

21 February 2017

Mr Alan Cameron AO
Chairperson
NSW Law Reform Commission
DX 1227 SYDNEY

By email: nsw_lrc@agd.nsw.gov.au

Dear Mr Cameron

Review of the Guardianship Act 1987 – Question Paper 2: Decision Making Models

NSW Trustee and Guardian (NSWTG) was established on 1 July 2009 by the NSW Trustee and Guardian Act 2009 merging the former Office of the Protective Commissioner and the Public Trustee NSW. The position of Public Guardian (PG) continues and remains separate in its functions but reports administratively to the Chief Executive Officer of NSWTG. NSWTG operates pursuant to the NSW Trustee and Guardian Act 2009 and the NSW Trustee and Guardian Regulation 2008.

NSWTG provides personal trustee, financial management and substitute decision-making services.

NSWTG welcomes the opportunity to contribute to the NSW Law Reform Commission Review of the Guardianship Act 1987. We welcome the move towards legislative and institutional change in line with the Human Rights Principles of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD).

We agree with the concept of building the capacity of persons to make their own decisions about various aspects of their life.

Responses to Question Paper 2 are set out below.

Questions

A formal supported decision-making framework for NSW?

Question 5.1: Formal supported decision-making

(1) Should NSW have a formal supported decision-making model?

In one form or another, in everyday life, family and friends assist in the making of decisions respecting the practical elements of supported decision-making such as personhood, will and preferences of the individual and supporting autonomy in the development of decision-making abilities. Informal supports can work well and many do not need to be formalised however there are advantages to formally recognising agreements, for example, the need to access financial and medical information of the person.

NSWTG supports a formal decision-making model and proposes that a decision-making framework is developed based on decision-making principles. Everyone has the right to make their own decisions and to receive whatever support they need to make those decisions.

A formal supported decision-making framework would ensure consistent application of and access to supported decision-making.¹ Formalising agreements should give status to decisions made using such agreements and codifies the duties of supporters to the person supported.²

The framework should describe both the formal and informal implementation of supported decision-making and the role of supporters.³

The model should be based on guiding principles⁴, namely:

- Everyone has the right to make decisions that affect their life and to have those decisions respected.
- Persons who may require support in decision-making must be provided with the support necessary for them to make, communicate and participate in decisions affecting their lives.
- The will, preferences and rights of the person who may require decision-making support must direct decisions that affect their lives.
- Decisions, arrangements and interventions for persons who may require decision-making support must respect their human rights.

Formalising agreements will provide another option to Guardianship Orders by supporting the person with impaired decision-making capacity to make decisions, thereby supporting their autonomy.

NSWTG believes that there should be a legislated requirement that supported decision-making is considered first and that Guardianship Orders should only be made where supported decision-making is not possible.

¹http://www.mhcc.org.au/media/75190/sdm_national_framework_discussion_paper_final.pdf?_cldee=bWFuZHIAYWN3YS5hc24uYXU%3d

² Supported Decision Making: A Case for Change, John Brayley.

³http://www.mhcc.org.au/media/75190/sdm_national_framework_discussion_paper_final.pdf?_cldee=bWFuZHIAYWN3YS5hc24uYXU%3d

⁴ <http://www.alrc.gov.au/publications/equality-capacity-disability-report-124>

(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?

It is preferable for a person with decision-making disability to have in place informal supported decision-making arrangements with family and/or friends rather than resorting to formal arrangements. If the informal support is working well, such supports should not be unnecessarily formalised as this will create an added burden for the supported person and the supporter.

If there were to be a formal supported decision-making model, the framework should articulate a common understanding of supported decision-making which will enable consistent, repeatable and accessible practice throughout Australia.⁵ The aim is to give structure and formality to informal decision-making, through negotiated support of decision-making agreements.

The legal framework should also contain safeguards to protect the person from abuse and undue influence.

Decisions of a more serious nature could be recorded in formal decision-making documents.

Both informal and formal arrangements should be entered into by agreement between the person seeking support and the person supporting.

Acknowledgement of informal supports should be written into legislation so that services and the community accept such agreements are valid. Legislative recognition of the role of informal arrangements is a step towards acknowledging and building a person's decision-making capabilities.

(3) If there were not to be a formal supported decision-making model, are there any ways we could better recognise or promote informal supported decision-making arrangements in NSW law?

Informal arrangements are already happening. They need to be recognised as part of our thinking. It is onerous and unrealistic to expect all support arrangements be provided through formal supported decision-making agreements.⁶

NSWTG is of the view that recognition of informal arrangements could be acknowledged in legislation through statements and principles contained within legislation as is the case in the Queensland Guardianship Legislation and the Commonwealth NDIS Act⁷ where the law recognises the role of an individual's personal network of family and friends assisting in decisions.

Whilst allowing the individual the freedom to make decisions, one of the potential negatives is that informal arrangements create opportunity for

⁵http://www.mhcc.org.au/media/75190/sdm_national_framework_discussion_paper_final.pdf?_cldee=bWFuZHIAYWN3YS5hc24uYXU%3d

⁶ Supported Decision Making: A Case for Change, John Brayley

⁷ <http://pearl.staffingoptions.com.au/Article/Index/1090>

misreading wishes and for potential abuse.⁸ To protect from potential conflict of interest and abuse, mechanisms to deal with such issues would need to be written into the legislation.

Institutions like banks, social security, insurance bodies etc. should acknowledge the role of the supporter. This can be done by changing the wording of forms to include a nominated person i.e. the “nominee”. This would also require education so that the organisation accepts the role of supporters, for example, meeting with the family, accepting a letter by a solicitor advising the role of the supporter and the need to accept decisions put forward by supporters⁹ so as not to cause unjustifiable hardship to the person.

Educating health professional, organisations and the broader community regarding informal support arrangements is also key to the acceptance of such arrangements.

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

(1) Should NSW have formal supporters?

Yes. There should be an avenue where there is recognition of the agreement reached with the aid of a supporter; an acknowledgement that the decision is that of the person and not a substitute decision. This is a way of claiming back rightful authority and the agreement is a marker of this.¹⁰

(2) If so, should NSW permit personal or tribunal appointments, or both?

NSWTG is of the view that NSW should permit both personal and tribunal appointments.

On a practical level, any person should be able to choose someone to assist them with day-to-day decisions. Done well, family and friends can assist the person to make decisions whilst respecting the person’s will and preference and supporting autonomy in the development of decision-making skills.

Tribunal appointments could be a secondary option where the Tribunal could consider the appointment of a support person thereby minimising the need for a substitute decision maker appointment.

More formal approaches will be required in decision-making when interacting with institutional legal requirements for example, to meet the needs of health care or financial institutions for clarity, certainty and accountability.¹¹

⁸ *Supported Decision Making as an Alternative to Guardianship Orders: The South Australian Trial* Mary-Ann De Mestre, accessed at: <http://www.austlii.edu.au/au/journals/ElderLawRw/2014/10.html>

⁹ http://www.idrs.org.au/pdf/Guardianship_and_administration_laws_across_Australia_by_Ben_Fogarty.pdf

¹⁰ Supported Decision Making: A Case for Change, John Brayley.

¹¹ <http://www.lco-cdo.org/en/capacity-guardianship-discussion-paper-partIII-sectionI>

In Yukon and Alberta, adults may execute personal appointments in order to formalise the role of their informal supports to decision-making. In Yukon's *Adult Protection and Decision-Making Act*, the purpose of supported decision-making agreements is explained as follows:

Part 1- Supported Decision-Making Agreements

- a) *to enable trusted friends and relatives to help adults who do not need guardianship and are substantially able to manage their affairs, but whose ability to make or communicate decisions with respect to some or all of those affairs is impaired; and*
- b) *to give persons providing support to adults under paragraph (a) legal status to be with the adult and participate in discussions with others when the adult is making decisions or attempting to obtain information.*

In both jurisdictions, a supporter is prohibited from making decisions on behalf of an adult, and a decision made or communicated with assistance is considered a decision of the adult. An adult's decision-making capacity is explicitly preserved.

In Alberta, an adult must have capacity to make his or her own decisions before receiving assistance. The process is recommended only for "capable individuals who face complex decisions, people whose first language is not English and people with mild disabilities". In Yukon, "[t]hese agreements are for adults who can make their own decisions with some help".¹²

(3) Should NSW have formal co-decision-makers?

NSWTG does not favour the appointment of co-decision makers. We are of the view that there is a potential for a power imbalance between the co-decision maker and the person needing support. It is possible that a co-decision maker will behave in a manner likened to a substitute decision maker. Also, such arrangements may be over complicated – whose decision is it?

However, if a co-decision-making model is to be considered, we believe that such appointments should only be made where the person needing support agrees with the appointment and further, that such appointments can be revoked by the person at any time.

Also, the question of liability must be considered. Will the co-decision maker be liable for any agreement made together with the supported person?

(4) If so, should NSW permit personal or tribunal appointments, or both?

NSWTG does not support the co-decision-making model.

(5) What arrangements should be made for the registration of appointments?

¹² <http://www.lco-cdo.org/en/capacity-guardianship-discussion-paper-partIII-sectionI>

Informal appointments will continue to occur regardless of a requirement for registration.

It has however been argued that informal decision-making arrangements should not be recognised unless firstly registered.¹³ Such registrations will assist investigations of inappropriate behaviour by supporters¹⁴ and will safeguard to protect the person from abuse and undue influence.¹⁵

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?

NSWTG is of the view that there will be situations where a substitute decision-maker will be required where all other support options are not suitable or not available.

In these situations, a supported decision-making model will not be possible especially when a person's will and preference cannot be determined due to the person's lack of capacity. In this case, the person must be protected from exploitation or from imminent risk.

As decision-making capacity can be decision specific, even in a substitute decision-making arena and wherever possible, support should be given to a person requiring it for any decision being made at any given time.

(2) If so, in what situations should substitute decision-making be available?

Substitute decision-making should be available in situations where a person is, for example, in a vegetative state and is unable to make decisions even with appropriate supports. It is in these situations and after all other avenues to support the person have been exhausted, substitute decision-making will be required.

Substitute decision-making should be available where a person does not have capacity to make a decision either permanently or temporarily. Where a person is being abused, intimidated, coerced or neglected. Also in situations where a person cannot articulate their will and preference, for example, they are in a coma.

(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?

The legislation should provide guiding factors to consider, for example:

- does the person lack capacity?
- is there a need for the appointment of a substitute decision maker?

¹³ Victorian Law Reform Commission, Guardianship, Final Report No 24 (2012) [8.123], [8.124].

¹⁴ Barbara Carter, Supported Decision-Making: Background and Discussion Paper (November 2009) Office of the Public Advocate, Victoria, 22.

¹⁵ Ibid

- the suitability of the substitute decision maker
- have other informal supports been explored?
- are any informal supports (if any) inadequate and/or inappropriate?
- what types of decisions need to be made?
- consideration of the person's will and preferences
- a process for reviews and revocation of appointments.

A substitute decision maker should not be appointed if there are other less restrictive measures available. The appointment of a substitute decision maker must be the option of last resort, limited in scope and time and must be reviewable.¹⁶

Question 5.4 Other Issues

NSWTG is of the opinion that powers of attorney and enduring guardianship instruments should be widely promoted including education and promotional talks and seminars.

NSWTG has endeavoured to do so with campaigns as "*Get it in Black and White*" to promote the importance of such documents.

6. Supporters and co-decision-makers

Question 6.1: When supporters and co-decision-makers can be appointed

(1) What requirements should be met before a person needing support can appoint a supporter or co-decision-maker?

NSWTG is of the view that the starting position is that the person requiring support must be of legal age and presumed to have capacity. The person should also have an understanding, even if in a general way, of the areas they are requiring support.

The person needing support should also have an understanding of the role their supporter plays and similarly, their supporter should also understand their role of supporter, being a person who "supports" the person to make a decision as distinct from a substitute decision maker.

In this regard, education and training may overcome any confusion relating to the role of the supporter.

Consideration must also be given to any potential conflict of interest especially in the context of co-decision makers.

(2) What requirements should be met before a court or tribunal can appoint a supporter or co-decision-maker?

Generally, in making an appointment the court must consider:

¹⁶ ALRC Safeguards Guidelines accessed at: <https://www.alrc.gov.au/publications/safeguards>

- Is there a need for such appointment?
- is the person's decision-making capacity compromised?
- that no less restrictive options are available;
- if the adult's capacity is impaired, can the adult still make decisions if given support.
- do both the person needing support and the supporter consent?

Question 6.2: Eligibility criteria for supporters and co-decision-makers

(1) What, if any, eligibility criteria should potential supporters and co-decision-makers be required to meet?

Potential supporters would need to meet the following criteria, They must:

- respect and value the supported person's autonomy and dignity
- know the supported person's goals, values and preferences
- form a trusting relationship with the supported person
- be willing in the role of supporter, to fulfil their duty to the supported person, and not use this role as a way of advancing their own interests or any other person's interests
- be able to spend as much time as is required to support a person make each decision.

Question 6.3: Characteristics that should exclude potential appointees

(1) What, if any, characteristics should exclude particular people from being supporters or co-decision-makers?

Those who push their own views regarding what they feel is in the best interests for the person needing support rather than building up the person's decision-making capabilities and determining the person's will and preference.

Those persons who may exude dominance creating a potential conflict relationship, undue influence, abuse and/or exploitation should also be excluded. Also, the support person must be in a position to dedicate sufficient time to the person needing support.

Question 6.4: Number of supporters and co-decision-makers

(1) What limits, if any, should there be on the number of supporters or co-decision-makers that can be appointed?

Just as a person may call on the support of various people, there should not be a limit on the number of supporters. Different supporters can cover different areas of the person's life decisions based on their expertise.

More than one supporter could create natural checks and balances of other supporter/s.

It must be said however that too many supporters may cause confusion and therefore there is an argument to limit support persons for this reason.

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 or co-decision-makers?

Some advantages are that public agencies are regulated and conduct internal checks and balances as a result of their internal procedures.

Public agencies do not know the person well i.e. their likes, dislikes, beliefs and behaviours. They may be impersonal and impatient and personal biases can filter through. Public agencies would need to be resourced to carry out this role.

(2) In what circumstances should public agencies be able to act as supporters or co-decision-makers?

NSWTG is of the view that public agencies could act as supporters where the person does not have any family or friends to fit this role. This could potentially occur where there is no one suitable or the potential support person has expressed they do not wish to take on the role.

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 or co-decision-makers?

NSWTG is of the view that paid workers should not be eligible due to the potential for conflict of interest, exploitation and abuse.

Whilst we do not favour this approach, there are people who rely on paid supports and who develop close relationships akin to friends e.g. dementia support workers. Paid workers have the benefit of training and abiding by a code of conduct of employment.

(2) In what circumstances should paid care workers be appointed as supporters or co-decision-makers?

NSWTG is of the view that paid care workers are not the best option to act as support persons as there is the potential for conflict of interest.

However if this is to be considered, there may be circumstances in which a paid carer may be appointed as a supporter, particularly where the person does not have family support or is socially isolated. The paid worker may in fact be the closest person to them who has some understanding of the person requiring support.

(3) What are the advantages and disadvantages of allowing professional organisations to be appointed as either supporters or co-decision-makers?

Professional organisations provide structure, checks and balances, procedures and training for staff. However professional organisations could be detached from the person needing support. They may undergo frequent staff changes thereby never truly connecting with the person needing care.

(4) In what circumstances should professional organisations be appointed as supporters or decision-makers?

Professional organisations could be appointed where the person does not have any suitable person who can fit this role.

This may be useful for those professionals working in particular industries e.g. psychiatric health, may have a better understanding of dealing with people facing such difficulties and the best way to support them.

Question 6.7: Volunteers as supporters and co-decision-makers

(1) What could be the advantages and disadvantages of appointing community volunteers as supporters?

Community volunteers would be an option where all other supports have been exhausted.

Volunteers may assist participants to build their capacity to make autonomous and informed decisions rather than having other people determine what is in their “best interests”.

Another benefit is that volunteers would undergo a police check.

However, the recruitment of suitable volunteers would be costly and time consuming. The person chosen would need to be a good “fit” with the person needing support and be able to be in the role of support person for an extended period. Furthermore, the volunteer would require ongoing education. Lack of resources e.g. time, staff, training could also be barriers to the success of volunteer programs.

(2) What could be the advantages and disadvantages of appointing community volunteers as co-decision-makers?

Community volunteers would be carrying out this role as something they believe in as opposed to paid care workers or other paid supporters. Therefore it would follow that their motives are authentic and they have a genuine desire to help the person.

As a negative, it may be difficult to enlist volunteers particularly for long periods. They may lose interest in their role.

The cost of ongoing education and limited resources is also a drawback of volunteer programs.

(3) In what circumstances do you think community volunteers should be appointed as supporters or co-decision-makers?

Where current supports are taking on more of a substitute decision-making role or where the persons needing support do not have anyone they can trust and depend on.

Question 6.8: Powers and functions of supporters

(1) What powers and functions should the law specify for formal supporters?

Supporters should at all times support the person determine their will and preferences and build their decision-making capabilities. They should assist the person in coming to a decision by weighing up options, leading to a decision and communicating the decision. Supporters should respect the person's private information. An appropriate balance must be struck between the client's right to privacy of their personal information and the need to share the information with others (including family members, support people or other service providers).¹⁷

(2) What powers or functions should the law specifically exclude for formal supporters?

Formal supporters should not be able to make decisions on behalf of the person requiring support without their explicit consent whether the decisions are of a financial or personal nature.

Question 6.9: Powers and functions of co-decision-makers

(1) What powers and functions should the law specify for formal co-decision-makers?

NSWTG is of the view that co-decision-making creates an inherently unequal partnership. The co-decision-maker may heavily influence the decision of the individual thereby acting as a substitute decision maker in the guise of a co-decision maker. This model raises the potential for abuse.

If this model is adopted and should a person choose a co-decision maker, the law should specify the process for the person needing support to revoke the agreement if they feel pressured or no longer wish the agreement to continue. Also, with whom does the responsibility for decisions lie? What responsibilities would third parties have if there is confusion regarding who is making the decision – the supported person or the co-decision maker?¹⁸

(2) What powers and functions should the law specifically exclude for formal co-decision-makers?

Should this model be adopted the co-decision maker should not assume the role of a substitute decision maker. The person should assist in the making of the decision with the full knowledge and consent of the person requiring support. They must not obtain, use and/or forward information to third parties without consent.

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

¹⁷ <http://www.communitydoor.org.au/how-to-hear-me/working-well-with-family-paid-workers-and-other-significant-support-people>

¹⁸ <http://www.lco-cdo.org/en/capacity-guardianship-discussion-paper-partIII-sectionI>

(1) What duties and responsibilities should the law specify for formal supporters?

The law should include key concepts of supported decision-making starting from the position that the person is presumed to have capacity.

The supporter:

- Is to determine the person's will and preference
- must assist the person in their decision-making process including advising the individual by providing relevant information and explanations
- should build the decision-making capability of the person requiring support
- should provide an avenue to access or obtain information relevant to the person, or assist the individual in doing so;
- should communicate or assist the person in communicating the decision to others;
- should endeavour to ensure that the decision is implemented;
- must not exert undue influence
- must not act in a manner which is fraudulent, or misrepresent the facts to the detriment of the person needing support
- must seek the consent of the person needing support especially where information regarding the supported person is sought.

Any decisions made under conditions of undue influence, fraud or misrepresentation are not to be accepted as a decision of the supported person.

(2) What duties and responsibilities should the law specify for formal co-decision-makers?

NSWTG is of the view that the same considerations outlined in 6.10 (1) applies to co-decision makers.

(3) What duties and responsibilities should the law specifically exclude for formal supporters and formal co-decision-makers?

Formal supporters and formal co-decision makers should not make decisions for the person requiring support. The formal supporters should not step into a paternalistic role.

Importantly, the consent of the supported person is required at all times particularly when obtaining and releasing information about the supported person to third parties.

Yours faithfully



Damon Quinn
Chief Executive Officer
NSW TRUSTEE AND GUARDIAN