses to agreements under the Assisted Decision-Making Act to vouch that the person appeared to understand the nature of the agreement. Based on our research in the context of people living with dementia, we specifically agree with the importance of including clear guidance about

(1) taking reasonable steps to conduct the assessment at a time and in an environment in which the person's decision-making ability can be assessed most accurately.

(2)(b) that inability to make a decision may be temporary or permanent

(2)(c) that decision-making ability may be different at different times

(2)(d) that a person may develop, gain or regain decision-making ability

(2)(e) that a person has decision-making ability for a matter if it is possible for the person to make the decision with practicable and appropriate support.

With respect to point (1), noting that assessments of decision-making ability often take place in the context of a hospital admission, it is important that the context be considered in assessing decision-making ability. While logistical factors often impinge on the settings in which decision-making ability can be assessed, this could be grounds for appeal of a determination or later review of a judgment by a court or Tribunal. It should also be made clear that assessments of decision-making ability should occur as close as possible to the time at which the decision is being made (ideally in the context of making the actual decision) and be functional assessments (not medical/clinical assessments of executive function).

5.15 Effect of order on other appointments

"The new Act should provide that a representation order (including an order of the Supreme Court to like effect) suspends any enduring representation agreement, support agreement, or support order in its entirety, unless the court or Tribunal order expressly allows a limited continuing operation."[2]

Given that representation orders are to be made only when (i) the person lacks decision-making ability for the decision, (ii) there is a demonstrated 'need' for the order, (iii) as a last resort and (iv) subject to review – provision 5.15, on its own, should not lead to any erosion of the person's autonomy (subject to the practice of making judgments relating to (i), (ii), (iii) and (iv). However, provision 5.15 does seem conceptually at odds with the Commission's stated

[2] NSW Law Reform Commission (2017), *Review of the Guardianship Act 1987: Draft proposals*, Sydney, 40.

intention that "…we envisage that a person might have two or more different assisted decision-making arrangements in place at any one time…".[3] Certain cognitive impairments or life situations may leave a person unable to make decisions about their own financial matters and lacking any options for these decisions other than a representation order, and yet still retain the ability to make decisions (perhaps with support) about health or lifestyle matters. Given provision 5.15, we foresee that where representation orders are deemed necessary for one domain of decision-making, courts and/or Tribunals will often need to make statements to the effect that an existing support arrangement or enduring representation agreement should be able to continue, perhaps with limitations and in circumscribed decisional domains or situations.

6.5 Advance care directives

We agree with the statutory recognition of advance care directives in the new Act. While it is but a matter of time before a conflict arises over the situation in which a person's current will and preference (at a time when their decision-making ability is contested) conflicts with their previously expressed will and preference in an advance care directive, this situation will occur, and be problematic, regardless of whether or not the advance care directive is given statutory recognition in the new Act. The statutory objects and clear definition of decision-making ability provided in 1.8 and 1.11 provide decision-makers with more transparent procedures for addressing these conflicts.

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The full list of investigators on the project is provided below:

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[3] *Ibid*., 17.

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Thank you for the opportunity to provide this submission.

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