

17 October 2016

NSW Law Reform Commission
GPO Box 31
Sydney NSW 2001
nsw_lrc@agd.nsw.gov.au

Guardianship Act review: Preconditions for alternative decision making

Dear Sir/Madam,

Carers NSW would like to thank the Law Reform Commission for the opportunity to provide a submission in response to *Question Paper 1: Preconditions for alternative decision making* (the paper). Our submission focuses on the role of carers in alternative decision making and comprises three sections: Capacity as a continuum; Carer involvement and support; and Legislative consistency. We have not addressed all of the questions in the paper, but refer to relevant questions in each section.

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 Tom Hinton, Policy and Development Officer, on (02) 9280 4744 or tomh@carersnsw.org.au.

Yours sincerely,



Elena Katrakis
CEO
Carers NSW



***Carers NSW submission to Question
Paper 1: Preconditions for
alternative decision making
arrangements***

17 October 2016

AN AUSTRALIA THAT VALUES AND SUPPORTS ALL CARERS

Background

Most people with disability, a mental health issue or an age related illness are able to make decisions about their own lives without additional support. However, some experience reduced decision making capacity as a part of their condition and require assistance. Assistance with decision making can take a range of forms, informal and formal, across a broad spectrum, depending on the type and amount of support required by each individual.ⁱ Family members and friends often play a key role in informally supporting a person's decision making.ⁱⁱ

The 2012 Survey of Disability, Ageing and Carers estimated that 277,800 people with disability in NSW, and 50,500 people aged 65 years and over, needed assistance with 'cognitive or emotional tasks',ⁱⁱⁱ a category that includes 'decision making or thinking through problems'.^{iv} The majority of these people (220,600 and 40,800 respectively) received this kind of support from 'informal providers', i.e. family and friend carers (see Table 1).

Table 1: NSW residents needing assistance with cognitive or emotional tasks

	Reported disability	Aged 65 and over	
<i>Receiving assistance from informal providers</i>	220,600	40,800	
Spouse/partner	75,200	21,800	
Parent	92,400	*	
Child	39,400	19,100	
Other relative	31,400	**	
Friend or neighbour	23,000	**	
<i>Receiving assistance from formal providers</i>	132,500	11,600	
	Government	52,700	**
	Private not-for-profit organisation	23,300	*
	Private commercial organisation	75,600	*
<i>Total receiving assistance</i>	248,700	45,100	
Total needing assistance	277,800	50,500	

* Data missing

** Data unreliable

Source: ABS (2014)^v

This data demonstrates the key role carers play in supporting people with cognitive impairments, including with decision making. While these arrangements can be highly effective in enabling decisions to be made that genuinely reflect the values and desires of the person being supported, they can also be complex and stressful, especially when either party is unsure of their roles and responsibilities.^{vi} This submission considers how best to articulate the role and support needs of carers acting as 'supporters' as they provide assistance with decision making to those they care for. It focuses on three key themes: Capacity as a continuum, Carer involvement and support, and Legislative consistency.

Capacity as a continuum

Carers NSW believes the NSW *Guardianship Act 1987* (the Act) should ensure that an individual's capacity is assessed as accurately as possible by appropriately trained professionals, and reassessed as required. Given that capacity can vary greatly depending on the task at hand, a person lacking

capacity in relation to one kind of decision making, such as managing their own finances, must not be assumed to lack capacity to make any decisions. Capacity should be determined in relation to individual decisions and situations, whenever practicable. An inaccurate or out of date determination of capacity can unnecessarily limit the autonomy of a care recipient, and present unnecessary risk and stress to carers and supporters.

Assumption of capacity should always be the starting point, until evidence to the contrary is presented. A person's diagnosis or the manner in which they present should never be automatically equated with a certain level of capacity, as individual persons differ considerably. This principle must be clearly and sensitively impressed upon supporters, who may bring pre-existing assumptions to the role.

The option of reassessment or review of capacity should always be available, as capacity may improve, decline or fluctuate over time, subject to the nature and stage of a person's condition. Supporters, especially those who, provide regular care and support in other domains, are well placed to notice such changes and should be given the opportunity to report them and seek advice about whether arrangements need to be altered. Regular monitoring of capacity should also be undertaken by trained professionals and carers trained to appropriately identify and respond to changing capacity.

Question 3.1 and 3.7

Carers NSW believes that decision making capacity should be clearly described and explained in the Act, however prescriptive legislative definitions can be overly restrictive in application. The Act should primarily acknowledge that capacity varies broadly depending on each individual and each decision, and require that capacity not be measured without a thorough, individualised, professional assessment, incorporating evidence of the individual's prior decision making history.

Questions 3.2, 3.3, 3.4 and 3.8

Carers NSW is cautious about the concept of linking a person's disability to the question of his or her decision making capacity. We believe that the Act should refer to the concept of impaired decision making capacity, or similar, rather than to specific named conditions, other than for the purpose of providing examples. The Act should lead the way in promoting a nuanced, holistic understanding of decision making capacity that is not limited by stereotypes and generalisations. It should acknowledge that capacity may remain stable, gradually decline or improve over time, or fluctuate, depending on a person's condition and individual circumstances. Assessment of capacity should also take into account what informal supports, if any, a person has access to, as these can assist a person to make decisions.

Question 3.5

The definitions of decision making capacity and disability in the Act should be consistent with other relevant pieces of legislation, in particular the *Mental Health Act 2007*, *NSW Disability Inclusion Act 2014* and *Cwth National Disability Insurance Scheme Act 2013*. Consistency between these pieces of legislation will be important in consistently upholding the rights of people with disability or a mental health issue and their supporters across all jurisdictions.

Carer involvement and support

The involvement of informal supporters can be highly effective in enabling a person to make 'good' decisions that reflect their values and preferences.^{vii} However it can be difficult for supporters – whether formal or informal – to balance support with taking over.^{viii} Good support takes time, patience and skill.

Identifying and responding to changing capacity can be especially complex; carers may be overcautious when the care recipient's capacity appears to have declined, unnecessarily limiting the person's input.^{ix} If a caring relationship is strained, or the carer is experiencing stress or other mental health issues as a result of their caring responsibilities, the quality and outcomes of decisions made with their support are likely to be reduced.^x Carers acting as supporters must receive assistance in performing their role.

While the wellbeing and protection of an individual with limited capacity should be the focus of the Act, carers also have a significant stake in the Act, which has the potential to both permit and deny a carer's involvement in supported decision making. Recognition, inclusion and support of carers acting as supporters is of prime importance and should therefore be enshrined in the Act. As a public sector agency, the NSW Law Reform Commission is obligated under the *NSW Carers (Recognition) Act 2010* to uphold the principles of the NSW Carers Charter, which includes the following principles, of particular relevance to these decision making arrangements:

- b) Carers' health and wellbeing are to be given due consideration.*
- c) The views and needs of carers and the views, needs and best interests of the persons for whom they care must be taken into account in the assessment, planning, delivery and review of services provided to persons who are cared for.*
- d) Carers should be referred to, and made aware of, appropriate services to assist carers in their caring role. Such referrals should be made after an assessment of the needs of carers or as part of the assessment or provision of services to the person being cared for.*
- e) The relationship between carers and the persons for whom they care should be respected.*
- j) Carers' choices in their caring role should be supported and recognised, including the recognition of carers in the assessment, planning, delivery and review of services that impact on carers and their role as carers.*
- l) Support for carers should be timely, responsive, appropriate and accessible.*
- m) Carers' unique knowledge and experience should be acknowledged and recognised*

Legislative consistency

Carers NSW believes the review of the Act is a timely opportunity to bring the philosophy, language and principles of the Act into line with other relevant State and Commonwealth legislation. Supported decision making has superseded substituted decision making as the preferred approach within the disability sector, and is consistent with the increasingly consumer directed, or person centred, models of support within disability, aged care and mental health services. For the Act to retain its influence and relevance within the sector, it should demonstrate compatibility with these approaches. Consistency will also be crucial in assisting carers, especially those acting as supporters, to navigate the multiple, complex service systems with which they are presented.

ⁱ Australian Law Reform Commission (2014) *Equality, Capacity and Disability in Commonwealth Laws: Final Report*, Australian Government, Canberra; Miller, L., Whitlatch, C., Lyons, K. (2014) 'Shared decision-making in dementia: A review of patient and family carer involvement' *Dementia* published online 3 November 2014.

ⁱⁱ ALRC (2014); Miller et al. (2014); Knox, L., Douglas, J., Bigby, C. (2015): 'Becoming a decision-making supporter for someone with acquired cognitive disability following traumatic brain injury', *Research and Practice in Intellectual and Developmental Disabilities*, Published online 15 October 2015.

ⁱⁱⁱ Australian Bureau of Statistics (2014) *Disability, Ageing and Carers, Australia: Summary of Findings, 2012*, NSW tables, Cat. No. 4430.0, Canberra.

^{iv} Cognitive or emotional tasks includes: making relationships or interacting with others; coping with feelings and emotions; and decision making or thinking through problems. ABS (2013) *Disability, Ageing and Carers, Australia: Summary of Findings, 2012: Glossary*, Cat No. 4430.0, Canberra.

^v ABS (2014).

^{vi} Knox et al. (2015); Miller et al. (2014)

^{vii} ALRC (2014); Knox et al. (2015); Miller et al. (2014)

^{viii} Miller et al. (2014)

^{ix} Ibid.

^x Ibid.