NSW Trustee and Guardian (NSWTG) welcomes the opportunity to provide a response to the first question paper issued by the New South Wales Law Reform Commission in its review of the *Guardianship Act 1987 (NSW)*.

Our response is as follows:

3. The concept of "capacity"

Question 3.1: Elaboration of decision-making capacity

(1) Should the *Guardianship Act* provide further detail to explain what is involved in having, or not having, decision-making capacity?

Capacity is the ability to make and communicate decisions. It is not a unitary or global concept but rather particular to the type of decision being made. It is different for every decision made even within one domain.¹

NSWTG is of the view that the *Guardianship Act 1987* should provide guidance to explain what is involved in having or not having decision-making capacity in a clear, easy to understand way. We support the general principles in the *Victorian Guardianship and Administration Bill 2014* and the *Queensland Guardianship and Administration Act 2000*. Furthermore, the assessment principles outlined in the NSW Capacity Toolkit ²are a good guide in determining capacity. The guidelines outlined in the "toolkit" together with those outlined in Victoria and Queensland should be considered in the legislative reform.

We are of the view that the focus should be on what the person can do, with appropriate supports, rather than the focus being on what they cannot do.

A person's decision-making capacity varies from domain to domain and from time to time and defines 'capacity' in relation to a particular decision with reference to the following:

- the ability to understand information relevant to the decision
- the ability to retain that information for a period that allows the decision to be made within an appropriate timeframe
- the ability to utilise that information in the decision-making process
- the ability to foresee the consequences of making or not making the decision
- the ability to communicate the decision to others
- what supports are available to enable the person's decision making capacity.

The common law already endorses autonomy by recognising the presumption of capacity³, that all adults are presumed to have capacity until proven otherwise. NSWTG is of the view that this should be made apparent by writing it into the legislation. We note that Queensland and Western Australian guardianship laws have explicitly included a presumption of capacity in their guardianship legislation. The presumption of capacity is fundamental to contemporary guardianship legislation.

¹ http://capacityaustralia.org.au/wp-content/uploads/2013/10/NSW-Legal-kit-8pp-sept-2013-version-.pdf

² http://www.justice.nsw.gov.au/diversityservices/Documents/capacity_toolkit0609.pdf

³ Masterman-Lister v Brutton & Co [2003] 3 All ER 162, 169; L v Human Rights and Equal Opportunity Commission (2006) 233 ALR

⁴ Guardianship and Administration Act 2000 (Qld) sch 1 pt 1 cl 1; Guardianship and Administration Act 1990 (WA) s 4(3). The presumption of capacity in Queensland was considered in the Queensland Supreme Court case of Bucknall v Guardianship and Administration Tribunal (No 1) [2009] 2 Qd R 402. In this case it was found that the Queensland Guardianship Tribunal was obliged to start from the presumption of capacity in determining an initial application for guardianship and in reviewing a guardianship order, but that an administrator was entitled to rely on the Tribunal's finding of incapacity in exercising its powers: at [21–6], [43]

(2) If the *Guardianship Act* were to provide further detail to explain what is involved in having, or not having, decision-making capacity, how should this be done?

We are of the view that the starting point should be that the person is presumed to have capacity and that the onus of proving the person lacks capacity should be on the person who calls the person's capacity into question.

We submit that a definition of capacity should not be considered in isolation. Capacity legislation should provide a comprehensive framework aimed at maximising the autonomy of the decision-maker.

Legislative principles to guide the assessment of capacity should include the presumption of capacity, recognising that capacity is decision and time specific, should not be assumed based on appearance, should not be based solely on the evidence of unwise decision making, and that incapacity should not be found if it is possible to support the person to make a decision.⁵

Question 3.2: Disability and decision-making capacity How, if at all, should a person's disability be linked to the question of his or her decision-making capacity?

Everyone should have the right to be recognised as a person before the law. Everyone should have the right to freedom from discrimination on the grounds of disability. This is the basis of equality.

A person's autonomy is to be enhanced as much as possible. As a society, we have the obligation to ensure that any restriction on a person's right to autonomy in decision-making is proportionate to and based upon finding that a person lacks the requisite capacity.⁶

NSWTG believes that the current link to disability within the act is discriminatory, out-dated and against human rights principles. The fact that a person has a disability should not lead one to infer that they lacked capacity. The term itself gives prevalence to views of incapacity.

A person's disability alone does not justify the appointment of a guardian or an administrator.⁷

We believe the focus should be on *decision making capacity*, enhancing this capacity by whatever means possible and not focusing on *disability*. Most importantly, the focus should also be on what supports will enable the person's decision making capacity.

Question 3.3: Defining disability

If a link between disability and incapacity were to be retained, what terminology should be used when describing any disability and how should it be defined?

There is argument that the reference to the word "disability" is discriminatory and against human rights principles.⁸

NSWTG is of the view that the language of disability should be avoided and instead steps put in place to shift the focus on a person's decision making capacity including drawing on supports to achieve this, rather than their disability.

⁵http://www.lawreform.vic.gov.au/sites/default/files/Guardianship FinalReport Ch%207 Capacity%20and%20incapacity.pdf

⁶ Report of the Secretary General, see Note 11, Chapter 3, para 17; WHO Resource Book at Note 1 Chapter 2, 7.2

 $^{^7} http://www.lawreform.vic.gov.au/sites/default/files/Guardianship_FinalReport_Ch\%207_Capacity\%20 and \%20 in capacity.pdf p114$

⁸ Submission CP 66 (Victorian Equal Opportunity and Human Rights Commission)

The term disability perpetuates the public's view that the way a person looks or acts dictates their decision-making capacity. We are of the view that it serves no purpose other than to create a perception of lack of capacity.

Question 3.4: Acknowledging variations in capacity Should the law acknowledge that decision-making capacity can vary over time and depend on the subject matter of the decision?

NSWTG is of the view that decision-making capacity covers a "spectrum" varying from domain to domain and from time to time. At any point in time, capacity can be impaired for a set of circumstances but not others.

A person with intellectual disability may need significant support to make major decisions, however this does not mean they cannot be independent in day to day decisions.

The law cannot be rigid. The law must take into account that capacity to make certain decisions can be effected either on a temporary or on a permanent basis.

NSWTG believes we need to develop a more flexible approach to capacity, one which considers the fluctuating nature of capacity and the varying nature of cognitive impairment. ¹⁰ Importantly, we are of the view that decision making capacity is also dependant on the support available.

(2) How should such acknowledgements be made?

We must acknowledge that a person may have capacity at one point in time and not another. Some examples are: psychiatric illnesses which are untreated; or in the case of dementia, capacity may be better earlier on in the day rather than at the end of the day, or decision making capacity may be impacted by the person's use of medical drugs.

When determining capacity the following must be considered:

- a person may have decision-making capacity for some matters are not others
- lack of decision making capacity may be temporary
- a person's appearance should not come into play
- it should not be assumed that a person does not have capacity simply because, in the opinion of others, a decision is unwise
- the information to be considered by a person should be provided in the such a way which is easily understood by the person dependent on the circumstances whether by using modified language, visual aids or by other means.

(3) If the definition of decision-making capacity were to include such an acknowledgement, how should it be expressed?

We are of the view that it should be acknowledged that a person may have the capacity to make decisions about certain areas of their lives and not others. A person will make a decision based on a set of circumstances at any given moment in their lives.

⁹ New South Wales, Legislative Council Standing Committee on Social Issues, Substitute Decision-Making for People Lacking Capacity (2010)

http://www.ncat.nsw.gov.au/Documents/speeches_and_presentations/20151013_paper_second_international_conference_on_capacity.pdf

For any given decision the person should:

- 1. understand the information relevant to making the decision
- 2. use and weigh that information as part of the decision making process;
- 3. appreciate the reasonably foreseeable consequences of the decision and not making a decision;
- 4. communicate the decision (whether through speech, writing, sign language or any other means). 11

We are of the view that decision making can be achieved with appropriate supports. It is important to acknowledge such supports in the definition.

Question 3.5: Should the definitions of decision-making capacity be consistent? (1) Should the definitions of decision-making capacity within NSW law be aligned for the different alternative decision-making arrangements?

We are of the view that the definition of capacity should be flexible and adaptable enough to apply to different decisions in civil law. Decision making capacity should be the main test with the recognition of supports and different means of communicating decisions in situations where lack of decision making would otherwise be the result.

(2) If the definitions of decision-making capacity were to be aligned, how could this be achieved?

We believe the focus should be on decision making capacity and not incapacity. There needs to be an acknowledgement that: decision making capacity may vary at different times, be decision-specific, be made with the support of another and be communicated by various means.

We look favourably on the *Victorian Guardianship and Administration Bill 2014* which outlines the meaning of when a person has decision making capacity and provides guidance on determining whether a person has decision making capacity. It uses terminology as having decision making capacity *"in some matters and not others" and that lack of capacity may be "temporary and not permanent."*

Current guardianship practice guidelines ensure supported decision making wherever possible. This needs to be extended in practice to NSWTG financial management services and to the support provided to private guardians and financial managers to achieve the same. Supported decision making will not be possible for all people under guardianship and financial management and staff will need to be trained to discern the difference. Monitoring and support will be essential to ensure its full implementation. For example, a person in a persistent vegetative state or advanced dementia is practically unable to participate in decision making. However it does not automatically follow that they will require substituted decision making on a continuing basis.

Question 3.6: Statutory presumption of capacity Should there be a statutory presumption of capacity?

In the law concerning the appointment of substitute decision-makers, a person must be proven to be incapable of managing his or her affairs before a substitute decision-maker is appointed. The presumption of capacity is implicit in the operation of those laws.¹³ Whilst capacity is implicit, NSWTG is of the view that the presumption of capacity should be written into the legislation.

A statutory presumption of capacity reinforces the right of autonomy in decision-making and the onus is on those questioning capacity to prove otherwise.¹⁴

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¹¹http://www.pwd.org.au/documents/pubs/SB06-Capacity.pdf

¹² Clause 4 of Guardianship and Administration Bill 2014, http://www.austlii.edu.au/au/legis/vic/bill/gaab2014314/

¹³ http://www.pwd.org.au/documents/pubs/SB06-Capacity.pdf

¹⁴ Ibid

NSWTG is of the view that the presumption of capacity and legislative capacity assessment principles guiding capacity assessments, together with supported decision-making principles, would go a long way in promoting autonomy in decision-making.

Question 3.7: What should not lead to a finding that a person lacks capacity

(1) Should capacity assessment principles state what should not lead to a conclusion that a person lacks capacity?

NSWTG is of the view that a broad description regarding what may constitute lack of capacity be provided rather than a list of possible reasons for lack of capacity. There are many factors in total which may lead to a decision that a person lacks capacity. This may include the need for medical evidence to confirm lack of capacity at any given time.

Some of the factors which should **not** lead to lack of capacity is:

- disability, both physical and/or mental and associated behaviours
- inability to communicate
- level of education
- age and frailty
- time of incapacity (may not be indefinite)
- appearance
- poor decisions according to others

The list above is not an exhaustive list.

(1) If capacity assessment principles were to include such statements, how should they be expressed?

Consideration should be given to the following capacity assessment principles¹⁵:

- a person's capacity is specific to the decision to be made
- impaired decision-making capacity may be temporary or permanent and can fluctuate over time
- an adult's incapacity to make a decision should not be assumed based on their age appearance condition or an aspect of the behaviour
- person should not be considered to lack capacity to make decision merely because they make a decision others consider unwise
- lack of capacity should not be found if it is possible for a person to make a decision with appropriate support
- an assessment of capacity should be made at the most opportune time and environment to accurately assess capacity.

The above is in line with the principles of the UN Convention whereby a person's capacity to make decisions should be facilitated at all times. As outlined in the *UK Mental Capacity Act*, a person is not to be treated as unable to make a decision unless all practicable steps to help him or her to do so have been taken without success.¹⁶

Question 3.8: The relevance of support and assistance to assessing capacity

(1) Should the availability of appropriate support and assistance be relevant to assessing capacity?

NSWTG is of the view that access to supports which will lead to a person making their own decisions is the best approach.

All adults should have access to relevant information and supports to make their decision.¹⁷ They should be given the time they need to reach a decision and be able to communicate the decision in whatever means they need: speech, writing, touch, eye gaze, tone of voice, body language, signing, actions, facial

 $^{^{15}} http://www.lawreform.vic.gov.au/sites/default/files/Guardianship_FinalReport_Ch\%207_Capacity\%20 and \%20 in capacity.pdf$

¹⁶ Mental Capacity Act 2005 (UK) s 1(3).

¹⁷ 7(3) in Sch 1 to the Guardianship and Administration Act 2000 (Qld)

expression, miming, behaviour, vocalisations, gestures¹⁸ and other more complex methods like communication boards.

Question 3.9: Professional assistance in assessing capacity

(1) Should special provision be made in NSW law for professional assistance to be available for those who must assess a person's decision-making capacity?

Consideration should be given to the development of a system of designated capacity assessors based in the Alberta model together with training and certification system for capacity assessment in place in Ontario and Alberta. ¹⁹ The cost of such programs will need to be considered.

In any event, the tribunal will need to have access to various health professionals to assist them in the assessment of person's decision-making capacity. Professionals with vast experience have suggested that capacity assessment actually gets harder over time, as practitioners become more aware of the complex into and individualised nature of cognitive ability and inability.²⁰

(2) How should such a provision be framed?

The language of the legislation should recognise the role of supporters and representatives.

Question 3.10 Any other issues?

Funding and education will need to be considered.

Training supporters to avoid their own inherent bias will be required.

4. Other preconditions that must be satisfied

Question 4.1: The need for an order

(1) Should there be a precondition before an order is made that the Tribunal be satisfied that the person is "in need" of an order?

NSWTG is of the view that before an Order is made the tribunal must be is satisfied the person is in *need* of an Order. The Tribunal currently ensures the welfare and interests of a person incapable of managing his or her own affairs are considered. This should continue.

To promote autonomy in the individual, we are of the view that all avenues must be explored first including assisting the person to make a decision with the aid of support persons. The least restrictive approach must be taken at all times.

If an order is required we suggest the Queensland and Australian Capital Territory model be considered where amongst other factors, not having an Order will pose unreasonable risk to the person's health, welfare or property, and the person's interests will not be adequately protected or will be significantly adversely affected.²¹

(2) If such a precondition were required, how should it be expressed?

In the making of either a Guardianship or Financial Management Order the person is *in need* of the making of such an order after exploring other avenues of assisted decision making in line with the principles of autonomy.

There will be circumstances where without the making of an Order the person will be exploited to such a degree that they are at risk, for example, of losing their home.

 $^{^{18}\} https://www.qld.gov.au/disability/documents/community/complex-communication-needs.pdf$

¹⁹http://www.lawreform.vic.gov.au/sites/default/files/Guardianship_FinalReport_Ch%207_Capacity%20and%20incapacity.pdf

²⁰ Consultation with Australian & New Zealand Society for Geriatric Medicine (7 April 2011)

²¹ Guardianship and Management of Property Act 1991 (ACT) s 7(1)(b) and (c), s 8(1)(b) and (c); Guardianship and Administration Act 2000 (Qld) s 12(1)(b) and (c).

Question 4.2: A best interest's precondition

(1) Should there be a precondition before an order is made that the Tribunal be satisfied that the order is in the person's "best interests"?

The best interests model has been criticised as being too paternalistic and for taking away the fundamental human rights of the person to self-determination. There is a greater need for empowerment of the person with a disability in the decision-making process. There is a shift away from the best interests model of substitute decision-making towards one that promotes and safeguards the adults rights interests and opportunities.²² Whilst the best interests test does not ignore the need to consider the individual's wishes, it remains an essentially paternalistic approach.²³

The language of the legislation must be changed to reflect the will and preference principle in line with the trend in international law and thinking, the emphasis being on the person concerned at the centre of the decision-making process. A supported decision-making model is preferred to the current substitutedecision making model in keeping with the Convention.

The emphasis should be shifted from 'best interests' to 'will and preferences' approach.²⁴ It reflects the framing principles of dignity, equality, autonomy, and inclusion and participation.²⁵ The term "will and preferences" reflects a person's values, priorities, deep desires and vision for their lives.

(2) If such a precondition were required, how should it be expressed?

We believe that a person's autonomy must be supported and maximised to promote their personal and social wellbeing as much as possible.

We support the four National Decision-Making Principles (and associated Guidelines)²⁶, namely:

- 1. everyone has an equal right to make decisions and to have their decisions respected
- 2. persons who need support should be given access to the support they need in decision-making
- 3. a person's will, preferences and rights must direct decisions that affect their lives
- 4. there must be appropriate and effective safeguards in relation to interventions for persons who may require decision-making support.

(3) What other precondition could be adopted in place of the "best interests" standard?

We are of the view that the will and preference approach should be adopted and that the person should have all necessary supports to make their decision with the help, if required, of support persons. Such supports are invaluable for building the person's decision making skills. Supports are also important to assist with communication, emotional health and wellbeing and in making and maintaining relationships. 27

In making an appointment, the Tribunal should consider: that no less restrictive options are available; that although the adult's capacity is impaired, the adult can make decisions if given the support of a codecision-maker; and that there is a need for such an appointment.²⁸

²² Queensland Law Reform Commission, A review of Queensland's Guardianship Laws, Chapter 4, 2010 available at http://www.glrc.gld.gov.au/publications [Accessed 9 September 2015].

²³ https://sydney.edu.au/law/slr/slr_35/slr35_1/06_Then.pdf p3

²⁴http://www.ncat.nsw.gov.au/Documents/speeches_and_presentations/20151013_paper_second_international_conference_on _capacity.pdf

25 https://www.alrc.gov.au/publications/will-preferences-and-rights

²⁶https://www.alrc.gov.au/sites/default/files/pdfs/publications/dp813._chapter_3_national_decisionmaking principles.pdf

²⁷http://www.publicguardian.justice.nsw.gov.au/Documents/Practice%20Guidelines/PG%20Decision%20Making%20 Guideline%20EXT.pdf

²⁸ https://sydney.edu.au/law/slr/slr_35/slr35_1/06_Then.pdf p7

The Queensland Law Reform Commission recommended that powers should be used in a way that 'promotes and safeguards' and is 'least restrictive' of an adult's 'rights, interests and opportunities.²⁹

The Victorian Law Reform Commission, for example, recommended that the 'promotion of the personal and social wellbeing of the person' replace 'best interests'.³⁰

NSWTG recommends replacing the *best interests* terminology with guidelines to be considered when making an order, similar to the models in Canada. Before making an order, a person's wishes and preferences must be determined if possible with the aid of supports as required; that the consequences of making or not making the order is examined taking into consideration the person's personal, social and/or financial wellbeing.

4.3: Should the preconditions be more closely aligned?

(1) Should the preconditions for different alternative decision-making orders or appointments in NSW be more closely aligned?

The preconditions should be more closely aligned with the ultimate goal of preserving autonomy as far as possible.

(2) If so, in relation to what orders or appointments and in what way?

No comment

Question 4.4 Are there any other issues you want to raise about the preconditions for alternative decision-making arrangements?

No comment

- 5. Other factors that should be taken into account Question 5.1: What factors should be taken into account?
- (1) What considerations should the Tribunal take into account when making a decision in relation to: (a) a guardianship order and (b) a financial management order?

Apart from the important concept of "need", the tribunal must take in to account the person's present and past views and wishes. To support the concept of "will and preference" the least restrictive option must be taken.

Decision-making must emphasise the human rights of the person. Article 12 cannot be viewed in isolation. The overriding principles set out in the CRPD should be considered including:

- respect for inherent dignity—preamble and art 3;
- non-discrimination—art 5;
- liberty and security—art 14;
- freedom from torture or cruel, inhuman or degrading treatment or punishment art 15
- physical and mental integrity—art 17;
- liberty of movement—art 18;
- independent living—art 19;
- respect for privacy—art 22;
- respect for home and family—art 23; and
- participation in political and public life—art 29

Valued relationships which are the support of the person must not be disturbed particularly when they are supportive and working well. Such supports enhance the "will and preference" of the person.

²⁹ Queensland Law Reform Commission, A Review of Queensland's Guardianship Laws, Final Report R67 (2010) [5].

³⁰ Victorian Law Reform Commission, Guardianship, Final Report No 24 (2012) 536 n 83.

(2) Should they be the same for all orders?

No comment

(3) Are there any other issues you want to raise about the factors to be taken into account when making an order?

- (a) In some cultures, extended families have a greater involvement in the care of family members than other cultures. We live in a multicultural society with different beliefs, support systems, languages and customs. Such factors must be taken into account when making an order. We applaud the Queensland principles which also specifically require consideration of Aboriginal or Torres Strait Islander culture, language and custom.³¹
- (b) It is also important to consider how to support the adult's right to privacy during guardianship proceedings where very private information is disclosed in a public forum.³²
- (c) Lastly, safeguards should be in place to ensure that interventions for persons needing decision-making support are the least restrictive available, subject to appeal and subject to review.

Damon Quinn
Acting Chief Executive Officer
NSW Trustee and Guardian

³¹ Guardianship and Administration Act 2000 (Qld) sch 1 pt 1 cl 9(2).

 $^{^{32}\,}http://www.qlrc.qld.gov.au/__data/assets/pdf_file/0005/372533/R62Vol1.pdf$