Chapter 8

Conclusion – A Checklist for Reform

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Chapter 8 is in four sections:

A. A summary of the useful provisions in the Mental Capacity Act that could be adopted with some modifications into revised New Zealand legislation.

B. Major gaps in current New Zealand law that need to be filled.

C. A Code of Practice to assist with implementation of the law.

D. Further features of the Mental Capacity Act in the checklist for reform.

Conclusion

8.1 The PPPR Act has provided New Zealand with a progressive model for adult guardianship law underpinned by sound human rights principles. The Act reflects the need to strike a balance between promoting autonomy and providing necessary intervention to safeguard the interests of people with impaired capacity in a range of circumstances. However, the legislation's weakness lies in its unnecessary complexity and lack of clarity about two essential concepts. These are firstly, capacity – the bright legal line determining whether intervention is permitted in people's lives; and secondly, best interests – the standard upon which others should make decisions when a person is unable to make decisions for themselves, taking into account the will and preferences of the person concerned.

8.2 Importantly, the PPPR Act lacks an adequate mechanism for oversight of its implementation in keeping with the principles underpinning it. There has never been a public body that champions it and educates the public, and professionals working within the health and disability sector, about it. For the legal framework to have more integrity, a clear and precise law is needed that is accessible to all. Otherwise it runs the risk of being largely ignored, or being considered ineffective in safeguarding and promoting the rights of people with impaired capacity.

8.3 This report has identified useful provisions of the Mental Capacity Act 2005 (for England and Wales) that could be adopted, with some changes, into revised New Zealand legislation. The MCA has codified decades of judge-made law, and English case law is relied upon for interpreting our law when it is similar to the MCA. The MCA provides for the specialised jurisdiction of the Court of Protection, which develops corresponding expertise and case law. It also provides for a Code of Practice. This has led to greater transparency (of both the standards and the process) concerning decision-making for people who lack capacity, under a single piece of legislation that has codified much of the common law. English law under the MCA has also embraced the growing role of human rights instruments – such as the European Convention on Human Rights (ECHR) and the United Nations Convention on the Rights for Persons with Disabilities (CRPD) – in developing its principles. New Zealand should draw on this English experience, using these positive features of the MCA in the revision of our law.

8.4 The CRPD offers new ways of thinking about capacity, particularly in its emphasis on supported decision-making and recognition of universal legal capacity. New Zealand lags behind comparable jurisdictions in its commitment to implement the CRPD. Much of the international discussion has been on the positive rights in the CRPD, plus access to decision-making support under Article 12(3) for people with impaired capacity for decision-making. There has been less discussion about how to provide the corresponding safeguards concerned, not only in respect for the "rights, will and preferences" of the person, but also safeguards from undue influence and dealing with conflicts of interest, under Article 12(4).[919] A finding of this report is that supported decision-making and substitute decision-making – as currently understood in adult guardianship law – are not mutually exclusive concepts. For a workable law, there is a need for a more integrated approach for these two models of decision-making for them to co-exist.

8.5 Implementing the concept of supported decision-making as understood in the CRPD presents challenges as well as opportunities for policy- and law-makers. New Zealand has a history of adding an innovative cultural dimension to its law and policy. We should develop a law that fits our population size, and our social and cultural expectations. There needs to be flexibility in the legal framework to reflect the fact that a wide range of people with impaired capacity and circumstances may be affected by it: people with learning disabilities, older adults with dementia, those with acquired brain injuries, and those whose capacity is affected by mental illness.

8.6 The law's approach to autonomy is often regarded as too individualistic. There is now greater recognition of the importance of relationships, as our autonomy is strongly influenced by our social and cultural context. The positive obligation to recognise support relationships in the CRPD has synergies with tikanga Māori, where values of individual autonomy and collective decision-making work alongside each other.

8.7 This report has put forward a number of recommendations for reform of the PPPR Act. These recommendations fall into four categories. Firstly, certain provisions of the MCA are identified that could easily be inserted (with some modifications) into the PPPR Act to give greater integrity to its legal framework and to assist with the interpretation of the HDC Code. Secondly, there are some major gaps identified in New Zealand law that need to be filled. Thirdly, the MCA Code of Practice is commended as an excellent model for implementing mental capacity law from which New Zealand could learn by introducing a similar Code with a statutory imprimatur. Fourthly, other useful aspects of the MCA are identified which this report has not covered in detail due to the scope of this research project but should form part of a wider review of the law.

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[919] A recent report released by the Essex Autonomy Project on legal reform across the UK on the rights of persons with disabilities provides informed discussion on legal reform of mental capacity legislation and the necessary safeguards contemplated by art 12(4) of the CRPD across the three jurisdictions in the UK: W Martin, S Michalowski, J Stavert and others *The Essex Autonomy Project Three Jurisdictions Report: Towards Compliance with the CRPD Art.12 in Capacity Incapacity Legislation Across the UK* (Essex Autonomy Project, University of Essex, 6 June 2016).

8A: PROVISIONS OF THE MCA THAT COULD BE INSERTED INTO THE PPPR ACT

8.8 The PPPR Act is in need of review and the HDC Code is silent on the definition of the capacity or "competence" that a person requires to make an informed healthcare decisions. The recommendations below aim to inject more clarity into the key concepts governing decision-making for those with impaired capacity, notably, into the concepts of supported decision-making; capacity itself; and the notion of best interests as a standard governing decision-making for others. These recommendations concern:

- *Supported decision-making – a legal principle, taking into account tikanga Māori*. The CRPD provides an opportunity to enhance and improve New Zealand's adult guardianship law by giving priority to supported decision-making as a legal principle, including incorporation of tikanga Māori. There is a need for clear statutory guidance about who bears the responsibility, and when, to provide support to people whose decision-making ability is impaired, to enable them to make their own decisions whenever possible.

- *Defining capacity – a single test*. As capacity or incapacity is the "brightline" for deciding whether the law permits intervention in people's lives, it is essential that there is a clear test for it. There are currently several tests for incapacity in the PPPR Act and no definition of incapacity in the HDC Code for the purposes of determining whether a person can give informed consent or refusal to healthcare. Section 3 of the MCA provides a single legal test, whereby a person lacks capacity if they are unable to make a decision due to an inability to: understand information relevant to the decision, retain that information, use or weigh the information, or communicate the decision. This test is recommended for adoption in New Zealand.

- *Best interests – a standard for decision-making*. The "best interests" standard recognises that where supported decision-making options have been exhausted, decisions by others need to be made. It can provide a transparent basis for decision-making when a person is unable to fully exercise their legal capacity. It is an essential complement to a supported decision-making framework: capacity is not an off-switch to a person's rights and freedoms. In New Zealand the phrase "best interests" is found in both the PPPR Act and in Right 7(4) of the HDC Code, but it cannot be regarded as a specified legal standard for decision-making of the kind codified in the MCA. Section 4 of the MCA provides a checklist setting out a series of matters that must be considered when best interests decisions are made on behalf of a person by a substitute decision-maker. These include: the person with impaired capacity should participate as much as possible in the process of determining their best interests; their present and past wishes and feelings (or will and preferences) should be recognised; and so should the beliefs and values that would likely have influenced their decisions if they had capacity.

8B: MAJOR GAPS IN CURRENT NEW ZEALAND LAW

8.9 The second category of reform concerns major gaps in New Zealand legislation where English law provides models from which New Zealand could learn and adapt into New Zealand law. From a New Zealand perspective, the most significant development in English law has been the realisation that the doctrine of necessity under the common law – the principle that necessary treatment and care can be provided to a person in their best interests – which is expressed in New Zealand through Right 7(4) of the HDC Code, provides inadequate legal safeguards for people who lack capacity and who are unable to consent or object to their healthcare, their living arrangements, or their participation in research. This report's recommendations for New Zealand law therefore include:

- *Liberty safeguards*: Liberty and freedom of movement are values of fundamental importance in our society, yet currently in New Zealand, for some people who lack capacity, there is no legal process governing their loss of liberty. In a broad range of settings, people who lack capacity are detained, and under the continuous supervision and control of those caring for them, and not free to leave. Yet, in many cases – such as where they are not under the authority of the mental health legislation (MH(CAT) Act) or an order made under the PPPR Act – no process is automatically triggered to review the lawfulness or appropriateness of their detention. This is the so-called "Bournewood gap" that has led to major developments in England under the MCA and in the European Court of Human Rights, including the establishment of the "Deprivation of Liberty Safeguards" (DoLS) to fill the gap. In New Zealand, courts (and the Mental Health Review Tribunal) review the position of people detained in psychiatric facilities under the MH(CAT) Act, and some orders for secure residential placement are made under the PPPR Act by the Family Court. In most cases, however, the PPPR Act does not provide an ongoing process for reviewing the detention of people who lack capacity. It is not designed to perform continuing review functions of this kind. Revised legislation should therefore provide what might be called "liberty safeguards", including: a process to identify, authorise and monitor deprivations of liberty; procedural rules regulating such deprivations of liberty; a code of practice to guide providers and facilities when the safeguards apply; a clear and speedy authorisation process; and the powers and procedures of an independent monitoring body.

- *Research on people who lack capacity*: Right 7(4) of the HDC Code, based on the common law doctrine of necessity, is also an inadequate legal basis for allowing participation in research by adults incapable of giving informed consent. Here too the MCA provides a useful legal model upon which New Zealand could base its own statutory protections where none currently exist. Sections 30 – 34 of the MCA provide lawful authority to carry out research on participants who lack capacity, where approved by a research ethics committee, as long as various safeguards are complied with. These safeguards relate both to the characteristics of the research and the participation of individuals in it. Among the numerous protections, the MCA provides that the research must have the potential to benefit the patient without imposing a burden that is disproportionate to that benefit, or be of wider benefit for persons affected by the same or a similar condition, and must impose no more than negligible risk to the patient.

8C: IMPLEMENTATION OF THE LAW IN PRACTICE

8.10 The MCA Code of Practice has been pivotal in making English law accessible. New Zealand should establish a Code of Practice concurrently with reform of the legislation. New Zealand is too small a country to have everyone "reinventing the wheel" by forming their own standards for best practice; greater-cross sectoral leadership is needed. The English experience shows it is vital that the professionals, as well as informal carers, know what the law is and how to implement it.

- *Code of Practice*: Revised legislation should provide for a Code of Practice to be developed by a government agency responsible for the legislation. The enabling provisions should be based on those in the MCA. The Code should be developed after consultation with the health and disability sector. It should recognise the legal interface with the rights under the HDC Code and give guidance on how supported decision-making can operate in keeping with tikanga Māori.

- *A Toolkit for Assessing Capacity*. The toolkit included in Appendix D is a practical legal and clinical guide to assist health practitioners in carrying out capacity assessments. It is a first step towards providing a consistent and systematic approach to assessing capacity within the New Zealand healthcare setting.

8D: FURTHER FEATURES OF THE MENTAL CAPACITY ACT

8.11 In addition, there are a number of areas that have been touched on in this report but require closer scrutiny in a future review of the law.

- *Register for enduring powers of attorney (EPOAs)*: There is no transparent mechanism in New Zealand to ensure oversight of attorneys appointed under an enduring power of attorney (EPOA). The 2007 amendments, which purported to address ongoing problems of misuses and abuse of EPOAs in New Zealand, have failed to provide a solution. A key factor promoting the success of the English model is the fact that there is a national register of enduring powers of attorney (referred to as LPAs), supported by a public agency, with the objective of ensuring more effective supervision of attorneys acting under EPOAs. It is now recognised in the UK that measures under existing mental capacity legislation, such as EPOAs and advance directives, should be utilised for their potential as instruments of support for the exercise of legal agency as contemplated by art 12(3), with accompanying safeguards under art 12(4), of the CRPD.[920] The establishment of a register to facilitate these measures, and associated safeguards that would accompany it, is an essential reform for New Zealand. It could be cost-effective, self-funded, and efficient through the use of an electronic register.

- *Advance directives*: As with EPOAs, advance directives are an important expression of a person's prior autonomy – as they are an advance direction made when a person is still capable, to refuse specified medical treatment for a time in the future when they may lack capacity to consent to or refuse treatment. In New Zealand, there is no mandated form for an advance directive. Right 7(5) of the HDC Code provides: "Every consumer may use an advance directive in accordance with the common law," but it does not tell us what the common law rules are. Under the PPPR Act, there is a confused relationship between EPOAs and advance directives. Where an attorney has been appointed under the PPPR Act, they must consult the person for whom they act. However, the paramount consideration for the attorney in these circumstances is to act in the person's best interests, and the attorney might, on occasion, consider this requires them to act contrary to the person's own prior instructions contained in an advance directive.[921] New Zealand law gives no clear indication as to whose views

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[920] Martin, Michalowski, Stavert and others, above n 919.

[921] Protection of Personal and Property Rights Act 1988, s 99A(2). There are limits on the powers of an attorney, (as with welfare guardians under s 18) including preventing the attorney from refusing consent

should prevail. The MCA, in contrast, has a clearly mandated framework for creating valid and applicable advance directives which state the circumstances in which a specified treatment either should, or should not, be carried out.[922] This clarifies the circumstances in which the advance directive is to prevail. These developments could encourage people to make advance directives for when they lose capacity for decision-making for a range of decisions. All advance directives and EPOAs could be included on one electronic register, so they can be readily known.[923]

- *Oversight and monitoring by a public body:* In England, the MCA established the Office of the Public Guardian (OPG). This is an executive agency of the Ministry of Justice. Its aim is to help make sure that adults who lack capacity to make decisions for themselves are protected from abuse. The functions of the Public Guardian fall into three categories: establishing and maintaining a register of LPAs (EPOAs); supervising deputies (welfare guardians or property managers) appointed by the court; and investigations – referred to as "safeguarding referrals". The Public Guardian's office can also provide a professional deputy (the equivalent of a welfare guardian) who can be appointed by the Court under the MCA. This kind of arrangement would go some way to assist with the shortage of independent welfare guardians available in New Zealand. Such a public body could also provide oversight of the legislation and its proposed Code of Practice.

- *Independent advocates*: New Zealand currently has no provision for the appointment of an independent advocate for adults with impaired capacity when serious medical treatment decisions need to be made or when they are deprived of their liberty. While there are health and disability advocates, they are largely concerned with complaints under the HDC Code. In England, the MCA has created an independent mental capacity advocate service (IMCA). This service is designed to help vulnerable people who lack the capacity to make such important decisions and who have no family or friends that it would be appropriate to consult. Recent law reform reports in the UK have emphasised that compliance with the CRPD requires that statutory advocacy services should be funded at a level that ensures genuine and effective access to independent advocates by persons with disabilities in any matter that impact upon their ability to exercise legal capacity.[924]

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for standard medical treatment or procedures intended to save that person's life or prevent serious damage to that person's health: Protection of Personal and Property Rights Act 1988, s 18(1)(c).

[922] Mental Capacity Act, ss 23-26.

[923] The establishment of an electronic "health directive register" for EPOAs and advance directives could also include organ donations. See recent health policy consultation document about the need to increase organ donation in New Zealand. The proposal is that the Ministry of Health should establish a consistent mechanism whereby health professionals around New Zealand can obtain independent assurance that new practices and processes are ethically acceptable: Ministry of Health *Increasing Rates of Deceased Organ Donation: Consultation document*. Ministry of Health, Wellington, June 2016). It is important to note that the Human Tissue Act 2008 would not need to be amended to establish a register. The Act already has enabling provisions to establish regulations for a national organ and tissue donor "opt-on" register: Human Tissue Act, s 78. See A Douglass, "The new Human Tissue Act" (2008) NZMJ 377.

[924] Martin, Michalowski, Stavert and others, above n 919 at 79; Law Commission interim statement (2016) above n 224.

8.12 It is said that the measure of a society is how well the most vulnerable are treated.[925] The PPPR Act is overdue for revision in line with contemporary thinking about the law for protecting and promoting the rights of people with impaired capacity for decision-making. The mental capacity law landscape in New Zealand is fragmented. A review of the law will require a coordinated approach across the social, health and legal policy sectors. It will create the opportunity for New Zealand to show a firm commitment to human rights principles in its construction of capacity as a legal concept, and the chance to develop the law from New Zealand's own cultural perspective. Such reform is urgently needed. It is likely to get full support from those working within the health and disability sector who want to make positive changes that will benefit people with impaired capacity for decision-making.

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[925] Mahatma Ghandi, "A nation's greatness is measured by how it treats its weakest members"; also: Pearl S Buck civil rights/Nobel prize author of "The Good Earth"; James Earl "Jimmy" Carter Jr, former US President; and Pope John Paul II – among others.