

31 January 2017

NSW Law Reform Commission
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Review of the Guardianship Act 1987, Question Paper 2: Decision-making models

Dear Sir/Madam,

Carers NSW would like to thank the NSW Law Reform Commission for the opportunity to provide a submission in response to *Question Paper 2: Decision-making models* (the paper). Our submission systematically addresses the questions in sections 5 and 6 of the paper. It focuses on the potential for greater regulation and resourcing of supported decision making models to uphold and strengthen the decision making assistance already being provided by many carers informally.

A carer is anyone who provides informal care and support to a family member or friend who has a disability, mental illness, drug or alcohol dependency, chronic condition, terminal illness or who is frail aged. Carers NSW is the peak non-government organisation for carers in NSW and a member of the National Network of Carers Associations. Carers NSW vision is an Australia that values and supports all carers, and our goals are to work with carers to improve their health, wellbeing, resilience and financial security; and to have caring recognised as a shared responsibility of family, community, and government.

Thank you for accepting our submission. For further information regarding this submission, please contact [REDACTED]

Yours sincerely,

[REDACTED]

Elena Katrakis
CEO
Carers NSW



***Carers NSW submission to Question
Paper 2: Decision-making models***

31 January 2017

Section 5: A formal supported decision making framework for NSW?

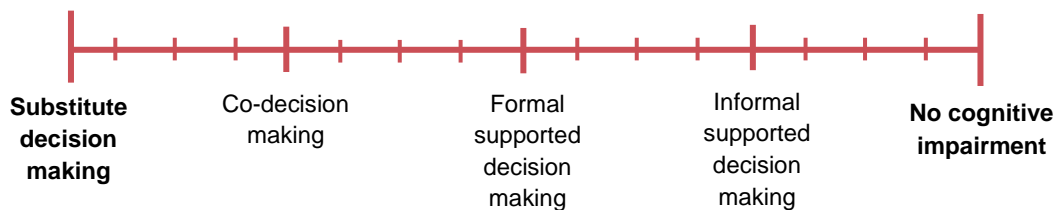
Question 5.1: Formal supported decision-making

Carers NSW believes that the best way to approach supported decision making is to view decision making itself as a spectrum, acknowledging that at times every person, regardless of their cognitive capacity, needs help making decisions. Although guardianship legislation is specifically concerned with persons with reduced cognitive capacity, the level and type of support, and the contexts in which support is required, vary from person to person, vary according to the type of decision that needs to be made and often fluctuate, progress or otherwise change over time and according to the persons' illness or condition.

Rather than retaining the separate categories of substitute decision making, supported decision making (formal and informal) and co-decision making, Carers NSW supports a flexible model that reflects the complexities of providing decision making support, and gives consumers and supporters the right to move across the spectrum as needed. We therefore recommend that the amended legislation reflect something along the lines of what is pictured in Figure 1.

Selena* has two teenage sons who are not able to make decisions independently. She helps by giving them two choices and giving reasons why those choices are preferable. If this fails to engage them, Selena simply makes the choice herself, which seems to alleviate their anxiety.

Figure 1: Decision making spectrum



In every case, the starting point should be the assumption that the person is capable of decision making until there is evidence to the contrary. The framework must uphold individual human rights and start with the least restrictive and least intrusive options, both for their person and for their family and carers. Each area of decision making and each type of decision should be able to be measured with this approach.

In this context, Carers NSW agrees that the amended legislation should allow for formal supported decision making. However, formalisation should not be required, and should only be pursued if existing informal arrangements are for some reason ineffective, and appointing a substitute decision maker inappropriate. For example, many carers providing decision making support express frustration at the lack of recognition and access to information they experience. In such cases, a formalised role may be beneficial.

"The reason for me applying to be my son's guardian was due to the lack of adequate coordination / management of [my son's] care by the community mental health team, and the inability for my views about his treatment to be properly considered." - Carer

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

A formal supported decision making model should:

- a) identify, uphold and support existing informal arrangements that are working well;
- b) provide formal recognition to carers providing decision making support, if desired;
- c) improve access by supporters personal information required to effectively support decision making;
- d) emphasise to professionals and agencies the importance of taking on board information provided by supporters;
- e) provide carers with ongoing information and training on best practice in supported decision making.

Should a formal supported decision making model be implemented, Carers NSW recommends that it represent a whole of government approach across human service agencies, in line with the introduction of person centred care across the federally funded ageing, disability and mental health sectors. This should be accompanied by a renewed commitment to the implementation of the NSW Carers Charter by all human service agencies in NSW, so that the principles of carer recognition and support expressed in the Charter are prioritised.

In examining how formal recognition of supported decision makers might be established within the guardianship legislation, policy makers should look to the *NDIS Act 2013* (Cwth), recently amended *Mental Health Act 2007* (NSW) and the aged care Quality of Care Principles 2014, which allow for 'nominees', 'designated carers', and 'representatives' respectively, hinging in each case on the consumer's nomination. Each of these appointed roles are required to engage the consumer as much as possible in supported decision making.

The current guardianship legislation does refer to an informal hierarchy of who may be considered a 'person responsible', which may form a useful basis for a formal supported decision making model. Providing a consistent register for supporters across the service system, similar to the above examples, would save time for both supporters and third parties with whom they and the consumer are dealing.

Carers NSW believes that, if an individual has the capacity to personally appoint their formal supporter, this form of appointment should be upheld. The tribunal should only be given authority in this matter where there is cause for concern, such as a documented conflict of interest or lack of capacity for the proposed supporter to fulfil that role.

Carers NSW is open to a co-decision making model as part of the decision making spectrum, but we have concerns about the practical elements of requiring two formal sign offs on every decision, and the potential for reaching a stalemate. Co-decision making may, however, be an appropriate option in instances where a decision will have an equal impact on both parties (such as whether or not a person lives with their carer).

Question 5.3: Retaining substitute decision-making as an option

Carers NSW recommends that the option of appointing a substitute decision maker remain on the spectrum of decision making as a last resort for rare occasions when formal supported decision making is too difficult due to the extent of the consumer's reduced capacity, or there is nobody who can adequately perform this role safely and effectively. However, even in substitute decision making arrangements, more flexible, person centred supported decision making processes should be encouraged and resourced.

The appointment of a substitute decision maker should always take into account information and evidence provided by carers as to the needs, function, capacity and behaviours of the person they care for, and any informal techniques or practices that currently work well to support the person to make decisions. Existing arrangements should always be upheld wherever possible to preserve caring relationships and provide continuity and effective support for the person requiring support.

Question 5.4: Other issues

Carers NSW also wishes to emphasise the importance of a holistic approach to 'supporting the supporters'. As the case study below demonstrates, supported decision making can be complex, time consuming and draining, requiring that the supporter possess knowledge, skill, experience and patience. Supporters may require more than simply information and training in the basics of supported decision making to perform their role effectively and maintain their own wellbeing. Their need for ongoing personal development in the role of supporter should be recognised, with emotional and practical support encouraged and resourced as much as possible.

Brian's* wife Marie* lives with a number of mental health conditions that can affect her judgement and coping skills at times. Marie recently decided to travel independently by public transport to an event far from her home. Brian encouraged this and helped her to prepare. Unfortunately, things didn't turn out as planned and Marie was stranded at a country station. When she rang Brian for help, he consciously decided not to simply drive over and rescue her, but to help her work through the situation herself. He asked her to identify the options available to her and helped her to evaluate each option. Together they came to a reasonable solution. When Marie arrived home safely, her self-confidence had increased and Brian was so proud of her. However, Brian explained to Carers NSW that stepping back like this is much harder than stepping in to make the decision himself. In fact, providing this kind of decision making support takes an emotional toll on him and he has learnt he must invest in self-care afterwards for his own wellbeing.

For example, carers may need support and training in self-care to replenish themselves after providing decision making support. Some may need replacement care or respite occasionally to have a break from supported decision making. They may need a peer support group or network with whom to share challenges, successes and techniques. They may need a coach or mentor who can advise and support them as they learn. An independent advocate to help them understand legal complexities and advocate for and with them may be required. Individual or group based counselling to improve resilience may be beneficial.

It should not be assumed that carers have ready access to the kinds of support listed above. Carers are often isolated, financially disadvantaged and unaware of what supports are available. Every effort should be made to connect supporters to existing services if needed, and to provide or advocate for additional services where gaps are identified.

Section 6: Supporters and co-decision-makers

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

Carers NSW agrees with the requirements proposed in the paper. However, of these criteria we wish to emphasise the following:

- that less intrusive and less restrictive measures have been considered and found unsuitable; and
- that the proposed supporter or co-decision-maker consents to the appointment.

The requirements should also ensure that the proposed supporter has the capacity to fulfil the role, including that:

- the role is sustainable for them;
- adequate information, training and support is available to the supporter;
- other caring or informal decision making relationships are not adversely affected.

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

Carers NSW agrees with the eligibility criteria proposed by the paper. The capacity of the supporter to sustain the role and understand the principles of supported decision making should also be considered.

Question 6.3: Characteristics that should exclude potential appointees

Carers NSW agrees with all but one of the exclusions suggested in this section of the paper, however further consideration should be given to the following exclusion:

- “was acting as a supporter or co-decision-maker in their capacity as the person’s spouse, and that relationship has ended”

Family relationships and care relationships are complex and the nature of any relationship can change over time. There are spousal relationships that end amicably and where the ex-spouse is still the person best placed and willing to support the person requiring care. Carers NSW is aware of instances where ex-partners provide ongoing informal care even though their relationship has changed. If a similar exclusion was to be included, it should be generalised to any relationship that has ended or is no longer functioning in the best interest of either party.

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

Nominating multiple supported decision makers should be an option as it would allow supporters to share tasks and skill sets to the benefit of the person being supported. It may also increase the potential for the arrangement to remain sustainable over time. Carers NSW believes the maximum number of supporters should be at the discretion of the tribunal.

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

Carers NSW believes the best supporters are those who have known the person needing support over a number of years, genuinely care for their best interests, understand how they communicate their preferences and have no vested financial interest in their decision making. These people would generally be family member and friends, however there may be some overlap with support workers or community members that have worked with the person before.

Representatives of public agencies are least likely to have built the relationship of trust and understanding required to effectively implement supported decision making, and therefore should only be appointed as substitute or supported decision makers when no other viable options exist. The staff member(s) playing this role should have specialised experience and support and do not have any conflict of interest with the person requiring support. Ideally, the role of supporter should be outsourced to someone such as an independent advocate who can perform this role expertly and with no vested interest.

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

Like public agencies, paid workers and organisations are less likely to have the personal knowledge and trust required to provide genuine supported decision making, and there are more likely to be conflicts of interest. If there are issues with either the decision making or the paid support provided to the person, their ability to make this known is diminished if one person is fulfilling both roles. This increases the risk and vulnerability of the person with disability. Carers NSW is aware that in some instances paid workers do have a strong relationship with their client and are exceptional at delivering person centred care, however ideally, an independent, externally funded advocate would likely provide more reliable support.

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

Like public agencies, paid workers and organisations, volunteers are less likely than family members and friends to have the required relationship of trust with the person requiring support. Volunteer turnover could also be an ongoing issue making it difficult to ensure an adequate, long-term understanding of an individual's needs and means of communicating.

Question 6.8: Powers and functions of supporters

Carers NSW believes supporters should be given legal recognition that enables them to access the information required to support a person to make a particular decision about their life. The permission of the person requiring support should, of course, be part of this process.

Due to the time and effort required to support some decision making, and the potential for techniques to fail at a given time, there should be room in the law to give permission to supporters to revert to substitute decision making in emergencies or other situations that require this authority. This may be especially applicable when the person requiring support has a fluctuating or episodic condition.

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

Please see above.

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

Carers NSW supports the suggestions outlined in this section of the paper.

Carers NSW considers that one of the greatest challenges in implementing a legal supported decision making framework will be its regulation. The law should provide some level of accountability to formal supported decision makers, however Carers NSW reiterates that adequate support must be given to supporters to understand their responsibilities and the weight and potential consequences of their actions in the first instance.

In particular, the allowance for people with impaired decision making ability “to take reasonable risks and make choices that other people might disagree with” is an important element of supported decision making, but has the potential to legitimise decisions that serve in the interests of the supporter only. Alternatively a supporter who genuinely supports a contentious or high risk decision may be less inclined to if their liability risk is too high. One way of mitigating this risk would be to ensure supporters have access to a formal mediator to provide legal support on contentious decisions.

* Names changed