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Tēnā koe Geof

Submission on the Preliminary Issues Paper for the review of adult decision-making capacity law

Background to my role

1. Thank you for the opportunity to provide comments on the Law Commission's Preliminary Issues Paper (the Paper) for the review of adult decision-making capacity law. My feedback is from the perspective of my complaint-handling and investigations role in respect to the administrative conduct of public sector agencies.
2. This submission also reflects my role under the United Nations Convention on the Rights of Persons with Disabilities (the Disability Convention) as part of the Independent Monitoring Mechanism (IMM), constituted under Article 33(2), to protect and monitor disability rights in New Zealand.
3. Moreover, my feedback also takes into account my function as a National Preventative Mechanism (NPM) with the designation for monitoring and examining the conditions and treatment experienced by people in places of detention. My role as an NPM emanates from the United Nations Optional Protocol to the Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment (OPCAT).

Accessibility and language

4. I am pleased to see that the Paper is available in a number of alternate formats which are accessible to disabled people and supports people with English as a second language and those with low literacy skills. Staff assisting with my review commented on the availability of both the Easy Read version and the audio file recording.
5. I am also pleased that the Paper approaches language in a disability-friendly manner. Language is an important component of the social model of disability and helps to ensure disabled people feel valued and included. At present, much of New Zealand's decision-making capacity legislation is written using outdated language which reflects a medical model approach to disability. The Law Commission should advocate for legislative change that is easy to understand and this Paper is a practical starting point.
6. However, I should note that there is limited reference to the needs of those who are Deaf or hard of hearing throughout the Paper.

Consultation questions

7. The Paper poses a number of consultation questions. I have focussed my submission on what I consider to be key guiding principles and legal concepts for reform in the adult decision-making capacity space (parts 3, 4 and 6), current decision-making processes and supports (part 7) and safeguards and accountability (part 8).

GUIDING PRINCIPLES AND LEGAL CONCEPTS

8. I agree with the Paper's premise that attitudes towards disability have shifted in recent decades. This is particularly important with New Zealand ratifying the Disability Convention in 2008. I also support the Paper's position that New Zealand's current law in this area does not generally take into account Te Tiriti o Waitangi/the Treaty of Waitangi (Te Tiriti).¹ Both the Disability Convention and Te Tiriti are essential if our law is to reflect contemporary best practice around adult decision-making capacity.
9. New Zealand's aging population means that the number of people living with dementia and psychogeriatric needs is projected to rise. Our legislation needs to represent the needs of this cohort of society.
10. New Zealand needs to comprehensively review the legal concept of 'decision-making capacity'. As the Paper infers most of our current legislation stipulates that people either have or do not have 'decision-making capacity'. My engagement with disabled people and those in places of detention clearly demonstrates that 'decision-making capacity' is not 'black and white'. Decision-making can depend on a number of factors and may vary in different circumstances and over time.
11. Article 12 (equal recognition before the law) of the Disability Convention recognises disabled people's right to exercise legal capacity on an equal basis with others. All measures must be taken to respect a disabled person's rights, will and preferences; and to prevent abuses, conflicts of interest, or undue influence over the exercise of legal capacity. Any restrictions on legal capacity must be of the shortest possible duration, and be subject to independent and impartial review and oversight.
12. In my role as part of the IMM, I have stated that genuine fulfilment of Article 12 of the Disability Convention requires a transformational shift in domestic legislation and practice; moving from substitute decision-making to supported decision-making, fully respecting disabled people's autonomy, and their right to appropriate decision-making support.
13. Access to diverse and guaranteed systems of supported decision-making is critically important for many New Zealanders, particularly those in the disabled community and those in places of detention. This is particularly so for people experiencing mental distress, and those with learning disabilities, who in some cases continue to be detained in institutional settings without their own consent, and lack independent support or advocacy.

¹ I acknowledge there are two texts with different meanings.

14. To date, the sporadic momentum for building competence in supported decision-making in New Zealand is disappointing. There has not been the necessary urgency, resource or sustained focus needed to progress this fundamental right.
15. Accordingly, I suggest that the seven guiding principles of the review listed in the Paper are expanded to include explicit reference to the need to uphold New Zealand's obligations under the Disability Convention (particularly Article 12). It should be directly noted that concerted change is required in order to move from substitute to supported decision-making.
16. The principles should also explicitly state that people with affected decision-making capacity should be involved in all stages of the Law Commission's review, given their personal lived experience. I note the term "empowerment" is used to refer to the need to ensure good outcomes for this group of people. I believe the guiding principles should go further and state that people with lived experience must be leaders in this review, as is stated in the Terms of Reference.
17. Aside from my earlier comments (paragraphs 14 and 15) I support the suggested guiding principles in the Paper. It is pleasing to see that Te Tiriti will be given prominence, and that there is recognition of the need to provide for tikanga Māori. Ultimately I hope that these principles will assist the Law Commission's review to enhance the rights of, and protections for, adults who have reduced capacity, including those who are, or may be, detained.
18. The Paper notes that some of the key laws relating to adults with affected decision-making capacity are:
 - The Protection of Personal and Property Rights Act 1988 (PPPR Act);
 - The Mental Health (Compulsory Assessment and Treatment) Act 1992 (the Mental Health Act);
 - The Substance Addiction (Compulsory Assessment and Treatment) Act 2017 (the Substance Addiction Act);
 - The Code of Health and Disability Services Consumers' Rights (the HDC Code); and
 - Common law found in Court decisions.
19. Each of these laws contain some safeguards, including requirements to ascertain, if possible, the views of a disabled or detained person, external oversight, and specific review periods. However, my view is that these provisions do not reflect a contemporary understanding of the right to access support to make decisions, or the shift to establishing a person's will and preferences rather than acting in a person's best interests. As noted earlier, laws in New Zealand that cover decision-making capacity are largely based on a medical model approach that conforms to institutional settings of the past, and they do not conform to the Disability Convention.
20. The Paper notes the Law Commission will not review decision-making capacity under criminal law which includes the Intellectual Disability (Compulsory Care and Rehabilitation)

Act 2003 (IDCCR Act) but that you may comment on the implications of its review for criminal law.

21. I hope that the Law Commission does comment on the IDCCR Act in any capacity it is able. My view is that the IDCCR Act permits differential treatment (including in certain circumstances detention, forced treatment and substitute decision-making) and adversely affects disabled detainees. There is concern that extensions to compulsory care orders, based on assessment of ongoing risk, can lead to some people being detained for periods exceeding the maximum length of sentence they would be liable for in the criminal justice system.
22. I consider that there are potential 'gaps' in legal protections for those with learning/intellectual disabilities who reside in secure care or residences but are not formally under the IDCCR Act. This is worth further examination. For example, if a person transitions off the IDCCR Act but remains in a secure residence, clarity is required as to protections the law should afford in terms of establishing their decision-making capacity, and ensuring informed consent.
23. Moreover, the Paper notes, that the review will not consider decision-making capacity in relation to children and young people (as defined under the Oranga Tamariki Act 1989) but the Law Commission may comment on the implications of its review for this cohort. I hope that the Law Commission does comment on implications for children and young people in any capacity it is able. The Oversight of Oranga Tamariki System Act was passed on 23 August 2022 and will come into effect on or before 1 July 2023. I will have an enhanced role in overseeing complaints and investigations relating to the Oranga Tamariki system and children and young people in state custody, and I believe it is important that their voices are heard.
24. In my IMM capacity I have commented that some young disabled New Zealanders are denied the opportunity to have full control over their own bodies due to substitute decision-making practices. I remain concerned about the possible practice of involuntary sterilisation, particularly of disabled girls and women, and the lack of robust data on the prevalence of this practice. Accordingly, in June 2020 the IMM recommended that the Government enact legislation to prohibit the use of sterilisation or any other non-therapeutic medical procedure on disabled children and disabled adults without their prior, full informed, and free consent.
25. Other legislation that I believe may have relevance to the Law Commission's review and is not listed in the Paper include:
 - The End of Life Choice Act 2019; and
 - The Accessibility for New Zealanders Bill (presently at Select Committee stage).

CURRENT DECISION-MAKING PROCESSES AND SUPPORTS

26. I agree with the Paper's statement that people's experiences of decision-making can vary widely. As previously covered I believe that New Zealand's current laws covering adult decision-making capacity are both complex and deficient and I encourage the Law Commission's review to provide for a range of decision-making provisions. This is

particularly pertinent for people who find themselves in secure care including those experiencing mental distress, those with complex learning disabilities or people with dementia. I support the Law Commission's position that it will consider how the law could make it easier for people and their supporting organisations to provide decision-making assistance, noting that at present it is challenging for informal supporters to assist due to the lack of formal legal power or status.

27. Your review provides an opportunity to advocate for law to be updated to reflect contemporary best practice, protect rights, and provide clarity to vulnerable people, their whānau and professionals and clarify each person's roles and responsibilities. As an NPM, and in accordance with my role under the Disability Convention, I want to ensure decision-making capacity law is fit for purpose and in line with international human rights standards.
28. Current decision-making capacity laws were not co-designed with disabled people or those who have experience of being detained, and were therefore not informed by a human rights approach that maximises participation in decisions affecting people.
29. Furthermore, adult decision-making capacity law plays an inimitable role in the case of aged residential care, particularly dementia care and specialised hospital/psychogeriatric care. Persons in secure aged residential care have generally been assessed to need secure care by a Needs Assessment Services Coordination (NASC) agency and are deemed to lack the capacity to make a decision as to whether to agree to secure care. On this basis, their authorised representative – generally an Enduring Power of Attorney (EPOA) or a Welfare Guardian – then agrees or 'consents' to the placement on the resident's behalf. This then renders the resident unable to leave without the consent of their authorised representative, and therefore detained for the purposes of OPCAT. I consider it concerning that current adult decision-making capacity law allows for such a significant limit on fundamental rights, the right to liberty, without the relevant procedural and legal safeguards that such deprivation of liberty would usually entail.
30. Aged residential care also provides clear examples of the complexity and confusion around current legislation². There is a significant gap in clarity of roles and responsibilities, in particular for ensuring that older people who may lack capacity to make a decision about their long term care needs and placement in residential care are appropriately represented. Providers of aged residential care can be put in a difficult position when they are asked to provide secure care for a resident but the relevant legal processes have not been followed prior to admission.
31. There appears a lack of clarity in some secure aged care settings about where responsibility lies for verifying that a valid authority is in place (such as an activated EPOA or Welfare Guardianship order) for those making decisions on behalf of residents about their personal care and welfare.

² <https://www.ombudsman.parliament.nz/what-ombudsman-can-help/aged-care-monitoring>

32. I am also aware of varying levels of understanding among aged care service providers, medical professionals, whānau and others of the current law and its operation as a safeguard against arbitrary detention.
33. In particular, I am concerned that the relationship between care needs and decision-making capacity may be currently unclear, not well understood, nor well practised in some cases.
34. For example, there sometimes appears to be:
 - a. confusion about the differences between a needs assessment and an EPOA, and between the different types of EPOA (property vs personal care and welfare);
 - b. unawareness or misunderstanding about the requirements for ‘activating’ an EPOA;³ and
 - c. varying practice from health practitioners regarding the extent to which an assessment of a person’s decision making capacity is completed and recorded, including for certification of incapacity.⁴
35. These observations highlight that, currently, it often falls to health and disability providers to administer a complex area of law in which they are understandably of varying degrees of familiarity, with limited oversight. This is in addition to the fact that, as in other areas, the current law under the PPPR Act largely provides for substituted, rather than supported, decision making.
36. The Paper touches on how law could provide more ways for other people, like family and whānau, to participate in decision-making arrangements, or to jointly support decisions with a person whose decision-making may be impaired. Sufficient, diverse and guaranteed systems of supported decision-making must be developed. I would strongly encourage the Law Commission to carefully review this area of law. I would hope that your review will reflect an understanding of substitute decision-making as an option only of last resort after all supported decision-making options are exhausted, and that any substitute decision should be based on best interpretation of the person’s rights, will and preference and with clear, robust and easy to follow procedures.
37. The Paper also features a section on how to make decision-making arrangements work better, and includes a consultation question on how effectiveness might be realised. I would encourage the Law Commission to consider enshrining the importance of regular reviews and robust monitoring mechanisms as part of review. Consideration should also be given to extending the scope of the Paper to review how law could regulate how a decision-making assessment is performed, and identify appropriate avenues for review and appeal. I would also encourage the Law Commission to consider the role of advocacy and oversight arrangements in ensuring the effectiveness of any proposals.

³ Set out in the PPPR Act.

⁴ The Law Commission may have, or may wish to, explore the relationship between an assessment of capacity and the issuing of a medical certification of incapacity.

38. While potentially outside the ambit of your review it would be good to ensure that adults with affected decision-making capacity (and their respective organisations) have sustainable resources to participate in supported decision-making capacity initiatives, and these opportunities do not solely fall on ‘duty bearers’ such as the health and disability workforce, those in the legal profession and/or financial institutions.

SAFEGUARDS AND ACCOUNTABILITY

39. As discussed earlier, all measures must be taken to respect a person’s rights, will and preferences. Measures must also be taken to prevent abuses, conflicts of interest or undue influence over the exercise of legal decision-making capacity. I am pleased to see the Paper gives weight to these issues.
40. During IMM consultation hui, disabled people have reflected how coercive practices rendered them ‘lesser’ before the law. An example of this was where medical professionals appear to drive substitute decision-making – for example, general practitioners being unwilling to provide primary care services without the consent of a third party.
41. Moreover, rates of compulsion in New Zealand remain high by international standards (and disproportionately so for Māori) and appear to have increased over time, raising concern that compulsion may have become a default setting rather than option of last resort⁵. Further, it is thought that around 75 percent of people subject to compulsory treatment orders actually have decision-making capacity⁶.
42. In my view, initiatives demonstrating good practice in supported decision-making, such as advance directives, are not accorded the same legal status as substituted decision-making authorities. This is despite Right 7 of the HDC Code recognising the right to make advance directives.
43. I have previously stated in my IMM capacity that access to safeguards and accountability through decision-making supports, second opinions or independent advocacy is limited. Disabled people’s organisations have developed resources to support people in decision-making, but they frequently lack sustainable funding for this work to be routinely offered on the scale required.
44. I see that the Paper articulates the view that there are insufficient monitoring processes for EPOAs, and raises the option of whether a specific oversight or complaints body could monitor or investigate actions taken under EPOAs or respond to concerns. I consider this concept worthy of further examination. As the Paper states, such oversight may lead to EPOA-related issues being identified proactively rather than reactively. It may also be possible to assign an educative function to such a body.

⁵ Office of the Health and Disability Commissioner, New Zealand’s mental health and addiction services: The monitoring and advocacy report of the Mental Health Commissioner, February 2018, p 60. See <https://www.hdc.org.nz/media/4688/mental-health-commissioners-monitoring-and-advocacy-report2018.pdf>, accessed February 2023.

⁶ Dr Sarah Gordon, Overview of keynote presentation, Kia whai tikanga te Kawenata: Making the Convention Real, Disability Matters Conference, Dunedin, 26–29 November 2017, p 41. See <https://www.otago.ac.nz/disability-matters/otago698588.pdf>, accessed February 2023.

45. The Paper and subsequent review should give additional consideration to the potential risk that piecemeal improvements – for instance limiting coercion or strengthening safeguards in existing legislation – may lead to the consolidation of substitute decision-making rather than its use as a last resort. Upholding the rights of those who may need support to make decisions requires a bold shift towards supported decision-making, and to invest in culture, practice and safeguards that actively support accountability, autonomy and free and informed consent.

United Nations Disability Committee’s Concluding Observations

46. Many of the views expressed in my submission are supported by the United Nations Committee on the Rights of Persons with Disabilities’ (the Committee) Concluding Observations which were promulgated in September 2022 after New Zealand’s review in Geneva. The Committee noted the current review into adult decision-making capacity by the Law Commission but expressed concern about the lack of progress made to abolish the guardianship system and substitute decision-making regime in New Zealand, and the absence of a timeframe to completely replace this regime with supported decision-making systems. The Committee formally recommended that New Zealand⁷:

...repeal any laws and policies and end practices or customs that have the purpose or effect of denying or diminishing the recognition of any [disabled person] before the law, and implement a nationally consistent supported decision-making framework that respects the autonomy, will and preferences of [disabled people].

Nāku noa, nā



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⁷https://tbinternet.ohchr.org/_layouts/15/treatybodyexternal/Download.aspx?symbolno=CRPD%2fC%2fNZL%2fCO%2f2-3&Lang=en