

Review of Adult Decision-Making Capacity Law

Preliminary Issues Paper 2023



New Zealand Council Of
Christian Social Services

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Ko wai au Who we are:	<p>The New Zealand Council of Christian Social Services (NZCCSS) welcomes the opportunity to provide feedback on the Preliminary Issues Paper for the Review of Adult Decision-Making Capacity Law.</p> <p>NZCCSS has six foundation members; the Anglican Care Network, Baptist Churches of New Zealand, Catholic Social Services, Presbyterian Support and the Methodist and Salvation Army Churches.</p> <p>Through this membership, NZCCSS represents over 230 organisations providing a range of social support services across Aotearoa. We believe in working to achieve a just and compassionate society for all, through our commitment to our faith and Te Tiriti o Waitangi. Further details on NZCCSS can be found on our website www.nzccss.org.nz.</p>

Tirohanga Whānui | Overview

We support the kaupapa to review adult decision-making capacity law, by the Law Commission. NZCCSS member organisations work alongside adults with affected decision-making across the lifespan, in a range of settings including disabled care services, dementia care homes, and aged care facilities. We advocate for improvements to the current legal framework to address issues of access, equity, and accountability.

Our main points are:

1. Rights of the affected person central to legal framework

NZCCSS agrees that our legal framework must first and foremost uphold the rights, freedoms and safety of people with affected decision-making.

2. Enactment of Te Tiriti must be foundational in this legislation

Legislation relating to adult decision-making capacity must reflect enactment of Te Tiriti o Waitangi, particularly the rights of citizens affirmed in Article 3.

3. Value of substitute decision-making frameworks requires greater promotion

Low uptake of EPA's or Welfare/Property Guardianship suggest that more could be done to educate the public of the value of forward planning for decision-making in the absence of capacity.

4. Education critical to the success of legislation

Greater education and accountability is needed to ensure that adult decision-making capacity law is effective and safe.

5. Increased accountability needed to ensure safety of those affected

Increased accountability mechanisms are needed to ensure people involved in decision-making supports such as EPA's have an accurate understanding of, and adhere to, the scope of their responsibilities.

6. Increased accessibility needed to ensure equitable access

Changes to our legal framework must prioritise accessibility of decision-making mechanisms for everyday New Zealanders.

Taunakitanga | Recommendations

We raise the following points and recommendations for consideration:

1. Rights of the affected person central to legal framework

NZCCSS agrees that our legal framework must first and foremost uphold the rights, freedoms and safety of people with affected decision-making. This must be guided by enactment of the United Nations Convention on the Rights of Persons with Disabilities with a specific emphasis on Articles 12 (Equal recognition before the law) and 14 (Liberty).

We observe the distinction between "legal capacity" and "mental capacity", noting that a finding of mental incapacity may subsequently lead to infringement of one's legal capacity to exercise rights and freedoms (Villios et al, 2020). Jurisdictions such as Ireland's Assisted Decision Making (Capacity) Act 2015 and Canada's Adult Guardianship and Trusteeship Act (Alberta) and Representation Agreement Act (British Columbia) offer examples of legislative frameworks that prioritise enactment of the UNCRPD. They also offer examples of supported decision-making alongside substitute decision-making, recognising that the need for support with decision-making is nuanced and may affect adults across the spectrum of mental capacity and lifespan.

We strongly advocate for Aotearoa to similarly prioritise the UNCRPD and supported decision-making mechanisms through our legal framework, education, and resourcing of supports that uphold the mana of those whose decision-making is affected. Included in this should be provisions for adults who are deemed mentally capable of making decisions but wish to be supported.

We also encourage a legal framework that accepts diverse means of communication with regards to the ability for someone to communicate their wishes. The use of Augmentative and Alternative Communication systems and the support of someone familiar with the affected person were both noted as being instrumental in facilitating communication where verbal/written skills are affected.

Recommendation 1: We recommend that legal frameworks and subsequent resourcing are guided by a human rights approach and prioritise supported decision-making mechanisms.

2. Enactment of Te Tiriti must be foundational in this legislation

Legislation relating to adult decision-making capacity must reflect enactment of Te Tiriti o Waitangi. NZCCSS supports the Law Commission's inclusion of *Principle 2: the law should uphold the Crown's obligations under te Tiriti o Waitangi* and *Principle 3: the law should recognise and provide for tikanga Māori*. Article 2 of Te Tiriti speaks to tino rangatiratanga and the right for Māori to have leadership over their own affairs and active participation within society, whilst Article 3 upholds their full rights as citizens. We applaud the inclusion of these principles within the review but seek further clarification as to how Te Tiriti and tikanga Māori will be interpreted and reflected within legal frameworks that have been shaped by Western understandings of property rights and welfare responsibilities.

One NZCCSS member reflected on the Māori concept of birthright, where the eldest child is understood to have responsibility for decision-making for elders when deemed necessary. They observed that where there is already a cultural understanding of how supported or substitute decision-making occurs within a whānau or a community, Māori may be less likely to establish a written legal document such as an Enduring Power of Attorney.

Recommendation 2: We urge the Law Commission to explore how our legal framework can best enact Te Tiriti and recognise tikanga Māori.

3. Value of substitute decision-making frameworks requires greater promotion

Low uptake of EPA's or Welfare/Property Guardianship suggest that more could be done to educate the public of the value of forward planning for decision-making in the absence of capacity.

There is a prevalence of adults with disabilities who do not have a Welfare Guardian and have never had the capacity to appoint an Enduring Power of Attorney. This raises questions as to how well-understood our legal framework is with regards to parents making decisions for their children as they transition into adulthood.

One large provider of disabled care services estimates that approximately 80% of people they work alongside have no legal provision for substitute decision-making. This presents a significant risk with respect to the wishes of an individual being maintained as far as possible, and potential cost to society in the requirement for court-appointed guardianship where arrangements have not been put in place.

Similarly, a survey of older New Zealanders found that of those participants without an EPA, 79% of thought their family would be automatically allowed to make decisions for them when they lack capacity to do so, and 69% were simply unaware of the existence of EPAs. (Park et al., 2017)

One member noted that even for those who do have an EPA or Welfare/Property guardianship in place, there may be no provision for a situation where that person is overseas or passes away.

With an ageing population and the likely increase in mental decline that may accompany this, there is a responsibility to ensure the public are better informed of the risks associated with not having put in place substitute decision-making arrangements.

Recommendation 3: Increase promotion of the benefits and risks associated with advance planning for decision-making capacity.

4. Education critical to the success of legislation

Greater education and accountability is needed to ensure that adult decision-making capacity law is effective and safe. Member organisations observe confusion experienced by various parties involved in substitute decision-making arrangements including the person with affected decision-making, whānau members, and medical and legal professionals. Misunderstanding results in a lack of uptake of decision-making mechanisms, inconsistency in how responsibilities are implemented and infringement of the rights of those with affected decision-making.

This is evidenced by a New Zealand study involving hospital and general practice doctors which found that many doctors demonstrated a lack of capability or confidence in assessing capacity. The same study noted that almost a fifth of doctors (both in hospital and GP settings) misunderstood the law relating to consent to medical treatment where decision-making capacity is affected, and greater numbers of hospital doctors (33%) and GPs (54%) misunderstood how a capacity assessment for one purpose relates to that required for another type of decision. Researchers involved in this study observed the urgent need for education in assessing capacity within the medical profession. (Young et al., 2018)

Providers of services to people with affected decision-making report similar challenges. Where incapacity in one area of decision-making is generalised to other aspects of a person's capacity, diminishing their ability to make decisions for themselves in areas where they do have capacity. In contrast, providers also observe a growing hesitancy among GPs to assess capacity or provide non-essential medical care to those with diminished capacity (for example, a vaccination). Members report cases where familiarity with a patient impacts a GPs willingness to assess someone as not having decision-making capacity.

Further challenges include a lack of understanding of legal or medical terminology or processes by parties involved. These observations suggest that greater understanding of capacity assessment law, legal and medical assessment processes and exposure to best practice guidance relevant to the Aotearoa New Zealand context, such as the [Toolkit for Assessing Capacity](#), would be beneficial. Similarly greater understanding among affected people and their whānau of the purpose, implications and limitations of legal and medical assessment processes appears to be needed.

Members also report confusion regarding the role and boundaries of legal mechanisms such as Enduring Power of Attorney or Property or Welfare Guardianship. Examples of abuse of power that may result from this lack of clarity include premature institutionalisation, the withholding of finance for basic necessities or the infringement of rights due to an EPA's own values or issues. An example of this is where an EPA might instruct a care home to withhold calls to a resident from a family member with whom the EPA is in conflict or instruct a care home to provide only vegetarian meals for a resident who has never themselves opted to become vegetarian. In more extreme situations, this lack of understanding can lead to cases of serious elder abuse.

Where there is misunderstanding there is increased risk that decisions being made are not centred on the person affected, or not being made in their best interests. NZCCSS observes that greater education for both public and specialist audiences is required to uphold the rights and safety of people with affected decision-making capability.

Lastly, there is a clear need for this education to be widely available, easily accessible and well-funded. This would ensure wide uptake from those who would benefit from this knowledge.

Recommendation 4: We advocate for education to be a key consideration in the review of current law and any future amendments.

5. Increased accountability needed to ensure safety of those affected

Increased accountability mechanisms are needed to ensure people involved in decision-making supports such as EPA's have an accurate understanding of, and adhere to, the scope of their responsibilities. We observe the difference in transparency and accountability between EPA's and court-appointed Welfare or Property Guardians who are eligible for reappointment every three years and in this respect have their performance reviewed.

Member organisations identify scope for people involved in the daily care of those with affected decision-making, such as Support Workers or management kaimahi, to be better consulted in the review process. One provider observed that in situations where their teams witness poor performance by a Welfare Guardian, it can be very difficult to challenge behaviour and the organisation must 'fight really hard' to be involved in the review process. Members commented that in 90% of cases, where there is a high degree of functionality within the network of support, there is little need for greater accountability mechanisms. Yet they maintained that increased accountability would protect the safety of the remaining 10% of cases where there is poor performance by a guardian or dysfunction between guardians.

We query whether there is a role for a Tribunal to oversee guardianship arrangements, EPAs etc. and disputes associated with these arrangements. A Tribunal approach could be beneficial in increasing access to legal oversight, dispute resolution and reducing costs for both individuals/whānau and the state.

Recommendation 5: Implementation of decision-making capacity law must be safe and effective.

6. Increased accessibility needed to ensure equitable access

Changes to our legal framework must prioritise accessibility of decision-making mechanisms for everyday New Zealanders. Currently the costs and processes associated with putting such arrangements in place are prohibitive for many.

A 2017 survey reported much lower rates of EPA among Māori (10%) than NZ European participants (63%), with cultural expectations and financial barriers considered possible contributors to lack of uptake (Park et al., 2017). Members' observations were consistent with this view, with one member observing that Māori and Pasifika people are adversely affected by the cost of legal fees for EPA's etc.. and querying whether alternative sources of funding existed. Accessibility of information is also a barrier, with one member suggesting that a platform is needed for Māori to be able to speak to other Māori about the need for such planning and how to put substitute decision-making

agreements in place. These challenges limit the extent to which the Crown is delivering on its Treaty commitments to tangata whenua and must be considered as part of this review.

In addition to the potential benefits of a Tribunal system for this area of law, we suggest that the ability to self-represent could be supported through improved resources and processes. We observe that in the area of care of children, there are accessible resources for self-representation, such as downloadable forms and step by step instructions. In contrast, the Welfare or Property order processes are challenging and mean that people seek costly legal assistance, particularly because Welfare Orders are often required urgently. We would also recommend an easily accessible fund to support low-income earners to access the support they require.

Recommendation 6: Accessibility must be prioritised in any changes to decision-making capacity law.

Tohutoro | References

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