

19 May 2017

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

Review of the Guardianship Act 1987, Question Paper 6: Remaining Issues

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 6: Remaining Issues* (the paper). Our submission briefly addresses questions 2.5, 2.6, 3.1, 5.3-5.5, 7.3 and 10.1, consistent with our previous submissions to the review.

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

Question 2.5: Language of disability

Carers NSW agrees with the proposed shift away from and language that assumes that all disabilities involve impaired decision making capacity. Terms such as decision making capacity and cognitive impairment would more accurately describe the factors determining whether or not a guardian or financial manager needs to be appointed. Where a broader reference to disability is appropriate, language should be consistent with the NSW *Disability Inclusion Act 2014*.

Question 2.6: Language of guardianship

Terms referring to supported and substitute decision making arrangements should be in plain, simple language, be descriptive of the arrangement and be consistent with existing related terminology.

The aged, disability and mental health sectors all have distinct terms for supported and substitute decision makers, from representative, to nominee, to person responsible. Even these terms can be used to refer to various arrangements, causing many carers confusion and frustration.

Question 3.1: Relationship between Commonwealth and NSW laws

In addition to consistent terminology across jurisdictions, clear, enforceable guidelines on the hierarchy of conflicting decision making arrangements should be available to carers and recognised by agencies and services.

Some carers have recently applied for guardianship with the fear that their caring role may not be recognised in new Commonwealth-led service systems. This action on their part reflects the expectation that state based guardianship provisions will supersede Commonwealth arrangements, however, even carers who are appointed guardians have reported incidents where their input as a carer has not been taken into account.

Question 5.3 Appointing young people as guardians

Many primary carers under the age of 18 adopt responsibilities beyond their years in caring for a parent, sibling or other family member.ⁱ Young carers are also more likely to be living in low-resource and lone-parent households with limited support from other family members.ⁱⁱ As a result, many young carers provide significant levels of decision making support.

However, young carers consistently report not being recognised in their caring role by health professionals and service providers, and being excluded in discussions about their family member's condition and treatment. Appointing a young primary carer as a guardian could improve their recognition and inclusion within the service system.

As the case study below demonstrates, some provision in the act for a limited guardianship order should be available to the tribunal in exceptional cases where the carer is under 18.

Kristy is 17 years old and lives in regional NSW with her mother Tabatha*, for whom she is the primary carer. Kristy began caring for her mother seven years ago when Tabatha sustained a traumatic brain injury. Afterwards, Tabatha developed uncontrollable epilepsy, requiring daily care and support. This happened when Kristy was 11 years old, and since then, Kristy has had to juggle her full time caring role with full time schooling as well as various social and sporting commitments.*

Kristy's caring role is quite significant and she undertakes many different tasks on a daily basis. Kristy helps her mother take her medication, provides general emotional support and accompanies her

mother to medical appointments. Kristy is responsible for relaying her medical history to doctors and other professionals as Tabatha is anaphylactic to codeine, and Kristy needs to outline the features of Tabatha's seizure. Most significantly, when Tabatha has a seizure, Kristy provides first aid. Kristy makes sure her mother is breathing and isn't hurting herself and places her into the recovery position. Each time this happens, Kristy makes an assessment as to whether Tabatha requires an ambulance or not. If the situation is dire, Kristy takes Tabatha to the hospital and becomes Tabatha's advocate as she is unable to speak if the seizure is particularly intense. According to Tabatha, Kristy has saved her life at least 10 times by providing a high level of first aid and removing hazards during a seizure. Kristy has had to perform CPR on her mother on a number of different occasions. Other tasks that Kristy completes on a day to day basis include: doing all of the household shopping, monitoring the mail, ensures that bills are paid, taking the rubbish bins out, and cleaning the house.

*Not their real names

Question 5.4: Young People in NSW Civil and Administrative Tribunal proceedings

Young primary carers should have their views taken into account whenever the decision at hand is likely to affect the nature or sustainability of their caring role, or their personal wellbeing.

Question 5.5: Process for appointing parents as guardians

Carers NSW has frequently heard from carers about the confusion, distress and practical inconvenience that arise when their child with profound intellectual disability becomes legally independent at age 18. The implications of this change are not well communicated, and can result in substantial adverse changes to care arrangements. Carers NSW agrees that a more streamlined approach should be introduced to facilitate the appointment of the parent as guardian at the age of 18, wherever appropriate in these circumstances.

Question 7.3: Resolving disputes between decision-makers

Disputes for guardianship should look favourably on the party who has provided the most significant amount of care and has been most consistently present in the life of the person with limited capacity. In cases of conflict, mediation should be attempted before going to the Tribunal or the courts.

Question 10.1: Access to personal information

Carers NSW is of the position that decision makers and supporters should be able to access a person's health or financial information whenever they require that information to make a decision with or on behalf of the person they represent. Not having access to necessary information may compromise the safety or appropriateness of the decision made. Recent changes to the NSW *Mental Health Act 2007* have provided comprehensive provisions to improve carers' access to information, which should be considered here.

ⁱ Australian Bureau of Statistics (2016) *Disability, Ageing and Carers, Australia: Summary of findings, 2015*, Carer tables, Canberra

ⁱⁱ Ibid; Canberra; Cass, B., Brennan, D., Thomson, C., Hill, T., Purcal, C., Hamilton, M., and Adamson, E. (2011) *Young carers: Social policy impacts of the caring responsibilities of children and young adults*, Report prepared for ARC Linkage Partners