

Review of the Health and Disability Commissioner Act 1994 and Code

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And to: Catherine McCullough:

Introduction

1. Thank you for the opportunity to provide comments and feedback on the Commissioner's consultation document, Review of the Health and Disability Commissioner Act 1994 (**Act**) and the Code of Health and Disability Services Consumers' Rights (**HDC Code**) (**HDC Review**)
2. Kia mōhio ai koutou, at the end of this submission I provide references to my law reform report (**Report**),¹ the Toolkit for assessing capacity (**Toolkit**),² our co-authored Book (**Book**)³ and two of my articles in international peer-reviewed journals.

Overall comment

3. The Commissioner and the office of the HDC are to be congratulated for the proposals in this review. Overall, I am very pleased with the general direction of travel for the HDC Review. I agree that:
 - there needs to be recognition and to reflect a shift in focus to support people in the exercise of their legal capacity and the principles of the Disability Convention;

¹ A Douglass, *Mental Capacity: Updating New Zealand's Law and Practice* (2016), New Zealand Law Foundation, available at www.alisondouglass.co.nz;

² A Douglass, G Young and J McMillan, *The Toolkit for Assessing Capacity*. (**Toolkit**) can be found at www.alisondouglass.co.nz.

³ A Douglass, G Young and J McMillan, *Assessment of Mental Capacity: A New Zealand Guide for Doctors and Lawyers* (2020) Victoria University Press now, Te Herenga Waka University Press.

- the move to embed tikanga and the use of te reo Māori into the HDC complaints processes and the HDC Code;
 - the revision of terms and language used in the HDC Code;
 - introducing a statutory requirement for review of HDC decisions and the option of a right of appeal from No Further Action (NFA) decisions or adverse HDC decisions in limited circumstances to an independent body or review panel. (Given the limited “appeal” right it will be important to have an independent panel / body as part of the re-design and amendment to the Act);⁴
 - lowering the threshold for access to the Human Rights Review Tribunal (HRRT) to put health complaints on an equal footing with the Privacy Act: this requires an investigation but the Commissioner does not have to conclude that there was substance to the complaint. (Noting the very real resourcing issue and minimal investigations currently undertaken – would it be possible to have a low level investigation process for some kinds of complaints?); and
 - the minor and technical improvements proposed which build on recommendations made in the 2014 review of the HDC Code which all seem practical and sensible minor amendments. (The recommended 10-year review period will only be satisfactory if a Commissioner is required to act on that process: what would be the criteria for a Commissioner to self-initiate a review of an aspect of the Code during the proposed extended 10 year period?).⁵
4. The Office of the Health and Disability Commissioner, the HDC Code and the complaints process are a vital and integral part of our health and legal system. They have a critical role in not only upholding consumer / patient rights in the provision of health and disability services, but also to contribute to positive changes in the legal system as it applies to the health and disability sector. Some of these proposed changes are long overdue.

⁴ I refer to the helpful article by Professor Jo Manning and endorse the proposed right of appeal under the complaints scheme despite the resource constraints. J Manning, *Access to Justice: the Quest for a Right of Appeal in New Zealand’s Health and Disability Commissioner Complaints Scheme* (2023) 30 JLM 822.

⁵ As former Chair of the Health Law Committee of the New Zealand Law Society, the Law Society we provided an extensive submission for the 2014 review by the former Commissioner and there was no discernible action on those recommendations, including recommendations for change from an earlier review.

5. The focus of my comments are in respect of embedding the HDC Code's compliance with Article 12 of the Convention on the Rights of Persons with Disabilities (Disability Convention / CRPD) and support for the exercise of a person's legal capacity into New Zealand law and Codes. This does not mean that I do not wish to have input into other topics and specific issues raised in the Review both from a policy and a legal perspective.
6. It is nearly eight years since I published my report for the New Zealand Law Foundation: *Mental Capacity: Updating New Zealand's Law and Practice in 2016 (Report)*. At that time the interpretation of the Disability Convention was in its early phases and while there was international academic debate, I found that there was very little discussion or awareness about Article 12 of the Disability Convention in New Zealand generally, or from the Government policy units.
7. This Review presents an opportunity to put greater emphasis on support measures, supported decision-making and the necessary safeguards into the informed consent process as set out in Rights 5,6 and 7, and recognising the umbrella rights.

Topics for comment

8. The areas I wish to comment on are as follows:
 - 8.1. Alignment of reviews by the Law Commission, Adult Decision-Making Capacity law (DMC law); HDC (Review) and the Ministry of Health (MoH) (Repeal and replacement of the Mental Health (Compulsory Assessment and Treatment Act) 1992 – (MHA).
 - 8.2. Defining capacity in the HDC Code;
 - 8.3. Right 7(4), respect for the rights, will and preferences – replacing “best interests” and introducing a well-being principle;
 - 8.4. Right 7(4), the defence of necessity and the Bournemouth gap;
 - 8.5. Right 7(5), advance directives and the interface with the PPPR Act; and
 - 8.6. Changes to the Act to allow for research on people unable to consent.

I. Alignment of reviews and changes to health and disability law

9. As I noted in my Report,⁶ the legal landscape of capacity law in New Zealand is fragmented. There is neither an overarching legal framework nor a cohesive social policy in New Zealand, yet the extent to which people are able to maximise the ability to exercise their legal capacity and be agents in law affects all aspects of people's lives in the legal and health system.
10. There are currently three Government reviews underway. These are:
 - 10.1. *Ngā Huarahi Whakatau* – Te Aka Matua o te Ture, the Review of Adult Decision-Making Capacity by the Law Commission (Law Commission Review of DMC Law): there is a proposal to replace the Protection of Personal and Property Rights Act 1988 (PPPR Act);
 - 10.2. Proposals for review and replacement of the Mental Health Act (Replacement MHA) by the Ministry of Health.
 - 10.3. This Review by the HDC of the Act and Code.
11. There is a danger of regulatory gaps and a silo effect isolating different aspects of the legal system because people do not know which part of the regulatory framework affects them.⁷ An example of this is people with learning disabilities held in psychiatric wards who have a mental illness but not meet the threshold for mental disorder under the MHA.
12. The issue of alignment of reviews is very stark in relation to both the issues of addressing reliance on Right 7(4) of the HDC Code as a basis to detain people unable to consent to their care: the Bournemouth gap and research on people who are unable to consent, discussed below.
13. I refer to my submission to the Law Commission. A number of the recommendations made in my report form part of the proposed new adult decision-making law to replace the Protection of Personal and Property Rights Act 1988 (**PPPR Act**). There is a strong need for the three Government agencies to be aligned not only in language and terms but importantly, policy and interface between the legal frameworks that operate so as to avoid harm to a vulnerable population.

⁶ A Douglass, *Mental Capacity, Updating New Zealand's Law and Practice 2016*, Report at [63].

⁷ Report citing Professor Graeme Laurie, Former Chair of Medical Jurisprudence, Edinburgh University (2015). See also: Laurie, G. (2017) *Liminality and the Limits of Law in Health Research Regulation: What are we Missing in the Spaces In-Between*. *Medical Law Review*, 25/1, 47-72.

II. Defining capacity in the HDC Code;

14. The Review proposes to revise the wording of “competence” in the HDC and replace it with “Capacity” in the HDC Code. This makes a lot of sense to have a consistent language across the HDC Code, DMC law and the replacement MHA.⁸
15. I recommend that capacity is defined in the HDC Code to expand on the understanding of supported decision-making and informed consent. This forms part of my recommendations for a single test for capacity in my Report in relation to changes to the current law, the PPPR Act.⁹
16. In my view, the HDC Code should provide a single and unified legal test for capacity that mirrors sections 3(1)-(4) of the Mental Capacity Act (England and Wales) 2005 (MCA), including a person’s *inability* to consent, as follows:

A person lacks capacity to consent or make an informed choice if they are unable to:

(a) understand the nature and the purpose of a particular decision and appreciate its significance for them;

(b) retain relevant essential information for the time required to make the decision;

(c) use or weigh the relevant information as part of the reasoning process of making the decision and to consider the consequences of the possible options, (and the option of not making the decision); or

(d) communicate their decision, either verbally, in writing or by some other means.

17. The Law Commission has recommended a single test for decision-making capacity. However, this is framed in the positive, that is, a person is *able* to undertake actions or make decisions rather than in the negative that they are “unable to”.
18. I recommend that the definition of “capacity” is consistent in both the HDC Code and the new DMC law with a single test as proposed above.
19. The core legal test is based on the functional test in Mental Capacity Act (England and Wales) 2005, s 3. It has been recognised in New Zealand legislation, the Substance Addiction (Compulsory Assessment and Treatment Act 2017¹⁰ and the

⁸ I personally do *not* like the term “affected person” and would prefer a neutral term for “person”.

⁹ Report at *Chapter 4*, p 116.

¹⁰ Capacity to make informed decisions, s 9. See also Book, Chapter 11, Substance Addiction.

End of Life Choice Act 2019.¹¹ In the Toolkit, we call this the “core legal test”.¹² If a person is unable to make or take an action in relation to one of the four abilities then they lack capacity in relation to that specific decision.

20. In case law, this definition of capacity has been accepted as the “Toolkit test” by the Family Court, involving a young woman with learning disabilities and her capacity to marry.¹³ The Expert advisor to Health and Disability Commissioner has also recognised the Toolkit as the accepted standard for health practitioners undertaking capacity assessments.¹⁴
21. In relation to the capacity to consent to health care, the legal test in the MCA has codified the common law test based on English case law. The person must be able to:¹⁵
 - understand the nature, purpose and effects of the proposed treatment;
 - weigh up the options, the risks and benefits, including the likelihood of success and any alternative forms of treatment;
 - appreciate the possible consequences of receiving, or not receiving, the proposed treatment; and
 - communicate their decision.
22. In addressing the revision of the HDC Code to include this definition, there could also be more emphasis on supported decision-making at the beginning of the informed consent process as provided for in Right 7(3) of the HDC Code. A capacity assessment is part of a process to maximise a person’s ability to participate in decisions that affect them, taking into account the person’s will and preferences and an opportunity to ascertain the person’s core values.

¹¹ The term “competence” rather than “capacity” inexplicably appears in “Meaning of competent to make an informed decision about assisted dying,” s 6.

¹² . *A Toolkit for Assessing Capacity* is shown at Appendix D of my 2016 Report. The Toolkit is freely available: www.alisondouglass.co.nz See also A Douglass, G Young and J McMillan *Assessment of Mental Capacity: A New Zealand Guide for Doctors and Lawyers* (Te Herenga Waka University Press, 2020). We are currently updating it.

¹³ *OD v NW by her litigation guardian AP* [2018] NZFC 3869, Judge Coyle; see Book, Chapter 9, Capacity and Personal Relationships.

¹⁴ Dr C, (Case 20HDC00126) – Book, Chapter 13 Professional Guidance for Health Practitioners.

¹⁵ Book, Chapter 3, pp 175-6. *Re C* (Adult: Refusal of Medical Treatment) [1994] 1 WLR 290; [1994] 1 All ER 819; *Re MB* (Medical Treatment) [1997] 2 FLR 426. *Foundation Trust v JB* [2014] EWHC 342 (COP) [25]–[26].

23. The advocacy service have a role in this aspect of operationalising support measures in terms of Art 12.3 of the Disability Convention.

III. Right 7(4), respect for the person's rights, will and preferences – addressing best interests and the wellbeing principle

24. In respect of the Review's proposal to review the wording of Right 7(4) the Review proposes a strengthening of Right 7(4)(ii).

25. I set out the proposed change to Right 7(4) with the changes in bold.

(4) Where a consumer **does not have decision-making capacity** ~~is not competent~~ to make an informed choice and give informed consent, and no person entitled to consent on the behalf of the consumer is available, the provider may provide services where –

(a) it is in the best interests of the consumer; and

(b) reasonable steps have been taken to ascertain the **will and preferences** ~~views~~ of the consumer; and

(c) either, -

(i) if the consumer's **will and preferences** ~~views~~ have been ascertained, and having regard to their **will and preferences** ~~those views~~, the provider believes, on reasonable grounds, that the provision of the services is consistent with the informed choice the consumer would make if they were competent; or

(ii) if **7(4)(c)(i) does not apply, --(the consumer's views have not been ascertained)**, the provider takes into account **the will and preferences of the consumer to the extent they are ascertained, and** the views of other suitable persons who are interested in the welfare of the consumer and available to advise the provider.

26. Firstly, I note that the proposed changes in wording reflects Article 12(4) of the Disability Convention by largely replacing the word "views" with "will and preferences" as it pertains to the consumer. However, it does not fully reflect Art 12.4 by including "**respect for the rights, will and preferences**" of the person.

27. Secondly, the proposed revised Right 7(4) retains the term “best interests” because after the will and preferences of the consumer and other persons’ views are obtained, ultimately the provider has to over and above this process make a “best interests” decision.
28. Thirdly, the checklist for best interests in our Book (in the supported decision making chapter),¹⁶ is based on s 4 checklist for Best interests in the MCA (England and Wales) and as noted in my articles on this topic is similar to Right 7(4).
29. The HDC Code does include the umbrella rights, Including Right 1, the right to be treated with respect.
30. Generally, in academic literature and English case law since the MCA, the traditional concept of “best interests” is rejected because of its paternalistic origins.¹⁷
31. The Law Commission proposes to shift from the term “best interests” to “rights, will and preferences” with an “in the round assessment” in relation to decisions that are made on behalf of another person.¹⁸
32. As set out in my comments to the Law Commission, in my view the new Act for DMC Law should provide a framework for decision-making to give transparency and accountability about how decisions are made by others in both informal and formal settings, the latter including representatives / welfare guardians etc and / or the court.
33. While the s 4 checklist of the Mental Capacity Act uses pre-CRPD terms of language, the general academic consensus is that the combination of wishes, feelings, beliefs and values is in essence a person’s “will and preferences”.¹⁹
34. Best interests is referred to in other legislation, not only in Right 7(4) of the HDC Code and is regarded as a secondary principle under the PPPR Act. It forms the

¹⁶ Book, Chapter 3, p 171 and following Best Interests.

¹⁷ See A Douglass *Best Interests – A Standard for Decision-Making in Mental Capacity Law in New Zealand* (Thomson Reuters). See also Law Commission paper.

¹⁸ See A Douglass Law Commission submission. The Law Commission are referring only to best Interests decisions - replaced with “In the round assessment” for formal situations where there is a court-appointed representative (10.7, 10.13-10.41). It is important in any Code of practice that informal situations are covered also. When, for example, a doctor makes a decision to provide a vaccination to an elderly person with impaired capacity under Right 7(4) this should be recorded in the notes to reflect the “informal” decision to proceed without the person’s consent.

¹⁹ There is vast literature on Best Interests and as per Lady Hale in *Aintree v James*, UK Supreme Court, there is a shift from the “what the doctor thinks best” to “the patient’s point of view”. See also Peter Jackson J in the Court of Protection “(in)capacity is not an off-switch to a person’s rights and freedoms”. *Wye Valley NHS Trust v Mr B* [2015] EWCOP 60 at [38].

basis of underlying decisions made in the *parens patriae* decision jurisdiction of the High Court. However, there is no statutory checklist such as in English law and there is limited case law on the meaning of best interests in New Zealand.

35. I do not agree with jettisoning the concept of “best interests” from the legislation or indeed the HDC Code. Both capacity and best interests are core concepts. Best interests and how to make decisions for others still has a role to play.
36. Professor John McMillan and I propose the introduction of a “wellbeing” principle and decision-making framework to replace and reframe the traditional concept of “best interests” as a standard for decision-making.²⁰
37. The proposed change in term aims to place greater emphasis on respect for a person’s rights, will and preferences - and how they wish to live their life to the same extent as others - where a person needs ongoing support and is regarded in law as not having DM Capacity to make a legal decision for themselves.
38. In our Book, we use case studies to demonstrate the ethical values used for capacity assessment, include the principles of liberty, wellbeing and first of all “do no harm” (see for example, Book, Chapter 1 and discussion of ethical principles). In situations where a capacity assessment is finely balanced, these principles need to be weighed and applied in order to “build a case” for the best way forward.²¹
39. The same approach applies when making decisions for others where a person is recognised and the law is not able to make the decisions for themselves.²²
40. We propose an emphasis on all four components of *respecting the rights, will and preferences* of a person under Article 12.4 of the CPRD in respect of reaching decisions:
 - Rights - respect for the persons mana and dignity;
 - Rights - equal recognition before the law;
 - Will – values (as expressed, past and present);
 - Preferences – expressed choice (as expressed, past and present).

²⁰ We are developing the notion of the well-being principle in our current update on the Toolkit.

²¹ J McMillan, *The Methods of Bioethics: An Essay in Meta-Bioethics*, Oxford University Press (2018) at 117.

²² See my chapter on *Best Interests* in Mental Capacity Law in New Zealand and also the Medical Law International article, *Rethinking best interests and necessity*.

41. This is not an exhaustive list. There are other factors which the Law Commission's paper touches on. An important inclusion would be the principle of the least restrictive intervention, referred to and embedding this as a principle in any new law.
42. In summary, the proposed changes in Right 7(4) are a step towards reflecting the need to respect the rights, will and preferences of a person under Art 12.4 of the Disability Convention.
43. Right 7(4) of the HDC Code has a very pragmatic and sensible place in health and disability law where decisions are needed to be made for a person who is unable to make a decision through impaired capacity and decisions should be made for their wellbeing (and in their best interests), taking into account the person's views:- variously described as "wishes and feelings" in English law and "will and preferences" under Article 12.4 of the Disability Convention. However, it is ultimately a defence of necessity for the provider, not a positive right for the consumer.²³
44. We propose that "best interests" is reframed as the "wellbeing principle" with a clear statutory framework to work from in the new DMC law.
45. There clearly needs to be a co-ordinated approach with the Law Commission as to how this standard and framework is reflected in both the new DMC law and any revisions of Right 7(4).
46. The addition of the wellbeing principle (or whatever term is used to replace best interests or retain best interests) provides an opportunity to link tikanga to these values and vice versa.
47. The wellbeing principle could also include respect for tikanga Māori, beliefs and values, and the formulation of this term should require consideration and understanding of that person's world views and to give effect to the preferences that stem from those world views.

IV. Right 7(4), the defence of necessity and the Bournemouth gap

48. There is no recognition in the Review of the Bournemouth gap and the issue of detention of people in care who are unable to consent or make an informed

²³ See Mental Capacity Act (England and Wales) 2005, s 5 and statutory defence. The statutory bar and ACC legislation in New Zealand creates a unique legal position as health professionals will not be sued for clinical negligence arising directly or indirectly out of a personal injury.

choice and the associated legal safeguards to ensure that decisions are made in a person's "best interests".

49. The "Bournewood Gap" refers to a House of Lords decision²⁴ which was overturned by the European Court of Human Rights (ECHR) in *HL v United Kingdom* (referred to as the Bournewood case).²⁵
50. This case concerned a profoundly autistic and non-verbal man, HL, who was detained and medicated in a hospital ward. Because he was compliant and did not resist, he had not been formally detained under the Mental Health Act 1983 (UK). In the absence of HL's ability to provide informed consent to the restrictions the hospital relied on the common law doctrine of necessity to authorise its actions. However, the ECHR found that the lack of procedural safeguards regarding the initial admission and lack of access to a court to review the lawfulness of the detention breached Articles 5(1) and 5(4) of the European Convention on Human Rights. In *HL v United Kingdom*, a key factor was that the healthcare professionals treating and managing HL exercised complete and effective control over his care and movement.
51. In the UK under the Mental Capacity Act, a statutory scheme was set up known as the deprivation of liberty safeguards. These safeguards referred to as "DoLS" attracted criticism and there is still work being done to streamline them following the 2019 amendment to the MCA and in light of a further UK Supreme Court decision involving young adults with learning disabilities in community care known as "Cheshire West".²⁶
52. The Bournewood case is relevant to New Zealand, and to the review of the HDC Act and Code because s 22 of the NZBORA protects the right not to be arbitrarily detained. New Zealand is also a party to the CRPD, which recognises the right to liberty.²⁷
53. The effect of the court decisions exposing the Bournewood Gap has been to reject the previous assumption that detention in these circumstances could be justified based on the common law doctrine of necessity – as set out in Right 7(4) of the HDC Code.

²⁴ *R v Bournewood Community and Mental Health NHS Trust*, Ex p. L [1988] 3 All ER 289 per Lord Goff at 298.

²⁵ *HL v United Kingdom* (2004) 40 EHRR 32.

²⁶ *P v Cheshire West and Chester Council* and *P v Surrey County Council* [2014] UKSC 19.

²⁷ CRPD, Art 14 and ICCPR, Art 9(1) and (4).

54. In New Zealand the closest reported example to date concerning an HDC Code complaint is the case of *Taikura Trust*.²⁸ This complaint involved the detention of a woman in a dementia unit against her wishes. Ms A was a 43 year old woman with a complex history of mental illness and alcohol abuse and was held in a secure dementia unit for almost a year without legal authority. The case was resolved in the Human Rights Review Tribunal where compensation was payable to Ms A's estate (after she died).²⁹ The Tribunal made declarations against Taikura Trust and Aranui Home and Hospital Limited for failures of care and breaches of Ms A's rights by failing to provide services in a manner that respected her dignity and independence and failing to provide services with reasonable care and skill.
55. The issue of deprivation of liberty in New Zealand results in applications for writ of habeas corpus and associated liberty rights that apply to people detained under the criminal law unlawfully, the Mental Health Act and under the PPPR Act. For example, a case where it was alleged that the person subject to care and welfare orders under the PPPR Act was unlawfully deprived of his liberty by his appointed welfare guardian.³⁰ And another where the husband of a woman who was detained in a secure dementia unit sought to challenge on appeal the lawfulness of her confinement.³¹
56. In my 2016 Report I prepared a chapter on liberty safeguards and made recommendations to provide legal mechanisms, criteria and procedures for liberty safeguards in New Zealand. No response was received to my report from the Health and Disability Commissioner or Mental Health Commissioner at that time or since.
57. *This is Not My Home*, published 2018, is a collection of perspectives on the provisions of aged residential care without consent was subsequently compiled and published by the Human Rights Commission (see my paper "*Filling the Gap – Liberty Safeguards for People with Impaired Capacity*", Chapter 90). This publication followed a road show across New Zealand involving a number of psychiatrists, lawyers and the late Judge Phil Recordon and attracted widespread attention from people and providers working in the health and disability sector.

²⁸ Health and Disability Commissioner Opinion 08HDC20957, Auckland District Health Board, Taikura Trust; Aranui Home and Hospital Limited (Trading as Oak Park Dementia Unit) 3 November 2010.

²⁹ *Director of Proceedings v Taikura Trust – Needs Assessment and Co-ordination Service* HRRT No. 024/2011 [2012] NZHRRT 3 (22 March 2012).

³⁰ *E v E* Wellington High Court CIV-2009-485-2335, 20 November 2009 Simon France J. I was counsel for the welfare guardian mother in this case.

³¹ *M v CEO of Counties Manukau District Health Board* [2016] NZHC 277 Thomas J; *N v Bupa Care Services (New Zealand) Limited* [2017] NZHC 499; and *AN v Bupa Care Services (New Zealand) Limited* [2017] NZSC 49. See also Book, Chapter 7 Liberty and Placement in Care 7.5 New Zealand's Bournemouth gap pp 204-207.

58. There have been numerous media features and stories particularly in the context of people being detained in a rest home without consent or proper legal authority. Anecdotally, I still receive many inquiries from lawyers and health professionals, and families where they are concerned about the both the ethical and legal authority to detain someone without consent. The situation applies to young people with disabilities not just older people in a whole range of settings- in institutions and in the community. We have no database in New Zealand so we do not even know the size of the problem. What we can say is that there is ethically a general consensus of concern about how we care for the most vulnerable in society, especially in these settings.
59. New Zealand's relatively small population and non-litigious culture is in my view an advantage to do things smarter and more administratively efficient than is the case in England and Wales where there have been difficulties implementing the Deprivation of Liberty Safeguards.
60. The terms of reference for the Law Commission provided that the scope of its Review would include (but was not limited to) consideration of "How the law should regulate situations where people, whose ability to make decisions may be limited are deprived of their liberty (other than in the context of criminal proceedings)".
61. However, it appears the topic of deprivation of liberty safeguards and how to address the Bournemouth Gap has been excluded in the Law Commission's review and the Second Issues paper.
62. The issue becomes relevant in the Law Commission's Second Issues Paper because it raises the question of whether a donor of an Enduring Power of Attorney (EPOA) has legal authority to deprive the donee of their liberty.
63. Relevantly, this is not just a matter of "mental health law " and even if it was the current legal framework including the orders available from the Family Court under the PPPR Act and Right 7(4) of the HDC Code, does not provide an independent means to check upon a person's liberty rights *before* a person's placement in care. A capacity assessment provides one of the checks and balances by placing the person at the heart of any of the decisions about their confinement and supports the fewest restrictions on their liberty. However, there remains no pro-active legal process to provide for these safeguards or a standard such as best interests as the basis for making a decision to deprive a person without consent.
64. To date the Health and Disability Commissioner has been silent on what if any is the Commissioner's position to the Bournemouth gap and processes under the

HDC Code where there is no legal authority to place a person in care without their consent.

V. Right 7(5), advance directives and the interface with the PPPR Act

65. The HDC Review does not address advance directives or provide much needed guidance on the operation of Right 7(5) of the HDC Code and when an advance directive may be considered valid and applicable “in accordance with the common law.”
66. If there was one part of the HDC Code which should be highlighted as a support measure under the Disability Convention, art 12.3, that would be Right 7(5).
67. In Chapter 12 of our Book (with a commentary from Professor Ron Paterson), we outlined the range of advance decisions that can be made. The UN Committee that interprets the Disability Convention recognises advance directives as a form of supported decision-making.³² For many people with disabilities the ability to plan in advance is an important form of support whereby they can state their will and preferences, which can then be followed at a time when subsequently they may no longer be in a position to communicate their wishes to others.
68. There is a move to place emphasis on the distinction between advance directives - decisions which enables the person while capable to refuse specified medical treatment when they lack capacity to refuse that treatment – a “negative”/right not to advance directives - compared to advance decisions made in the mental health context for recording a person’s preferences for treatment – a “positive” advance decision sometimes referred to as the Ulysses contract and used as an important tool in mental health care.
69. While progress is being made in the mental health context to formalise advance preferences, there remains a need to address the right to refuse medical treatment as understood in Right 7(5) of the Code. The interface with the replacement MHA is not mentioned at all.
70. As noted by the Law Commission in Chapter 15 of the Second Issues Paper the current law is unclear about how an advance directive is considered by attorneys under EPOAs or by appointed welfare guardians and a weight to be given to them by such decision-makers.
71. There is the issue of how representatives and attorneys should consider advance directives, the discretion that arises, and whether to act on them. The same issue

³² UN Committee on the Rights of Persons and Disabilities General Comment No. 1 Article 12 (2014) at 17. Book at Chapter 12 Advanced Decisions, p 352.

arises for health professionals who may be presented with an advance directive in a clinical context. They too must consider the person's will and preferences and not ignore the directive if there is evidence that the person had capacity to make the advance directive at the time it was made.

72. Consideration should also be given to whether the Law Commission's proposed Register for EPOAs and court orders could also include registration of a person's advance directive. Once again this requires a co-ordinated approach with HDC and more guidance under Right 7(5) of the HDC Code.
73. Finally, there is a concern that the Law Commission recommends a non-binding "expression of wishes" (similar to an advanced care plan (ACP) – although this term does not appear to be used). An expression of wishes could undermine and indeed usurp the role of a valid advance directive as advance directives are seen as being "too hard" to implement and may become obsolete.

VI. Research on people unable to consent

74. In 2015, as part of my international research fellowship, I interviewed key stakeholders in England and Wales, and in Scotland regarding the changes made by their respective parliaments 20 and 25 years ago to address the then considered prescient need to allow research on people who lack capacity to consent and to provide the necessary safeguards. My recommendations were provided to the Health and Disability Commissioner in 2016 and are set out in Chapter 6 of my Report.
75. The key driver for such changes is to secure the benefits of research for people who lack capacity. Right 7(4) and legal justification for research without consent is on the narrow basis that it is in the person's individual "best interests" whereas in some situations there may only be societal benefits resulting from the research. Such research may still be ethically justified, but it may not be in the best interests of the individual participating in the research, as required under Right 7(4).
76. In Chapter 6 of my Report, I gave two clinical trial examples. I also interviewed the Chair of the Oxford Ethics Committee that had undertaken a clinical randomised trial in the use of adrenaline for people suffering heart attacks which involved a population of 10,000 people and a process negotiated with the Ethics Committee which allowed for an opt out consent.
77. I refer to my article with Professor Angela Ballantyne in the international journal, *Bioethics*. Again, this is a pressing issue for allowing ethical research that will benefit not only individuals but society as a whole and to adhere to international

guidelines and to promote the rights of people with disabilities who are being excluded from valuable research.

78. There are also issues with the interface with the PPPR Act including the limitation of powers such as a welfare guardian or an attorney under an EPOA for personal care and welfare may not exercise under s 18 or s 98 of the PPPR Act, namely consent on behalf of a person to medical experimentation.
79. The current gap in the law is hugely problematic for researchers, discriminatory against people with disabilities – a wide sector of society given the broad definition of “disability”, as they do not receive the benefit of ethical research. This runs counter to health policy and public good research in New Zealand and advancing health care and social research.
80. More recently, I represented a researcher based at a research unit at Middlemore Hospital who was declined ethics approval. Dr Mark Marshall, principal investigator of the RESOLVE study appealed to HRC Ethics Committee as the Ethics Committee (Southern HDEC) on 28 August 2020, declined the investigator’s resubmission application for ethical review of the RESOLVE study where written consent could not be obtained. The RESOLVE study aims to establish the comparative effectiveness of sodium dialysate concentration comparing two standard-of-care practices in dialysis patients in New Zealand in haemodialysis units.
81. This was a low risk public-good research that is part of an international study involving mainly elderly patients on dialysis, some of whom had impaired capacity. The opt-out consent process for this study without written consent was declined approval by the Ethics Committee and on appeal to the HRC Ethics Committee on the grounds that there was no legally effective consent in a manner consistent with New Zealand law and in particular, Rights 5, 6 and 7 of the HDC Code.³³ Ultimately, this public good study with funding of \$1.2m from the Health Research Council was withdrawn as the study could not proceed.³⁴
82. I acknowledge the progress towards consideration of HDC’s draft recommendations relating to unconsented research (Review pp 40-41). However, in my opinion, amending Right 7(4) and associated Rights of the Code is insufficient to give the necessary legal authority for decisions by an Ethics

³³ The Ombudsman also issued an opinion on the question of transparency and privilege of the Ministry of Health’s legal opinion provided to the Ethics Committee s 37086 (Complaint Ground: s 37088).

³⁴ Advice from Dr Mark Marshall, Principal Investigator, July 2024.

Committee that will allow exceptions to the requirement for written informed consent.

83. The National Ethics Advisory Committee (NEAC) is an advisory committee appointed by the Minister. It has been placed in the difficult position of issuing standards that do not allow research in this context. Whilst NEAC is charged with setting the ethical standards for ethics committees it has no overarching legal responsibility for the ethics committees or the basis upon which exceptions to the requirement for the right to informed consent can be made to health and disability research.

84. Therefore, I recommend as follows:

84.1. **Legislation not regulation.** There needs to be an amendment to the Health and Disability Commissioner Act,³⁵ not the HDC Code, so that Right 7(4) remains a defence of necessity for short-term treatment decisions in an individual's best interests: its proper purpose. The HDC Act would provide the legal authority to allow an ethics committee to authorise an ethics committee to approve research involving non-consenting participants;

84.2. I agree in principle that identifying suitable persons interested in the welfare of the person to be able to veto their participation in the research as part of the necessary safeguards;

84.3. I agree that the proposed test of no more than minimal foreseeable risk and no more than minimal foreseeable burden is an appropriate test to be applied to the research in this context. I refer to s 51 of the Adults with Incapacity Act 2000 (Scotland). As with the Mental Capacity Act 2005 (England and Wales) ss 30-34 both these Acts provide useful examples for providing for such change to the legislation; and

84.4. While specialist ethics committees could oversee such research, a better safeguard would be to ensure that there is an overarching regulatory framework for *all* ethics committees to ensure the rigour of decision-making expected of ethics committees.

85. The Commissioner could recommend revisiting the changes made to ethics committees in 2012 and the undermining of the ethics review system under the former New Zealand Public Health and Disability Act 2000. Currently members of an ethics committee are appointed by the Minister of Health under the Pae Ora

³⁵ Another possibility is for the new decision-making capacity law proposed by the Law Commission to replace the PPPR Act includes a section in that Act, as is the case in the MCA (England and Wales) and the AWIA (Scotland).

(Health Futures) Act 2022. There appears to be a further watering down of the requirement for the appointment of ethics committees by the Minister.³⁶

86. There is a wide range of clinical research, therapeutic / non-therapeutic and social science research where some participants, but not necessarily all of them, may be unable to consent to their participation. For example, research on people with early stages of dementia.
87. All ethics committees should have the skill, knowledge and attributes as a body to make case-by case decisions about participation in such research which goes to the heart of informed consent and ethical justification for allowing the research to proceed with necessary safeguards.
88. There remains no overarching legal framework for research ethics committees which in New Zealand are accredited by way of convention by the HRC Ethics Committee. The downgrading of protection of research participants and restructuring of ethics committees is not in line with international standards. There is a danger of losing the necessary independence of the ethical review system. Ethics committees that are independent of the researchers and the institutions, was a key recommendation of the Cartwright Inquiry in 1988. The WHO standards and operational guidance for ethics review of health-related research on human participants have consistently been advocated by NEAC.

Conclusion

89. Thank you for the opportunity to provide these comments and feedback on the HDC Review. I am available for further consultation and would value the opportunity to support the Commissioner with some of the proposed changes to the Act and Code.

Nāku noa iti, nā



Alison Douglass

³⁶ The new Act simply states that the Minister's role includes: "establishing committees under this Act." Pae Ora Act 2020, s 10(1)(f). The establishment of ministerial committees gives a wide discretion to the Minister as to their establishment, purpose, membership and function: s 87. Section 8 allows for continuation of pre-existing committees, presumably ethics committees, under s 11 of the former Act to continue "as if they were established under section 87 of the Act". Once disestablished by the Minister there would appear to be no mandate to appoint ethics committees in accordance with international standards. NEAC – the National advisory committee on health services committees is now established under s 92 of the Pae Ora Act and continues to have no oversight role of ethics committees appointed by the Minister.

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- A copy of s 51 of the Adults with Incapacity Act 2000 (Scotland) (**Scottish law**)

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- A Douglass, G Young and J McMillan, *The Toolkit for Assessing Capacity*. (**Toolkit**) can be found at: www.alisondouglass.co.nz. The *Toolkit* is a clinical, legal and practical guide for health practitioners and lawyers when assessing an adult's capacity to make decisions. It provides a three-step method for carrying out a capacity assessment when deciding whether an individual has capacity to make legal decisions such as consent to treatment or property decisions or making a will, and, if not, whether others will be appointed to make decisions on their behalf
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