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NSW Law Reform Commission Review Guardianship Act 1987 (NSW): Submission Question Paper 2: Decision Making Models

The Mental Health Coordinating Council (MHCC) is the peak body representing mental health community managed organisations (CMOs) in NSW. We provided a preliminary submission in March 2016 and a second submission to the earlier Questions Paper in August 2016. We thank the NSW Law Reform Commission (NSWLRC) for inviting us to comment on this second question paper review made public in November 2016.

Questions

5. 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?

MHCC propose that there is no 'one-size fits all' model. What we deem critical is that supported decision-making (SDM) principles are determined, and that a framework is developed and established from which a supporter/facilitator can draw upon, when supporting an individual, according to need. The framework should be considered as a best practice approach informed and underpinned by a human rights approach and principles as defined by the ALRC in the National Decision-Making Principles:¹

Principle 1: The equal right to make decisions

- All adults have an equal right to make decisions that affect their lives and to have those decisions respected.

Principle 2: Support

- Persons who require support in decision-making must be provided with access to the supports necessary for them to make, communicate and participate in decisions that affect their lives.

Principle 3: Will, preferences and rights

- The will, preferences and rights of persons who may require decision-making support must direct decisions that affect their lives.

Principle 4: Safeguards

- Decisions, arrangements and interventions for persons who may require decision-making support must respect their human rights.

¹ ALRC National Decision-Making Principles. Available: <https://www.alrc.gov.au/publications/national-decision-making-principles>.

The Mental Health Coordinating Council have been developing professional training targeted specifically for the community mental health and disability sectors working with people living with mental health conditions and coexisting cognitive functioning difficulties. We have developed a visual that we believe is broadly applicable in looking at how SDM sits in a broader context, across service settings and including the people who are part of the individual's informal support networks (e.g. carers and family members).



Source: Copyright © Mental Health Coordinating Council, 2016, Supported Decision-Making: Choice and Control in Recovery, Professional Development Training, MHCC Learning & Development, Sydney: Australia.

MHCC's stakeholders' interests may vary in relation to other disability groups, and the corresponding support skills required and special features of a framework will naturally differ. It is only the underlying philosophy and principles that should span across the different interest groups.

Therefore, we strongly advocate that SDM principles be acknowledged in the Act as encompassing what we propose constitutes a best practice approach. This would enable NSW legislation to align with the UNCRPD, and provide an opportunity for NSW to be a signatory to the Optional Protocol, and meet the necessary obligations that this entails. Nevertheless, we acknowledge there is only anecdotal evidence of SDM as best practice, rather than robust research evidence of evaluation and outcomes.

We agree that appropriate skills and competences are developed in the community underpinned by service delivery policy, protocols and standards and appropriate monitoring safeguards, and that where possible the law need not be utilised.

(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?

Following on from question (1) MHCC do not support a formal supported decision-making model per se.

Nevertheless, as already indicated, there should be a framework and guidelines from which those seeking to facilitate SDM can draw upon to assist the people they support. However laws and legal frameworks must contain appropriate and effective safeguards in relation to any interventions on behalf of persons who may require decision-making support, including to prevent abuse and undue influence.

We propose that the National Decision-Making Principles should be embedded in the legislation to ensure that:

- supported decision-making is encouraged;
- representative decision-makers are appointed only as a last resort; and
- the will, preferences and rights of person's direct decisions that affect their lives.

MHCC propose that particularly in the context of the *National Disability Insurance Scheme Act 2013* which "enable(s) people with a disability to exercise choice and control in the pursuit of their goals and the planning and delivery of their supports", that SDM is promoted through service delivery organisations; and that a strategy that includes community development, education and culturally diverse ways of communicating the necessary information be high on the NSW Government's agenda in order to ensure that the community understands what SDM is and where and how it can be accessed.

(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 measures supporting SDM could be recognised in the legislation as it is in the UK in their *Mental Capacity Act 2005* (UK) and the *NDIS Act 2013* in Australia, in the same way that the 'Recovery approach' is acknowledged in the *NSW Mental Health Act 2007* (NSW).

Likewise, whilst remaining informal, it is necessary that a safety and monitoring mechanism be established to ensure that support facilitators understand their role and that those they support are adequately protected. There could, for example be guidelines that provide for scrutiny of conflicts of interest that may arise between disability service staff and informal supporters. In this way understanding of the 'relationship/role' would be clear, while the SDM model could remain responsive to specific needs and contexts. For example where normally an informal supporter may not have access to what might be thought as confidential information.

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

(1) Should NSW have formal supporters?

An independent body should be established under the Ombudsman/ Attorney General / or NCAT. People requiring assistance, their carers or support workers could apply on a basis of assessed need/merit.

Several states (WA, Qld, SA, Vic) have an Office of the Public Advocate, all of which appear to take on a broader role than exists in NSW. A Public Advocate has a role in plugging some of the gaps that exist in a NSW context, e.g., dealing with complaints, mediation/ resolution services, research projects and community education, publications and resources etc.

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

Both. Support workers could play a significant role if suitably trained and skilled, and be appointed personally or by a tribunal whilst in the role as a support facilitator to an individual. The independent body could appoint support facilitators; and workers could acquire this "qualification" or "appointment", once having completed a training program. Part of accreditation could be to receive ongoing SDM 'practice supervision'. Nevertheless, we recognise how difficult it would be to regulate an activity that in the mental health sphere is central to the work of a mental health rehabilitation worker. The only way of protecting people from abuse and ensuring that informal supporters act appropriately, is likely to be reflected in the provision of quality and safety guidelines underpinned by best practice principles.

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

MHCC assume that what is meant by co-decision making is what is otherwise known as '**shared decision-making**' which involves the integration of a person's values, goals and concerns with the best available evidence about benefits, risks and uncertainties of for example, health care treatment and day-to-day decisions. It involves making decisions with 'a trusted other', who may be a carer, family member or a worker. In partnership, a person can flesh out the likely benefits and disadvantages of their options and be assisted to communicate their preferences, and select the course of action that best fits their needs.

When done well, this can be an exceptionally helpful process. However, it is easy for shared decision-making to become 'proxy decision-making' where the support person makes a decision for the individual. The primary distinction between shared decision-making and proxy decision-making is that the individual retains control of the decision-making process. In proxy decision-making, this control is not retained by the individual.

We understand that in a number of international jurisdictions that this has been introduced as a formal scheme additional to substitute decision-making. In some places the potential risk of inappropriate influence is mitigated by a review officer who is tasked to report on potentially unsuitable appointees.

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

MHCC see no problem in providing a wider range of options, providing safety mechanisms are in place; and that the appointee fully understands their role and the principles and guidelines that underpin their practice. It is important for individuals to be able to personally nominate a co-decision-maker (CDM), but our preference would be for independent CDMs to be appointed by a Tribunal or Independent Statutory Body.

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

We note that some jurisdictions require appointment by a court. We think this limits the breadth of decisions, projecting a legal lens on decision-making. Many decisions people require assistance with are day-to-day and personal. Our preference would be for a model similar to that which has been established in Ireland, where personal appointments can be made, but appointees must be registered to have effect. However, we appreciate that it may not be practical, and that

establishing mandatory appointments may then limit choice and flexibility. It is likely that informal arrangements will always occur whatever registration formalities are put in place.

Where a person's capacity to appoint an individual supporter is in question, a tribunal or other independent body should have the power to appoint that individual. This may be necessary for example when a person suddenly becomes unwell, but where it is undesirable to appoint a substitute decision-maker; or where a person is able to exercise limited autonomy. We agree with the suggestion from the Victorian Law Reform Commission that appointment should only be made with consent which can be revoked by the person needing decision-making assistance.

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?

In our view there are always circumstances in which substitute decision-making may be necessary, especially where a person needs to be protected. Whilst we totally endorse the preference for supported decision-making, substitute decision-making is characteristically decision specific, unless a person is in a coma or vegetative state. Therefore, a person should have access to appropriate support that is fit for purpose. This may result in a number of people providing different levels of support as required. Apart from there being a 'no one size fits all' model, there is also a need to maintain flexibility in order to maximise self-determination and autonomy as different circumstances present.

It might be that in NSW in the future, the role of the Public Guardian in relation to substitute decision-making could shrink. Since substitute decision-making should always be a position of last resort, and supported decision-making should become more broadly available. If this occurs, we could see the PG playing a valuable role in that space. The desirability of a step-up-step-down process, where a person could have access to the PG providing a supported decision-making role, which could be stepped-up once they had established a relationship with the client, if that was necessary and conversely stepped-down if the PG assessed that the person required something less or in-between, using a shared / co-decision-making arrangement.

Such a model could provide an opportunity for clients to learn how they might make decisions with support, or have a co-decision-maker work with them, rather than immediately go to a full guardianship order. MHCC would certainly favour a model that enabled more levels of support for different circumstances and to more fully assess needs at the beginning of the journey. It would also provide an opportunity to assess compatibility of the person supporting the individual.

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

If a person's 'will and preferences' are impossible to determine at the time a decision needs to be made, either as consequence of medical difficulties rendering the person incapable of making a decision (e.g. vegetative state) or by virtue of a continuing condition in terms of the *Mental Health Act 2007* (NSW) the Act; where a person is for example, psychotic or delusional to the extent that they are deemed permanently without capacity to give informed consent or make decisions in their best interests, their 'will and preferences' expressed should always be taken into account, and efforts made to establish preferences expressed at a time when they had capacity.

MHCC note in the discussion paper that several other submissions advocated that substitute decision-making should be available in a number of circumstances including where the person does not have capacity to articulate their wishes. We emphasise here that a broad interpretation of "articulate" must be adopted. By this we mean that there are many ways in

which a person can express their preferences without language, as clearly demonstrated in the work of researchers in the speech therapy field.^{2 3}

We strongly recommend that a diversity of levels of support be available to a person according to their needs and preferences. However, the overarching principle which we endorse is expressed by Martin et al., (2016) when they propose that people must be supported “to exercise their legal capacity even in circumstances when they lack the ability to make the requisite decisions themselves.”⁴

Likewise we agree with the UN Convention Committee that after meaningful and determined attempts have been exhausted and it is “still not practicable to work out a person’s will and preferences.... that a third party’s “best interpretation” of a person’s will and preferences is used instead of a “best interests” test.⁵

(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?

MHCC support the principle that substitute decision-making only be an option of last resort. We also agree with the ALRC Safety Guidelines and IDRS’s suggestions regarding appointments (described in 5.43 & 5.44 respectively).

Question 5.4: Other issues

Are there any other issues about alternative decision-making models you would like to raise?

MHCC are keen to convey an understanding of the particular difficulties for people with mental health conditions who frequently experience coexisting problems including cognitive difficulties. Decision-making is considered to be an advanced cognitive skill that involves a range of other abilities such as concentration, memory, planning, problem solving and the ability to think through future consequences of an action. These difficulties can also influence the beliefs of others about the person’s decision-making ability and a person’s confidence in their own ability to make decisions.

People with mental health conditions experience a diversity of difficulties that characteristically fluctuate and may be not necessarily be permanent. Many research studies have shown that for people with mental health conditions, ‘community functioning’ and participation can be enhanced by improved access to supported decision-making. Supported decision-making can assist a person to live a more independent, dignified and meaningful life. Decision-making is a skill that can be developed and practised with support, which is particularly important in relation to the NDIS and other emerging reform initiatives.

When people can make and implement their own goals their sense of empowerment can significantly affect their ‘world view’.

MHCC strongly advocate that in addition to offering the flexibility of a number of informal types decision-making support. That safety mechanisms be introduced and that persons providing decision-making support along the continuum can be appointed either by the individual or with

² Littlejohn S & Foss K 2008, *Theories of Human Communication* (9th Ed.) Belmont, CA: Thomson Wadsworth.

³ Malkmus DD 1989, ‘Community re-entry: Cognitive-communication intervention within a social skill context’, *Topics in Language Disorders*, 9, 50-66.

⁴ W Martin et al., 2016, ‘The Essex Autonomy Project: Three Jurisdictions Report: Towards Compliance with CRPD Art 12’, in ‘Capacity/Incapacity Legislation across the UK, Position Paper’, (2016) 13.

⁵ United Nations, Committee on the Rights of Persons with Disabilities, General Comment No 1: Article 12: Equal Recognition Before the Law, UN Doc CRPD/C/GC/1 (2014) [20]–[21].

their consent a tribunal or other independent body and that the individual can revoke that consent at any time.

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?

MHCC decline to answer Questions 6.1; 6.1.2 & 6.2. We propose that others are more qualified to respond to these matters.

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

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

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

Question 6.3: Characteristics that should exclude potential appointees

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

- People who have a financial interest/ conflict of interest in the person's assets
- People who have a criminal record, including use of use and misuse of illegal substances, etc.
- People with a record of sexual, physical and emotional abuse.
- People subject to an AVO, whether breached or not.
- People only accessible by telephone, e.g. resident overseas.

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

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

MHCC agree with the ALRC (6.14) in that a person should be able to appoint whoever they want as a supporter. They may have a Guardian appointed to make specific decisions, but they may want other levels of decision-making supporters for different circumstances, and they should be able to appoint such persons whether from their network or an agency, or non-government (community managed) service.

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?

The discussion paper clearly outlines the pros and cons attached to the appointment of both public agencies and volunteers. However, we don't necessarily agree that the risk of conflict of interest is reduced by a supporter being unpaid. Volunteers may represent supports with close personal relationships that cannot be replicated by professional appointments. However, we acknowledge that it is often personal relationships that gives rise to conflict. We recommend that personal choice is paramount and that the person to be supported should be able to exercise their preference, including not to be supported.

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

MHCC would like to make clear that we promote supported decision-making as part of the skill set of the mental health workforce across service settings. The term 'agency' usually refers to public services. We emphasise the need to include the non-government, community managed workforce with regards to appointments/ registration.

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?

MHCC consider SDM as core competences and a part of the skill set required for the mental health community workforce. If a person has established good rapport with their case manager, care coordinator; mental health or disability support worker; peer support worker; consumer advocate, etc., and they want that person appointed, we see no disadvantage to that, except in regards to potential continuity. A paid worker is more likely to move elsewhere to another job, whereas a personal supporter is likely to be more consistently available.

Many people with psychosocial disability are socially isolated and have no natural networks. Paid support workers in either community managed organisations or agencies may be the only people available to these individuals.

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

When the person concerned has a good relationship with a support worker and is comfortable with appointing an independent person to the role. Also where they understand that this role will only operate within the boundaries of that worker's role, time available etc.

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

This question is unclear to us. We assume that what is meant is that a professional organisation, either an agency or organisation, rather than an employee is appointed as the supporter or co-decision maker. In this case, an employee is answerable to his/her employer who in turn has a responsibility to provide safe and best quality services to its clients.

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

The circumstance might be appropriate where a change of staff may occur and a transition period may occur when alternative arrangements need to be made.

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

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

Whilst there is nothing intrinsically wrong with volunteers, and flexibility should be maximised, we are concerned about oversight mechanisms, training and supervision as well as availability. These are all issues that must be duly considered. There should be no difference in the skills of volunteers when performing the same role as a paid worker. If the NSW Public Guardian were able to undertake this role, recruit, train and supervise those selected, we would be much more comfortable about such appointments. A pilot program to evaluate the outcomes of such an initiative would be most valuable. In such a case, it will be particularly important to match volunteers with an understanding of the specific difficulties people experience, e.g., mental

health and coexisting conditions. However, we agree with reservations expressed by the VLRC in this regard (6.13).

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

We propose that the issues are no different. Both roles need to fully understand the principles and boundaries attached to each role. We would be concerned if the role of a supporter was seen as needing less rigour than that of a co-decision-maker.

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

Only if these volunteers have been recruited, trained and receive ongoing supervision and professional development from the Public Guardian or another appointed body, and that they commit to particular availability.

Question 6.8: Powers and functions of supporters

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

MHCC agree that supporters should only have a role in 'personal' matters, this can include legal matters of concern to the person. Support for matters of a 'financial' nature must be oversighted by T&G. However, there is no reason that appointed supporters with the same skill set (recruited, trained and supervised by the T&G) could not be appointed to support people who have capacity to manage financial matters with some assistance.

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

That disclosure of any material accessed for other than the matter under consideration be prohibited, and that this information be securely kept from unauthorised access.

MHCC agree with the VLRC that supporters cannot act on any matter without the knowledge and consent of the person concerned.

Specific powers that a supporter cannot exercise should be listed, such as significant financial transactions, signing documents with legal effect, etc.

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

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

With the consent of the person concerned, a supporter must be able to gain access to personal information, in order to undertake his/her support role. The law must specify what information can be accessed, and how it can be used.

A co-decision-making agreement should specify the areas of shared decision-making, e.g., personal matters including gifts and donations and property matters etc.

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

Co-decision-makers should be prohibited from signing and document unless co-signed by the person they are assisting. If they believe the person they are assisting does not have the capacity to make that particular decision, they must seek some higher authority to approve this decision. Likewise, if they consider the person capable of making the decision in this circumstance, they

would also inform the oversight authority to that end. Also that co-decision-makers cannot act on any matter without the knowledge and consent of the person concerned.

MHCC agree that matters including a person's will, management of their estate after death, voting, marriage and divorce arrangements and adoption should sit outside co-decision-making powers and functions.

Question 6.10: Duties and responsibilities of supporters and co-decision-makers
(1) What duties and responsibilities should the law specify for formal supporters?

It is the duty and responsibility of supporters and co-decision makers to act ethically and ensure that "the wishes and preferences of people with impaired decision-making ability inform decisions made in their lives; that people with impaired decision-making ability are entitled to take reasonable risks and make choices that other people might disagree with; any limitations on the rights and freedoms of a person with impaired decision-making ability to make their own decisions must be justified, reasonable and proportionate" (VLRC)⁶.

Likewise that "people may choose not to be supported; a person's decision-making ability is to be assessed, not the possible outcomes of their decisions; and that a person's decision-making ability may evolve or fluctuate over time" (ALRC).⁷

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

MHCC also agree that "'interventions' must have due regard to the need to respect the right of the relevant person to dignity, bodily integrity, privacy, autonomy and control over his or her financial affairs and property" (Ireland).⁸

Also that a supporter/ co-decision-maker "shall not attempt to obtain information that is not reasonably required for making a relevant decision or use information other than for a relevant decision, and shall take reasonable steps to ensure that information is kept secure from unauthorised access, use or disclosure and is safely disposed of when he or she believes it is no longer required" (Ireland).⁹

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

Any decisions outside of the support or co-decision-making agreement.

When the person assisting does not have the necessary skills and competences to assist, e.g. with financial property matters etc.

MHCC thanks the NSW Law Reform Commission for providing this opportunity to comment on decision-making models in its review of the *Guardianship Act 1987* (NSW). We express our willingness to be further consulted on any matters related to this review and this submission.

⁶ Victorian Law Reform Commission, *Guardianship*, Final Report 24 (2012) rec 21.

⁷ Australian Law Reform Commission, *Equality, Capacity and Disability in Commonwealth Laws*, Report 124 (2014) rec 3-2.

⁸ Assisted Decision-Making (Capacity) Act 2015 (Ireland) s 8(6) (b), s 8(10).

⁹ Assisted Decision-Making (Capacity) Act 2015 (Ireland) s 8(6) (b), s 8(10).

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Yours sincerely,



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