

31 January 2017

NSW Law Reform Commission
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Sydney NSW 2001
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Review of the Guardianship Act 1987, Question Paper 3: The role of guardians and financial managers

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 3: The role of guardians and financial managers* (the paper). Our submission addresses the questions 2.7, 4.1, 4.2, 4.3 and 4.4 of the paper. It supports a succession planning mechanism in the revised Guardianship Act (the Act) and recommends that decision making models remain flexible in order to accommodate for 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,



Elena Katrakis
CEO
Carers NSW

Question 2.7: Should the Act include a succession planning mechanism?

Carers NSW supports the inclusion of a succession planning mechanism in the Act as we believe this will promote stability for both carers and care recipients. Carers regularly express concern about what will happen to their loved one when they are no longer able to provide care. This question is particularly problematic for carers who have no appropriate family member or friend to succeed them.

Many carers plan for the absence of their care only after health or other concerns become apparentⁱ. This lack of planning can restrict the succession options available, reduce the time they have to organise alternative care arrangements, and result in substantial stress and anxiety for the carer.ⁱⁱ Formally documenting succession plans can be a valuable step in avoiding these potentialities and ensuring that any long term plans that have been made, such as transition into a group home, can be seen through to completion once the carer is no longer involved.

Yvonne is 74 years old and cares for her son Joshua,* who has an intellectual disability and mental illness. Yvonne and Joshua access case management and respite services but have no other relatives in Australia. Yvonne is beginning to worry about who will care for Joshua when she is no longer able to.*

Joshua rarely makes his own decisions, but Yvonne feels that as his mother she is well acquainted with what he does and doesn't like. She is afraid that nobody will be available to advocate for Joshua when she is not around, and that the public guardian will not be able to meet his needs.

Carers NSW commends the work done to date by the NSW Government to raise awareness of the importance of planning for the future, and supports this campaign as we work with carers. In particular, our FACS funded Older Parent Carer Support Coordination Program addresses future planning as a critical support we provide to ageing carers. We believe that incorporating a succession planning mechanism into the Act could further these goals.

However, one challenge of including succession planning in the Act would be managing carers' expectations. Many carers provide a type and level of support that exceeds what is available from government funded services, while at the same time being less likely to have acquired the capital to fund additional services in the long termⁱⁱⁱ. One possible solution would involve the Tribunal providing preliminary approval to succession plans in order to determine which aspects of the plan will be reasonable to implement, and the degree of flexibility available to the Tribunal in the event that aspects of the plan are no longer practical or relevant in future.

Question 4.1: What decision-making principles should guardians and financial managers observe?

Question 4.2: Should guardians and financial managers be required to give effect to a person's "will and preferences"?

As outlined in the Carers NSW submission to question paper 2, Carers NSW believes decision making capacity is best represented by a spectrum of required support. Legislation should recognise that capacity can fluctuate depending on the type of decision or level of support and can vary from person to person. Only in rare cases will an individual be entirely unable to express an opinion in all circumstances. Decision making principles should

therefore require that guardians and financial managers involve the person with limited capacity in decisions affecting them. This process would involve elements of supported decision making but should also enable flexibility for guardians and financial managers in instances where substitute decision making is required; for example, where a person's 'will and preferences' contradict their 'welfare and interests', are illegal, or impact adversely on others, such as family or a primary carer. In such cases Carers NSW recommends that decisions should fall on the discretion of guardians and financial managers in consultation with affected parties. While substitute decision should be implemented only as a last resort, it needs to remain an option to allow for circumstances where mediation and supported decision making cannot produce a viable course of action.

Question 4.3: Should NSW adopt a "substituted judgment" model?

Question 4.4: Should NSW adopt a "structured will and preferences" model?

Carers NSW wishes to reiterate that decision making capacity can vary greatly over time and according to the nature of a decision and the support available. Prescribing a rigid model of decision making is not likely to take these variables into account and would not reflect the variety of supported decision making practices currently being implemented by carers. 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 a spectrum of decision making models as needed.

*Names have been changed

ⁱ Bowey L and McGlaughlin A (2007) Older carers of adults with a learning disability confront the future: issues and preferences in planning. *British Journal of Social Work* 37(1): 39–54.

ⁱⁱ Taggart, L., Truesdale-Kennedy, M., Ryan, A. & McConkey, R. (2012) 'Examining the support needs of ageing family carers in developing future plans for a relative with an intellectual disability', *Journal of Intellectual Disabilities*, 16, 217-234.

ⁱⁱⁱ Carers NSW 2016 Carer Survey: Main report [Carers NSW, 2016]

<http://www.carersnsw.org.au/Assets/Files/Carers%20NSW%202016%20Carer%20Survey%20Report.pdf>