

Law Reform Commission Review of Guardianship Act QP2

This submission is a collaborative effort between Disability Advocacy NSW ('DA') and Mid North Coast Community Legal Centre ('MNCCLC'). DA and MNCCLC are grateful for the opportunity to provide the NSW Law Reform Commission ('NSWLRC') with input relevant to their review of the *Guardianship Act 1987* (NSW) ('the Act').

About Disability Advocacy ('DA')

DA helps people of all ages with any type of disability or mental illness get fair treatment in the Hunter, New England, Mid North Coast, Central West and Hawkesbury-Nepean regions of NSW. DA's core purpose is to ensure that people with a disability realise these rights in practice by advocating with and for them.

About Mid North Coast Community Legal Centre ('MNCCLC')

MNCCLC provides safe, reliable and accessible legal services to socio-economically disadvantaged people living in the local government areas of Kempsey Shire, Port Macquarie-Hastings and MidCoast (Manning region). MNCCLC aims to increase access to justice and empower individuals with knowledge of their rights and the ability to resolve their legal issues.

Both organisations believe strongly in advocating for people with impaired ability. In a just and fair society, where the legal system is accessible to all members of the community, there is a need for our laws to reflect current normative values regarding disability. As the NSWLRC has noted, the increased frequency with which the NSW Civil and Administrative Tribunal ('NCAT') is dealing with guardianship applications from people with diminished capacity, shows there is a need to review the suitability of the current legal framework governing guardianship in NSW.¹

MNCCLC and DA have not addressed every question in Question Paper 2, but rather have identified those questions to which our work and experience relates. We have chosen to provide responses to the following questions.

¹ New South Wales Law Reform Commission, *Review of the Guardianship Act*, Background Paper, (2016) 12–13 [3.1]–[3.5].

Question 5.1: Formal supported decision-making

1. *Should NSW have a formal supported decision-making model?*

Informal supported decision-making is already in effect throughout Australia, however there are no legislated Commonwealth, State or Territory frameworks to govern its operation. MNCCLC and DA recognise that there are persuasive arguments both for introducing formal frameworks and refraining from doing so. However, our organisations conclude that there is more benefit to be gained from formal supported decision-making models, and we therefore support their implementation.

This change will ensure that Australia meets its international obligations under the United Nations Convention on the Rights of Persons with Disabilities, according to which people with a disability should be provided with the support they may require to exercise their legal capacity.² Under the supported decision-making model, the individual retains his or her capacity; the decision, although supported, is still effectively autonomous. In this way, variances in decision-making capacity can be accommodated and substitute decision-making used only when necessary.

2. *If there were to be a formal supported decision-making model, how can we ensure there was an appropriate balance between formal and informal arrangements?*

A formal supported decision-making framework should continue to recognise informal support measures and maintain a balance between the two. This will ensure that existing support networks are not unnecessarily formalised, and that onerous duties are not placed on informal supporters. To help achieve a balance between the two models, it is important that new legislation specifically recognises and promotes informal support networks. Australia has made some progress in this regard in Sections 4 and 5 of the *National Disability Insurance Scheme Act 2013* (Cth), which emphasises that the role of informal supporters should be recognised and respected.

International examples demonstrate what an effective balance between formal and informal decision-making models may look like, and how that balance could be maintained.

Overseas jurisdictions which have adopted formal supported decision-making have not mandated that all arrangements be formalised; informal measures continue, with formal

² United Nations, *Convention on the Rights of Persons with Disabilities*, (2006) Article 12.

arrangements only arising where certain conditions are met. For example, in Alberta, Canada, a court will only impose formal supported decision-making if it is satisfied that less intrusive and restrictive measures have been considered and are unlikely to be effective.³

Question 5.2: Key features of a formal supported decision-making model

1. *Should NSW have formal supporters?*

MNCCLC and DA understand that supported (or assisted) decision-making is less restrictive on the autonomy of the individual than co-decision-making. A supporter will assist the individual by collecting information needed to make the decision. They will communicate that information to the individual in the most appropriate way for that individual. The supporter will then help the individual communicate their decision to third parties. The decision is therefore the individual's decision.⁴

Our organisations submit that the principles of supported decision-making should be articulated in NSW law. However, this does not mean that the roles and responsibilities of a formal supporter must be legislated. It is of key importance that the principles articulated by the Australian Law Reform Commission⁵ are integrated into NSW law.

As every individual with impaired capacity experiences and articulates his or her will, preferences and needs in different ways, the law should not prescribe a format to which supporters must adhere.

Case study MNCCLC

B was a client of MNCCLC and attended a drug and alcohol clinic. The clinic applied to NCAT to have B placed into a mental health facility. B wanted to avoid this outcome. B had some difficulties remembering information such as Tribunal dates.

In this case, a supporter could assist B through the process, and give B the opportunity to discuss aspects of the application with someone acting in B's best interests.

³ *Adult Guardianship and Trusteeship Act 2008* (Alberta, Canada).

⁴ Shih-Ning Then, "Evolution and Innovation in Guardianship Laws: Assisted Decision-Making" 35 *Sydney Law Review* 133, (2013) 149-151.

⁵ Australian Law Reform Commission, *Equality, Capacity and Disability in Commonwealth Laws: Summary Report*, (2014) 19-29.

This approach would allow individuals to use different support arrangements for different decisions, with flexibility and autonomy preserved to the extent possible. Considered this way, either the Tribunal or the supported individual would be able to appoint a formal supporter.

Case study MNCCLC

X has an intellectual disability. X was a client of MNCCLC. A financial management application for X was made to NCAT. Rather than appointing a financial manager, NCAT decided that X's mother could continue with informal arrangements to manage X's finances.

In this case, appointing X's mother as a formal supporter would enable X to maintain autonomy over X's financial affairs, but with the recognition that X's mother has a formal role in assisting X to make those decisions. This would give X's mother the ability to interact with other parties (for example, telephone services or banking services) to get more information to assist X in decision making.

2. *If so, should NSW permit personal or Tribunal appointments, or both?*

MNCCLC and DA consider that NSW should permit both personal and Tribunal appointments of formal supporters. It may be that formal Tribunal appointments would be more acceptable to other parties such as service providers or companies.

3. *Should NSW have formal co-decision-makers?*

MNCCLC and DA understand that co-decision-making involves more external intervention and less individual autonomy than other forms of supported decision-making.⁶ This is because a co-decision-maker's primary function is to make decisions jointly with the individual, which may require the individual to compromise his or her wishes.

⁶ Victorian Law Reform Commission, *Guardianship Final Report 24*, (2012) Ch 9, 9.3.

Our organisations submit that whilst formal co-decision-making may appear useful for many people, in practice, this model may be of limited value. We understand that co-decision-making demands accountability and management skills at levels similar to substitute decision-making. This may necessitate the imposition of more onerous responsibilities on co-decision-makers, thus reducing the popularity of co-decision-making compared to alternative models.

Co-decision-making recognises that many people do not fall within neat categories of either possessing or lacking legal capacity. It can be considered an additional 'step' in supported decision-making, which allows for individuals' prolonged involvement in decision-making where their capacity has diminished.⁷

Should the Commission consider formal co-decision making, we submit that as this arrangement is more complex than that of supported decision-making, there could potentially be confusion between these new legal appointments. We would also anticipate that problems in the interaction between (for example) Power of Attorney appointments and co-decision maker appointments might lead to confusion in the community

Another concern held by MNCCLC and DA is around the level of liability which a co-decision-maker may incur in agreeing (or disagreeing) with a decision made by the supported individual. If the result of the co-decision-making process is entry into a contract which is subsequently disputed, will the co-decision-maker assume joint liability for that contract?

For these reasons, our organisations believe that formal co-decision making will not add significant benefit to people with impaired capacity.

⁷ Office of the Public Advocate of South Australia, *Promoting Rights and Interests: Supported Decision-Making*, Annual Report 2012-2013, 52.

Question 5.3: Retaining substitute decision-making as an option

1. *If a formal supported decision-making framework was adopted, should substitute decision-making still be available as an option?*

MNCCLC and DA do not consider it appropriate for the potential adoption of a formal supported decision-making framework to supersede entirely the substitute decision-making model currently operating in NSW.

It is possible for a proposed framework to address circumstances in which total support (or the equivalent of substitute decision-making) is required, in which case the retention of substitute decision-making may be unnecessary. However, if the supported decision-making model did not extend this far, there would be merit in retaining substitute decision-making as an option.

It is not uncommon for individuals to require or desire total support (involving total abdication or delegation) for some or all of their decisions. These needs inform and underpin the existing legislation. It is not necessarily the case that the adoption of a rights-based approach to decision-making requires the complete dissolution of the substitute decision-making concept.

Retention of substitute decision-making may also serve to clarify the difference between supported decision-making and substitute decision-making, thereby enabling these arrangements to be more easily interpreted and implemented by Courts, Tribunals and individuals.

2. *If so, in what situations should substitute decision-making be available?*

In some circumstances, substitute decision-making may be the only viable option to ensure the protection of an individual's best interests. The most obvious example is where a relevant Court or Tribunal objectively determines that an individual cannot, due to diminished capacity, make an informed decision about something which requires a decision to be made, even if supported by informal networks.

One option would be to define substitute decision-making according to the circumstances in which it is *not* available (or where direction from a Court or Tribunal must be sought⁸), rather than when it is available. Our organisations make this suggestion on the basis that legislation in this space must be open and fluid enough to allow for practical interpretation and application by guardians and supporters, while maintaining a level of specificity to protect against current systemic issues such as exploitation and impingement on individual rights. Focus should be placed on reducing opportunities for abuse of substitute decision-making powers, rather than limiting the extent of such powers themselves.

3. *Should the legislation specify what factors the Court or Tribunal should consider before appointing a substitute decision-maker and, if so, what should those factors be?*

Ideally, the Act should make clear and direct reference to the factors that a relevant Court or Tribunal should consider. Although it may not be possible to provide an exhaustive list, it is imperative that the Act provide clear direction so that Courts and Tribunals can strive to make a fair and a balanced assessment.

General factors to consider include the following:

- Does the individual in question have impaired capacity?
- If so, does the impairment have a substantial impact on the individual's ability to make informed decisions in areas where decisions currently need to be made (for example, accommodation, access to services, medical care, etc.)?
- Is there an actual need for the appointment of a substitute decision-maker at the time that the Court or Tribunal is considering the matter?
- Are there any supported decision-making arrangements already in place which may negate the need for the appointment of a substitute decision-maker?
- Are the types of decisions that the individual needs to make small in scale (for example, choice of weekly social and community activities), as opposed to significant decisions such as consent for a medical procedure, choosing support services or applying for a rental property?

⁸ As per the current *Guardianship Act 1987* (NSW), Part 4.

Once a Court or Tribunal has concluded that a substitute decision-maker is required, additional factors should be considered in determining whether a private or public decision-maker is most appropriate in the circumstances.

Where private individuals are appointed as substitute decision-makers, considerations should include the following:

- The availability of a private individual, such as a trusted friend or family member, to perform the role of substitute decision-maker.
- Any identifiable or potential conflicts of interest which may arise.
- Whether the appointment of a private individual could be detrimental to existing personal relationships (for example, family disputes).

Where a private trustee firm or company is appointed as a substitute decision-maker, the Court or Tribunal should consider the appropriateness of such a firm or company performing the role. Where a public agency is appointed, considerations should include whether any private individuals are available to act in lieu of the agency.

Question 6.2: Eligibility criteria for supporters

What, if any, eligibility criteria should potential supporters be required to meet?

MNCCLC and DA have not identified eligibility criteria for co-decision makers. We suggest that the eligibility criteria for appointing an appropriate supporter should include the following:

- The wishes of the supported individual.
- The desirability of preserving existing family relationships, and other relationships of importance to the supported individual.

- The nature of the relationship between the supported individual and the proposed supporter or co-decision-maker, and in particular whether the relationship is characterised by trust.
- The ability and availability of the proposed supporter or co-decision-maker to assist the individual to make the necessary decisions.
- Whether appointment of the proposed supporter or co-decision-maker poses a conflict of interest in relation to any of the relevant decisions, and whether he or she will make themselves aware of and respond appropriately to any potential conflicts.

Question 6.5: Public agencies as supporters or co-decision-makers

1. *What are the advantages and disadvantages of allowing public agencies to be appointed as supporters?*

MNCCLC and DA have not answered this question with reference to co-decision making models. We submit that a key advantage of allowing public agencies (as opposed to paid workers, organisations or private individuals) to be appointed as supporters or co-decision-makers is that a level of expertise will be ensured. This may avoid issues related to the possible inexperience of service provider staff members or individuals. Further, public agencies are likely to adopt a structured approach to the process and implement policies and guidelines, ensuring a measure of standardisation and transparency.

However, this structured approach may also operate as a disadvantage. In our organisations' experience, formal processes and 'red tape' at public agencies can inhibit the smooth functioning of the existing substitute decision-making procedure. These issues are likely to persist in a supported decision making model.

Another disadvantage is that it is more difficult for large public agencies to form relationships with clients and to develop a full understanding of their situation and needs. In our organisations' experience, especially in rural areas, public agency staff are often not based locally and have minimal contact with clients. This can result in negative outcomes and leave clients feeling misunderstood and unheard. While the nature of supported or co-decision-making may foster closer working relationships between agency staff and clients, these institutional issues are still likely to have some impact. If public agencies were funded

to provide more localized support, they will bring the benefits of transparency and expertise with less of the disadvantages outlined above.

Case study DA

X is a young man with an acquired brain injury and various psychiatric disabilities. There was a Guardianship Order in place for X and substitute decisions were made for him by a public agency. X sought DA's assistance because he was unhappy with his treatment by his guardian. X asserted he had never met his guardian in person. He also could not recall his guardian ever asking him about his life, goals and needs. He was unhappy that his guardian made major decisions for him without consulting him or letting him know what was going on. For example, his guardian told him he would have to move towns, away from his community and family support network. X did not understand the reason for this, despite querying his guardian about the decision.

In light of these significant disadvantages, MNCCLC and DA conclude that public agencies should be appointed as supporters where there is requisite funding to provide time and proximity to develop relationships necessary to underpin successful supported decision making.

Question 6.6: Paid workers and organisations as supporters and co-decision-makers

1. *What are the advantages and disadvantages of allowing paid care workers to be appointed as either supporters?*

AND

3. *What are the advantages and disadvantages of allowing professional organisations to be appointed as either supporters?*

MNCCLC and DA have not answered this question with reference to co-decision making models.

There are important advantages of appointing paid care workers and professional organisations as supporters. Care workers have direct and regular contact with clients. Professional organisations may also be more likely to have a local presence than public agencies. This proximity allows for a closer and more personal working relationship with the individual, resulting in a deeper understanding of his or her situation, wishes and requirements, and thus a more sensitive and informed decision-making process.

Paid workers and organisations are also likely to be more flexible in their decision-making approach, catering for individual needs while ensuring a measure of consistency with codes of ethics and workplace policies. It should be noted, however, that some large not-for-profit organisations may have restrictive procedures similar to those in public agencies, potentially affecting the smooth functioning of the supported or co-decision-making process.

DA has observed several examples of informal supported decision-making by paid care workers operating effectively in practice and delivering positive results for clients.

Case Study DA

A, B and C are siblings living in separate supported accommodation. The three siblings have an intellectual disability, limited literacy and numeracy skills, and are supported by the same disability services provider on a day-to-day basis. Service provider employees help the siblings to make financial decisions about the spending and management of their money. If the subject amount is over a certain figure, DA is called in to discuss the decision with A, B or C and confirm that he or she has expressed an independent desire for the expenditure to occur. Two service provider staff members are also co-signatories on each sibling's bank account. This arrangement has proven successful and satisfactory to A, B and C. The siblings' financial safety is protected whilst their autonomy in decision-making is preserved.

Case Study DA

X is an older woman with an acquired brain injury, who lives in a nursing home. X's sibling had been making financial and other decisions for X for a lengthy period of time. DA became involved in X's situation when several service providers raised concerns that X's sibling was not competently managing her finances and that bills had been left unpaid. X's nursing staff asserted that X did in fact have capacity to make financial decisions however lacked instruction and experience in doing so. Together with DA, nursing home staff worked with X to explain the situation, and supported her to make a decision to pay the outstanding bills by instalments. Afterwards, the nursing staff continued to assist X to make financial decisions autonomously. In this case, the paid care staff had an existing relationship with X, which enabled them to identify her financial needs and help her to exercise her capacity to make decisions.

While such cases illustrate that supported decision-making by care workers can be effective and beneficial, a note of caution in appointing workers and professional organisations is the risk of staff pursuing alternate agendas and acting against the interests of clients. A new atmosphere of competition in the disability sector with the introduction of the National Disability Insurance Scheme ('NDIS') has the potential to exacerbate any problems in this regard.

A lack of monitoring and accountability in some organisations may also leave clients open to exploitation. DA has witnessed instances where care workers wielding significant informal decision-making power have used it to neglect or take advantage of vulnerable clients, or otherwise promote or protect organisational interests. This may be overcome by ensuring that organisations have good policies in place to ensure transparency and accountability.

Case Study DA

A is a middle-aged woman with an intellectual and various other disabilities. She is entirely non-verbal. B is a young man with an acquired brain injury and intellectual disability, who is also non-verbal. Neither A nor B has an appointed guardian, nor any family or informal supports outside of their disability service provider. A and B's group home was scheduled to close, meaning that they would need to select a new residential service. Their existing service provider intended to open a new group home which A and B were invited to transfer to. The service provider requested DA's involvement to ensure that A and B made an autonomous decision about the move and their selection of a new home. While the service provider made a conscious effort to protect A and B's decision-making rights and no abuse occurred, this case highlights the potential power of paid workers and the vulnerability of clients in situations where they lack external support.

The actions of the service provider were important in ensuring that A and B's decision making rights were upheld.

Case Study DA

Z is a middle-aged man with an acquired brain injury, living in supported accommodation. Z is financially managed by a public agency. He has very few people in his life outside of his disability service provider. Z was referred to DA when a holiday was booked for Z and his care worker. The holiday cost a substantial amount of money and would use a large portion of Z's savings. Z had expressed that he was not interested in many of the scheduled holiday activities. DA worked with Z and his financial manager to explain the financial implications of taking the trip and ensure that the decision had not been inappropriately influenced by Z's paid carer.

Question 6.10: Duties and responsibilities of supporters and co-decision-makers

1. *What duties and responsibilities should the law specify for formal supporters?*

The terminology and definitions used in relation to both formal supporters and formal co-decision-makers in the legislation should be consistent with other states and the Commonwealth. This is particularly important with the rollout of the NDIS.

The law should specify that decisions made with the assistance of a supporter are the decisions of the individual, and that the supporter must act honestly, diligently and in good faith.⁹ The law should state that the supporter must only act within the limitations of the supported decision-making agreement, and that a supporter cannot receive any financial remuneration for the performance of the role.

The law should also specify that formal supporters must respect supported individuals' privacy and confidentiality, collect only relevant and necessary information, and only disclose information with the individual's consent.¹⁰ Finally, the law should exclude supporters from liability where they have acted in good faith.

⁹ Ibid., 8.113.

¹⁰ Ibid., 8.108-8.109.

