MHCN mental health carers nsw

NSW Law Reform Commission
Level 3, Henry Deane Building
20 Lee Street
Sydney NSW 2000 Australia

Attention: nsw_lrc@justice.nsw.gov.au

Re: Question Paper 1 Preconditions for alternative decision-making arrangements

Dear Sir/Madam

Mental Health Carers NSW is the peak body in NSW representing the interests of the carers of people with a mental illness. Our vision is for an inclusive community and connected carers; and our mission is to empower carers for mental health. We undertake systemic advocacy on behalf of mental health carers to improve their recognition and support in mental health and related social services.

Thank you for providing the opportunity to us to comment on the review of the Guardianship Act 1987 (NSW), hereafter referred to as the GA, in April 2016 and for this opportunity to comment on question paper 3. We have noted the format of the questions detailed in this 'question paper' and have structured this paper to respond to the questions raised.

We have also noted the submission to this enquiry by the Mental Health Coordinating Council (MHCC). We strongly agree with the points raised by the MHCC in their submission and wish to add our voice to their submission. We have framed our responses below in recognition of the MHCC submission and for purposes of economy we do not repeat their submissions but have indicated where we support their views. For some questions we would like to add new comments or expand on those of the MHCC.

Question 3.1: Elaboration of decision-making capacity

(1) *Should the Guardianship Act provide further detail to explain what is involved in having, or not having, decision-making capacity?*

Yes. We support the comments made by the MHCC in arguing that the GA should clearly define the test required to determine if someone has or does not have decision making capacity.

(2) *If the Guardianship Act were to provide further detail to explain what is involved in having, or not having, decision-making capacity, how should this be done?*

We are in agreement with the submission by the MHCC in recommending that consideration be given to the examples from the UK Mental Capacity Act 2005 and the Queensland Law Reform Commission 2010. These definitions include the elements of consumer understanding, retention of understanding,

ability to communicate decisions and the ability to 'weigh up' the information in making a decision. This 'weighing' element is particularly important when the GA is applied to persons with a mental illness. People who experience delusions or emotional dysregulation because of their mental illness can have their capacity to weigh up elements of decision making and subsequently fail to appropriately manage risks. This element of risk, and primarily the element of risk assessment and management, we believe should be a primary and essential element to be included in any explanation in the GA on the assessment of capacity.

We note that the element of risk is a foundational principle of the NSW Mental Health Act 2007, for determining that a person be held and given treatment against their will as an involuntary patient. For such a determination to be made under the Mental Health Act there must be present the risk of serious harm to the person with the mental illness or to someone else. While capacity is not mentioned specifically, lack of capacity is inferred by the criterion for involuntary treatment in section 12 which states:

> *(1)(a) that the person 'is a mentally ill person or a mentally disordered person' and*
>
> *(1)(b) 'no other care of a less restrictive kind, that is consistent with safe and effective care, is appropriate and reasonably available to the person'.*

This is expanded to include a risk element under section 14 which defines a mentally ill person:

> *(1) A person is a mentally ill person if the person is suffering from mental illness and, owing to that illness, there are reasonable grounds for believing that care, treatment or control of the person is necessary:*
>
> > *(a) for the person's own protection from serious harm, or*
> > *(b) for the protection of others from serious harm."*

The clear inference in this definition is that the involuntary patient, within the terms of the NSW Mental Health Act 2007, is lacking the capacity to determine their own needs for treatment and security in a safe environment and managing the risks to their safety. While we recognize that the assessment of capacity is not an explicit recognition in the Mental Health Act, in practice it is that lack of capacity which ultimately justifies involuntary treatment. However, we also would recognize that this lack of capacity is not the only element required to justify limiting a person's right to self-determination and this test for capacity needs to be coupled with serious risks to the person's health and safety, ('risk' being broadly defined as in the Mental Health Act).

We believe that the GA should be revised to include the assessment of risk as an essential component in the determination of capacity as is the case with the Mental Health Act, but not so as to eliminate all risk. It is particularly important for people with a mental illness to retain the freedom to make decisions on their own, where it is appropriate for them to do so. This is an important component of recovery principles which are clearly outlined in the 'A National framework for recovery-oriented mental health services: policy and theory' available from the Australian Department of Health at http://www.health.gov.au/internet/main/publishing.nsf/Content/mental-pubs-n-recovpol. Inclusion of the concept of risk is important as many people who are mentally ill may also fall within the provisions of the GA.

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There is also a need to include in the Act, or in its regulations, explanatory details covering the method of assessing capacity, including risk assessment capacity. To recognize recovery principles the assessment of capacity should allow the individual to make decisions that include minor risks without interference. The assessment should determine the inability of the individual to weigh risks at all and their capacity to make decisions in relation to major risks. There may stronger grounds for imposition of external oversight in relation to activities with the potential for significant negative consequences. That is, the determination of a guardianship order should not eliminate the individual's participation in decision making completely and on all occasions, but should focus on allowing decision making where the consequences of an inappropriate decision are relatively minor while applying support and curtailment of decisions which involve unacceptable risks.

Question 3.2: Disability and decision-making capacity

> *How, if at all, should a person's disability be linked to the question of his or her decision-making capacity?*

We are in agreement with the MHCC that a person's disability should not automatically be linked to their decision making capacity and that this association as it is written within the GA is inappropriate. Cognitive impairments which impact upon a person's ability to make decisions as described above effect this type of capacity and other disabilities (e.g. physical), will not usually be relevant.

Question 3.3: Defining disability

If a link between disability and incapacity were to be retained, what terminology should be used when describing any disability and how should it be defined?

The question should not be 'does disability indicate a lack of capacity?' but rather 'does a lack of capacity indicate a level of disability?' In other words, not all people with a disability lack decision making capacity but perhaps all people with a lack of capacity have some level of disability. By way of example, consider a person suffering from a severe form of agoraphobia, a form or anxiety disorder that prevents him or her from leaving the house. In such a circumstance the person is disabled by their inability to function, their illness prevents them from going to the shop to buy food, but they are not incapable of decision making in relation to the need to buy food or the capacity to make purchasing decisions. They are, however, suffering a disability as their illness prevents them from leaving their house.

We believe that the question is how to define 'capacity' not how to define disability. A clearer definition of capacity including the elements of understanding, retention of understanding, ability to communicate their decisions and the ability to 'weigh up' the information in making a decision and the consequences of this lack of capacity to assess risk. A lack of capacity is one kind of disability which, depending upon its nature and severity, may warrant the introduction of alternative decision making arrangements using the GA.

Question 3.4: Acknowledging variations in capacity

(1) Should the law acknowledge that decision-making capacity can vary over time and depend on the subject matter of the decision?

We strongly support the arguments made by the MHCC in their submission that the GA should acknowledge that a person's capacity can vary over time. Consider for example, the wide variation in mood and cognitive function experienced, over time, by a person suffering from Bipolar Disorder. Such a person's capacity to assess risk and make decisions that are safe and in their own best interest can vary significantly over relatively short periods. Such a person may well need an alternative decision maker for those periods when they symptoms are most acute but not at other times.

(2) How should such acknowledgements be made?
(3) If the definition of decision-making capacity were to include such an acknowledgement, how should it be expressed?

We agree with the MHCC's argument that consideration be given to the element of time as captured by the Irish Capacity Decision–Making (Capacity) Act 2015. When any decision is made to appoint an alternative decision maker this decision should always be time limited. This is particularly important if this is in relation to a mental illness where the capacity of the person with this experience is likely to alter over time. However, variation in capacity over time may not be experienced by others with limited capacity, such as those with severe traumatic brain injury or late stage dementia.

A time limit would set up an automatic mechanism for the decision to be reviewed. This would work in a similar way to the Mental Health Review Tribunal established under the NSW Mental Health Act 2007. Such a provision may allow for short or long periods between reviews. Provision could also allow for application for a a review if a person's symptoms alter or reduce prior to a scheduled review; subject to safeguards against vexatious or inappropriate applications such as specialist medical or psychological assessment as to changes in a persons capacity.

(4) If capacity assessment principles were to include such an acknowledgment, how should it be expressed?

We believe that capacity will vary over time in mental health contexts and this should have a bearing on the continuing need for the imposition of an alternative decision maker. Alternative decision makers should always consult with the people they support and to make decisions consistent with their reasonable preferences. If they demonstrate strong capacity for decision making in some areas this should be encouraged with a view to reducing their dependence upon such support by building their autonomy.

Question 3.5: Should the definitions of decision-making capacity be consistent?

(1) Should the definitions of decision-making capacity within NSW law be aligned for the different alternative decision-making arrangements?
(2) If the definitions of decision-making capacity were to be aligned, how could this be achieved?

Yes, we agree that the definition of decision making capacity with NSW legislation should aligned. We believe that particular attention should be paid to the assessment of risk as defined by 'serious harm'

in the Mental Health Act and how this definition is used to determine that a mentally ill person is incapable of determining that they should be a involuntary patient under the Mental Health Act.

Question 3.6: Statutory presumption of capacity

Should there be a statutory presumption of capacity?

Yes, we agree that there should be a statutory presumption of capacity, just as at common law.

Question 3.7: What should not lead to a finding that a person lacks capacity

(1) *Should capacity assessment principles state what should not lead to a conclusion that a person lacks capacity?*

Yes, this is a sound practice. For example, the Mental Health Act lists elements that cannot be considered to constitute a mental illness. In a similar manner the GA could include provisions that a finding of a lack of capacity in limited areas, such as unusual preferences, should not necessarily result in a finding of a lack of capacity in all areas. The test should be that the lack of capacity involves reckless risk taking in regard to personal safety, the safety of others or significant loss of assets. That is, the assessment should allow for a distinction between a general recklessness and a recklessness just in regard to a specific issue or issues, such as when a generally competent person lacks capacity only in relation to a narrow domain of decision making.

For example, food preferences may or may not constitute a lack of capacity, and one that warrants the appointment of an alternative decision maker. For many individuals food preferences do not constitute a risk to themselves or others. On the other hand a person with an eating disorder may lack capacity to make appropriate choices regarding their intake of food where that risk is relatively minor or time limited. Such a person's lack of capacity may not impact on their capacity to make appropriate decisions in other areas of their life. However, a person with a more serious eating disorder, or the same person at a different time, whose decisions regarding their food intake seriously threatens their health may be assessed as lacking in capacity to make decisions to the extent it constitutes a serious risk. That is, the assessment principles that should lead to a conclusion that a person lack capacity should be based on the assessment of risk.

(2) *If capacity assessment principles were to include such statements, how should they be expressed?*

We note the examples in the Mental Health Act NSW 2007 of certain words of conditions that **do not** indicate a mental illness, such as those related to [inter alia] political or religious beliefs, or, sexual or criminal behavior. We support the submission made by MHCC on the elements that **should not** determine a lack of capacity, unless accompanied by unacceptable risk taking. Further, the imposition of guardianship could be expressed as the alternate decision maker being appointed, '**until** the person under guardianship recovers their decision making capacity with regard to the relevant decision making domain'.

Question 3.8: The relevance of support and assistance to assessing capacity

(1) *Should the availability of appropriate support and assistance be relevant to assessing capacity?*

We see a danger in any determination that the availability of a level of support or assistance may be relevant to the determination of a capacity. Such a determination runs the risk that those individuals who live in locations with low population density or in poorer communities may face the risk that they are more likely to be determined as having lower capacity than a person with the same capacity who lives in a denser, more affluent community or one with a different ethnic mix.

It should be noted that the Mental Health Commission's 'Living Well' Strategic Plan found that around 50% of people with experience of mental illness do not receive treatment, and even less receive adequate treatment, because of a lack of access to appropriate support and assistance. We believe it would be unethical to assess a person's capacity based on the level of appropriate support and assistance available. While appropriate support can build capacity, capacity itself is an inherent quality which is not substantially altered through the provision of assistance. Appropriate assistance can allow people with compromised capacity to participate in decision making to the degree they are able, but may still require extensive support to appropriately manage the risks to their safety. Provision of such support however does not actually alter their underlying capacity. The determination of capacity must be free of biases' based on location, education, culture, ethnicity sexuality or wealth; and this includes biases relating to ability to access decision making support, (which is often a function of these other 'biases').

(2) *If the availability of such support and assistance were to be relevant, how should this be reflected in the law?*

We support the submission by the MHCC that decision making principles should be based on those espoused for national use by the Australian Law Reform Commission. We would only support a rule which stated that capacity cannot be assessed without adequate support being provided to assist the decision making of the assessor. Generally once guardianship has been awarded over a person we would also advocate that person acting as guardian should always attempt to support the person in making decisions and only substitute their own decision when this is impractical. The application of recovery principles support the general practice that a person under guardianship should be supported to participate in decision making with the provision of adequate support to them on all occasions they will be required to make significant decisions and only over ruled for sound risk management reasons.

Question 3.9: Professional assistance in assessing capacity

(1) *Should special provision be made in NSW law for professional assistance to be available for those who must assess a person's decision-making capacity?*
(2) *How should such a provision be framed?*

Ideally those who assess another person's capacity to make decisions for the purpose of determining the appointment of an alternative decision maker should be professionally qualified to make such an assessment. Where the person making that decision is not appropriated qualified professional assistance must be available for them. Assessment of capacity in a number of areas that may affect decision making capacity, such as with mental illness, is a highly skilled and technical exercise that cannot be adequately performed reliably and consistently by people without specific training. The processes required by the NSW Mental Health Tribunal in assessing a person's need for continuing involuntary treatment may provide a useful starting point for consideration of the provision of professional assistance to any tribunal set up under the GA. The assessment of capacity is a technical task and would seem to generally require a high degree of skill and therefore legislation should restrict assessments only to those with appropriate professional qualifications and experience.

Question 3.10: Any other issues?

Are there any other issues you want to raise about decision-making capacity?

We support the arguments made by the MHCC in relation to the consistency and reliability of assessment. Consistency between different decision makers I necessary to avoid variation in decisions, such as those that are too proscriptive or too lenient. We also note that in a mental health context, assessments of a person's mental state often benefit greatly from input from their family and carers and that this could be included among the type of evidence an assessor considers, although principles of natural justice should apply to such ancillary evidence.

4. Other preconditions that must be satisfied

Question 4.1: The need for an order

(1) *Should there be a precondition before an order is made that the Tribunal be satisfied that the person is "in need" of an order?*
(2) *If such a precondition were required, how should it be expressed?*

A person would be 'in need' of an order if they lacked capacity generally and this was likely to be a continuing condition, (for example , a person who exhibits severe impairment in all decision making domains due to severe long standing psychosis, dementia or severe brain damage). In less severe cases a person may be 'in need' for support with regard to a particular decision making domain if they lacked decision making capacity about a particular area, (e.g. a person experiencing eating disorder might have an order relating to their diet), and so may require a partial order over a particular area, or if it was concerning a condition where recovery is possible, it may be reviewed at a particular time.

In general, we would refer to the analogous idea in the Mental Health Act that treatment can only be imposed if it is in the least restrictive form. So with guardianship, it may be that an order should only be imposed if this is the least restrictive way of supporting a person safely and/or to create the potential for building their capacity for autonomy.

Question 4.2: A best interests precondition

(1) Should there be a precondition before an order is made that the Tribunal be satisfied that the order is in the person's "best interests"?

A person's autonomy should only be limited by guardianship, or anything else, if it is in their 'best interests'. This should also recognize that people with capacity often make less than ideal choices and that only unacceptable risks or damaging behavior should really be precluded in limiting a person's autonomy.

(2) If such a precondition were required, how should it be expressed?

As above.

(3) What other precondition could be adopted in place of the "best interests" standard?

In addition to the inclusion of a 'best interest' clause we believe that the GA should contain an 'own interest or preference' clause. That is, decisions should be guided by the known interests and preferences of the person and not the interests and preferences of the decision maker. These interests and preferences should be guided by carers and relatives where possible and based on the persons past history of decision making. This may include for example, past preferences to spending rather than wealth accumulation, preferences in relation to alcohol consumption or gambling, or preferences in relation to food.

Question 4.3: Should the preconditions be more closely aligned?

(1) Should the preconditions for different alternative decision-making orders or appointments in NSW be more closely aligned?

Yes, as far as possible these definitions and principle on the limitation of autonomy should be aligned as closely as possible.

(2) If so, in relation to what orders or appointments and in what way?

Having standard definitions in relevant Acts for such things as capacity and cognitive impairment would greatly facilitate this.

Question 4.4: Any other issues?

Are there any other issues you want to raise about the preconditions for alternative decision-making arrangements?

Supported rather than substituted decision making should be used on all occasions when this is practical, in line with the UN declarations on the rights of people with disabilities.

5. Other factors that should be taken into account

Question 5.1: What factors should be taken into account?

(1) What considerations should the Tribunal take into account when making a decision in relation to

(a) a guardianship order

(b) a financial management order?

(2) Should they be the same for all orders?

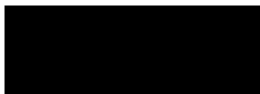
(3) Are there any other issues you want to raise about the factors to be taken into account when making an order?

We think there should be some generally applicable factors taken into account for all types of order. Currently guardianship seems to have an excessive focus on generating and preserving assets for the benefit of estates. We believe that a person's property is of no further use to them once they are dead and that the standard of living they enjoy while alive should not be compromised by such irrelevant considerations.

We have heard many anecdotal stories of people being refused permission to spend their own money to replace even important items or equipment to help reduce their level of disability, which is considerably broader in the mental health context than in other disability contexts. A pet dog might be a crucial mental health support, just as much as a guide dog is for a blind person. Inevitably, when such requests are denied, the family or carers of that person will usually try to fill that need with their own resources, (if they are able). Such examples have led to perception of unfairness and to speculation by carers that the government agency charged with supporting their loved one is only interested in the share of the estate it will receive on their demise. (We raise this suspicion for your consideration, rather than suggesting it is based in fact).

We urge that the human rights and standard of living of the person under guardianship be explicitly given as much weight as their financial health in any revised Act. This could be done by stating that the order is to assist the person in maintaining their life and health, as they would for themselves if able; or to assist them in building their independence and their autonomy, until they are able to do so for themselves.

Yours Sincerely



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