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. In particular, this submission draws from preliminary evidence collected from:

• examination of legislation and case law relating to Guardianship and supported decision-making across three jurisdictions in Australia, and one overseas (WA, NSW, SA, and British Columbia), with particular reference to people with dementia;
• interviews with people living with dementia and their family carers, investigating their experiences with decision-making;
• interviews with aged-care service providers, investigating their established policies and practices with respect to healthcare and lifestyle decision-making among recipients of aged-care services.

Terms of Reference:

Considering the scope of this research project, and the fact that our work is still underway, 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.

Question 2.1: Witnessing an enduring guardianship appointment

What changes if any, should be made to the Guardianship Act 1987 (NSW) concerning:

2.1(a) the eligibility requirements for witnesses

The inclusion of an employee of Service NSW should be removed as this encompasses any number of people, working in a variety of settings, who may
have little, if any knowledge of mental capacity and substitute decision making. It is also unclear as to why the CEO of NSW Trustee and Guardian, rather than the Public Guardian should be nominated as the person to approve someone as an eligible witness as the role of the NSWT&G is financial – not personal and health. Also there should be transparency as to what constitutes “... an approved course of study”.

2.1(b) the number of witnesses required

The inclusion of a medical practitioner, in addition to the current list (removing employees of NSW Service), would be of benefit (as has been noted 2.13 QP4).

2.1(c) the role of a witness

The witness should ensure that the appointer understands the instrument (as per the Queensland legislation), also an identity check should be undertaken (as per the VLRC recommendation). It is of concern that in 2.22 the comment is made that “... some potential witnesses may be unable to explain the effect of the appointment accurately or be satisfied that the person has the required level of understanding” this in itself demonstrates a fundamental flaw in the current legislation as to the eligibility of witnesses.

Question 2.2: When enduring guardianship takes effect

Should the Guardianship Act 1987 (NSW) contain a procedure that must be followed before an enduring guardianship appointment can come into effect? If so, what should this process be?

Yes. The current definition of a person in need of a guardian that is “… a person who, because of a disability, is totally or partially incapable of managing his or her person.” This is totally inappropriate when combined with the definition of a disability

“(2) In this Act, a reference to a person who has a disability is a reference to a person:
(a) who is intellectually, physically, psychologically or sensorily disabled,
(b) who is of advanced age,
(c) who is a mentally ill person within the meaning of the Mental Health Act 2007, or
(d) who is otherwise disabled,
and who, by virtue of that fact, is restricted in one or more major life activities to such an extent that he or she requires supervision or social habilitation.”

It can be seen that the above definition does not take into account “mental capacity”. “Advanced age” is not defined nor does it justify any claims that a person has a disability. Furthermore, the term “partial” is not defined and thus is open to interpretation and abuse.

1 Powers of Attorney Act 1998 (QLD), Chapter 3 s 44(3), 44(4), 44(5).
An assessment of the cognitive capabilities of the individual should be undertaken, by a health practitioner qualified to undertake such an assessment, before an enduring guardianship appointment can come into effect.

**Question 2.3: Reviewing an enduring guardian appointment**

Are the powers of the NSW Civil and Administrative Tribunal to review an enduring guardian appointment sufficient? If not, what should change?

The powers should align with the powers given to the Tribunal in respect of reviewable powers of attorney.

**Question 2.4: Ending an enduring arrangement**

What changes, if any, should be made to the *Guardianship Act 1987 (NSW)* concerning:

2.4(a) the resignation of an enduring guardian

The current arrangement in respect of the resignation of the enduring guardian (prior to the appointment taking effect) is satisfactory.

2.4(b) the revocation of an enduring guardianship arrangement

The first option, i.e. the appointor revoking the instrument (before it takes effect) is satisfactory. The second option, i.e. the Tribunal revoking the entire document poses problems if an advance care directive has been incorporated into the instrument. Clarification is required as to the ongoing status of an advance care directive under such situations. We suggest that the advance care directive should remain binding even if the guardianship has been revoked by the Tribunal. The third option, i.e. the automatic revocation of the enduring guardianship arrangement if the appointor marries someone other than the enduring guardian,\(^3\) removes the rights of the individual to make a choice as to whether they would want someone else to continue as their enduring guardian. The instrument itself should provide an option whether the appointment is to continue after marriage to someone else, or is to be revoked – as per the Queensland legislation.\(^4\)

**Question 2.5: Other issues**

Would you like to raise any other issues about enduring guardianship procedures?

The current legislation makes no provision for supported decision-making, which could exist alongside the legislated ability to appoint an enduring guardian. We believe that a scheme similar to the Victorian legislation should be adopted.

\(^3\) Guardianship Act 1987 (NSW), s 6HA.

\(^4\) Powers of Attorney Act 1998 (QLD), Chapter 3 s 52.
**Question 3.1: Applying for a guardianship or financial management order**

What are your views on the process for applying for a guardianship or a financial management order?

The process appears fair, though assistance should be available to assist people in completing the application.

**Question 3.2: Time limits for orders**

3.2(1) Are the time limits that apply to guardianship orders appropriate? If not, what should change?

The time limits for guardianship orders are appropriate as the legislation allows for flexibility.

3.2(2) Should time limits apply to financial management orders? If so, what should these time limits be?

These should be consistent with the time limits applicable for guardianship orders, in keeping with the principle of least restriction.

**Question 3.3: Limits to the scope of financial management orders**

Should the *Guardianship Act 1987 (NSW)* require the NSW Civil and Administrative Tribunal to consider which parts of a person’s estate should be managed?

This should mirror the NSW Trustee and Guardian Act 2009\(^5\) to avoid confusion and unnecessary parts of the estate being placed under management.

**Question 3.5: Reviewing a guardianship order**

3.5(1) What factors should the NSW Civil and Administrative Tribunal consider when reviewing a guardianship order?

An extra factor should be taken into consideration, and this is whether the person under a guardianship order could manage with a support person, in other words supported decision-making.

3.5(2) Should these factors be set out in the *Guardianship Act 1987 (NSW)*?

Yes, under an amended s 25.\(^6\)

**Question 3.6: Grounds for revoking a financial management order**

3.6(1) Should the *Guardianship Act 1987 (NSW)* expressly allow the NSW Civil and Administrative Tribunal to revoke a financial management order if the person no longer needs someone to manage their affairs?

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\(^5\) NSW Trustee and Guardian Act 2009 s 40.

\(^6\) Guardianship Act 1987 (NSW) s 25C.
Yes there should be specific provisions in the Act to allow for the revocation on the grounds the person can be supported in their financial decision-making, by another person i.e. supported decision-making.

**Question 4.1: Benefits and disadvantages of a registration system**

4.1(1) What are the potential benefits and disadvantages of a registration system? Do the benefits outweigh the disadvantages?

See response below 4.1(3)

4.1(2) Should NSW introduce a registration system?

See response below 4.1(3)

4.1(3) Should NSW support a national registration system?

Yes. With a “movable” population and the fact that some families remove a member under guardianship to another jurisdiction, a national registration system would be ideal. This would permit all third parties reliant on enduring guardianship instruments, or guardianship orders, to determine whether the instrument is in fact valid. A national register would greatly assist in making this information available promptly and reliably. One possibility would be to join in with the current effort to create a National Electronic Conveyancing System.

**Question 5.1: A statement of duties and responsibilities (for guardians and financial managers)**

5.1(1) Should the Guardianship Act 1987 (NSW) and/or the NSW Trustee and Guardian Act 2009 (NSW) include a statement of the duties and responsibilities of guardians and financial managers?

Yes, the current system provides little guidance in this respect.

5.1(2) If so:

5.1(2)(a) what duties and responsibilities should be listed in this statement?

See for example the Queensland legislation in this regard.7

5.1(2)(b) should guardians and financial managers be required to sign an undertaking to comply with these duties and responsibilities?

Yes, this would help to ensure that they understand fully their role and responsibility, and the penalties for misusing their powers. This could be integrated within the existing steps for accepting an appointment, and could be supported by accessible educational materials. Access to additional support in terms of advice and guidance in these roles would also be beneficial, both to the person appointed, and, indirectly, to the appointor.

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7 Guardianship and Administration Act 2000 (QLD) Schedule 1 P1, P2.
5.1(2)(c) what should happen if guardians and financial managers fail to observe these duties and responsibilities?

They should be required to pay a substantial penalty if it has been proven that they acted *ultra vires* and/or to the detriment of the person for whom they are guardian/financial manager. As an example, the *Advance Care Directives Act 2013* (SA) specifies financial penalties and potential imprisonment for exerting undue influence, fraudulent behaviour and/or falsely purporting to act as a substitute decision-maker.8

**Question 5.2: The supervision of private managers**

What, if anything, should change about the NSW Trustee and Guardian’s supervisory role under the *NSW Trustee and Guardian Act 2009 (NSW)*?

This role should be removed from the NSW Trustee and Guardian as there are disproportionate costs associated with their oversight of individual private guardians, not to mention the issue of surety bonds. Furthermore, private managers are hampered by the process of applying to NSW Trustee and Guardian each time they wish to make a financial decision involving the estate of the person under private management.

**Question 5.3: Reporting requirements for financial managers**

Should the *NSW Trustee and Guardian Act 2009 (NSW)* be amended to allow the NSW Trustee and Guardian to decide how often private managers should lodge accounts?

This role could be taken on by expanding the powers (and resources) of the Guardianship Division of NCAT.

**Question 6.1: Safeguards for a supported decision-making model**

If NSW introduces a formal supported decision-making model, what safeguards should this model include?

The safeguards for a supported decision-making model should include the following:

1. Amendments to the legislation to enable the appointment of a public advocate. For the Public Guardian to take on this ‘oversight’ role would pose a potential conflict of interest, particularly should they ever be appointed as a person’s guardian in the future.
2. The introduction of a statement of “duties and responsibilities” as outlined in point 5.1.
3. The appointment of a monitor as also noted in the legislation in other jurisdictions, most notably British Columbia. The ‘powers’ of the monitor would need to be clearly defined to prevent an over-zealous monitor

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8 *Advance Care Directives Act 2013* (SA) s 55, s 56.
exceeding their role to the detriment of both the person requiring support and the supporter.

4. It is essential that there is some record-keeping requirement, in the interests of transparency. However, if the record-keeping requirements are too onerous, then it would be difficult to recruit and retain supporters.

**Question 7.1: Assisting people without guardianship orders**

Should the *Guardianship Act 1987 (NSW)* empower the Public Guardian or a public advocate to assist people with disability who are not under guardianship?

Yes. But this role should not be given to the Public Guardian. It should be given to a newly created position of Public Advocate, to avoid any conflict of interest.

**Question 7.2: Potential new systemic advocacy functions**

What, if any, forms of systemic advocacy should the *Guardianship Act 1987 (NSW)* empower the Public Guardian or a public advocate to undertake?

Given the likely changes to guardianship legislation, and the inadequate understanding of the current systems of substitute decision-making among professionals and the broader community, there is a substantial role for public awareness campaigns, advocacy for development of organisational policies, and professional training.

**Question 7.3: Investigating the need for a guardian**

Should the *Guardianship Act 1987 (NSW)* empower the Public Guardian or a public advocate to investigate the need for a guardian?

Yes, a Public Advocate should be empowered to investigate the need for a guardian but only after taking into consideration whether the person could be better accommodated by a supported decision-making arrangement.

**Question 7.4: Investigating suspected abuse, exploitation or neglect**

Should the *Guardianship Act 1987 (NSW)* empower the Public Guardian or a public advocate to investigate suspected cases of abuse, exploitation or neglect?

Yes, the Public Advocate should have these powers as per the powers given to the Public Guardian and Trustee of British Columbia. The grounds in which the Public Guardian and Trustee can investigate are set out in the *Representation Agreement Act 1996* and include if the representative is:

(i) abusing or neglecting the adult for whom the representative is acting,
(ii) failing to follow the instructions in the representation agreement,

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9 Ben White, Lindy Willmott, Colleen Cartwright, Malcolm Parker, Gail Williams, ‘Doctors’ knowledge of the law on withholding and withdrawing life sustaining medical treatment’ (2014) 201 *Medical Journal of Australia*

10 *Representation Agreement Act 1996 (British Columbia)* s30 (1)(h)
(iii) incapable of acting as representative, or
(iv) otherwise failing to comply with the representation agreement or the duties of a representative.

These criteria could be further elaborated by tying them to the observation of ‘duties and responsibilities’ as in 5.1.

**Question 7.8: A new Public Advocate office**

Should NSW establish a separate office of the “Public Advocate”? If so, what functions should be given to this office-holder?

Yes, these functions and powers should be consistent with those of the Queensland Public Advocate, as set out in the *Guardianship and Administration Act 2000* (QLD).\(^{11}\) We additionally suggest that consideration be given to the role of the Public Advocate in mediating and resolving disputes (as per our submission in relation to 5.1(3) in Question Paper 2), particularly where this may facilitate the continuation of existing supported decision-making arrangements.\(^{12}\)

**Question 8.5: When a person can be represented**

When should a person be allowed to be represented by a lawyer or a non-lawyer?

A person appearing in the Tribunal may have a McKenzie friend, without seeking leave, and this should be extended to those who do require representation, whether it be from a lawyer or a non-lawyer, particularly in the case of someone who requires supported decision-making, which may go beyond the role of the McKenzie friend.

**Question 8.7: Representation of a client with impaired capacity**

Should the *Guardianship Act 1987 (NSW)* or the *Civil and Administrative Tribunal Act 2013 (NSW)* allow a person to be represented by a lawyer in Guardianship Division cases when the person’s capacity is in question?

Yes, for consistency with the *Mental Health Act 2007 (NSW)* which states:

The fact that a person is suffering from mental illness or an intellectual disability or developmental disability or is suffering from a mental condition that is not a mental illness or an intellectual disability or developmental disability is presumed not to be an impediment to the representation of the person by an Australian legal practitioner before the Tribunal.\(^{13}\)

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\(^{11}\) *Guardianship and Administration Act 2000* (QLD) Ch.9

\(^{12}\) *Advance Care Directives Act 2013 (SA)* s45

\(^{13}\) *Mental Health Act 2007 (NSW)* s152
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