

He Puka Kaupapa | Issues Paper 49

# He Arotake i te Ture mō ngā Huarahi Whakatau a ngā Pakeke

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## Review of Adult Decision-Making Capacity Law: Preliminary Issues Paper

Te Aka Matua o te Ture | Law Commission is an independent, publicly funded, central advisory body established by statute to undertake the systematic review, reform and development of the law of Aotearoa New Zealand. Its purpose is to help achieve law that is just, principled and accessible and that reflects the values and aspirations of the people of Aotearoa New Zealand.

Te Aka Matua in the Commission's Māori name refers to the parent vine that Tāwhaki used to climb up to the heavens. At the foot of the ascent, he and his brother Karihi find their grandmother Whaitiri, who guards the vines that form the pathway into the sky. Karihi tries to climb the vines first but makes the error of climbing up the aka taepa or hanging vine. He is blown violently around by the winds of heaven and falls to his death. Following Whaitiri's advice, Tāwhaki climbs the aka matua or parent vine, reaches the heavens and receives the three baskets of knowledge.

***Kia whanake ngā ture o Aotearoa mā te arotake motuhake***

***Better law for Aotearoa New Zealand through independent review***

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The Māori language ingoa | name of this review was developed for Te Aka Matua o te Ture | Law Commission by members of the Commission's Māori Liaison Committee.

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Kei te pātengi raraunga o Te Puna Mātauranga o Aotearoa te whakarārangi o tēnei pukapuka.

A catalogue record for this title is available from the National Library of New Zealand.

ISBN 978-0-9951291-9-1 (Online)

ISSN 1177-7877 (Online)

This title may be cited as NZLC IP49. This title is available on the internet at the website of Te Aka Matua o te Ture | Law Commission: [www.lawcom.govt.nz](http://www.lawcom.govt.nz)

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# Have your say

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## HOW TO SUBMIT ON THIS PAPER

We would like to hear your views. Your input will help us think about options for reform.

To help us understand your views, we ask questions throughout this paper. Not all questions will be relevant to all people, and there is no need to answer all the questions.

You can provide a submission to this paper by:

- Visiting [our project website](#) and filling out a survey
- Emailing us at [huarahi.whakatau@lawcom.govt.nz](mailto:huarahi.whakatau@lawcom.govt.nz)
- Texting us at 0297799009
- Writing to us at:  
Review of Adult Decision-Making Capacity Law  
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Submissions are due by 5pm on 3 March 2023.

## WHAT HAPPENS TO YOUR SUBMISSION?

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If you send us a submission, we will:

- Consider the submission in our review.
- Keep the submission as part of our official records.

We may also:

- Publish the submission on our website.
- Refer to the submission in our publications.
- Use the submission to inform our work in other reviews.

Your submission may contain personal information. You have the right to access and correct your personal information at any time.

You can request that we do not publish your name or any other identifying information in your submission. If you request this, we will not publish your name or any other information that we think might identify you or others on our website and in our publications.

However, if you make a submission on behalf of an organisation, we will publish the name of that organisation.

If we receive a request under the Official Information Act that includes your submission, we must consider releasing it. If the information requested includes your personal information, we will consult with you.

If you have questions about how we manage your submission, you are welcome to contact the Law Commission's General Manager ([gm@lawcom.govt.nz](mailto:gm@lawcom.govt.nz)).

## **SEEKING HELP WHEN MAKING YOUR SUBMISSION**

Some people may find it emotional or distressing to make a submission. If you want to make a submission, you may want to arrange to have a support person ready to help. If you need someone to talk to, you could call or text 1737. This helpline service is free and is available 24 hours a day. You'll get to talk or text with a trained counsellor. The service is provided by Whakarongorau Aotearoa | New Zealand Telehealth Services.

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## CHAPTER 1

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# Introduction

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- 1.1 We all make decisions every day. Some of these decisions may be relatively minor or routine, such as what to eat for breakfast. Other decisions may be less routine or more significant, such as where to live, starting a new job, or having an operation. Sometimes we make decisions alone and sometimes we seek support or help.
- 1.2 In this review, we will consider what role the law should have when a person's decision-making is affected. There are many things that can affect a person's decision-making. These can include a traumatic brain injury, dementia, learning disabilities and experiences of mental distress. People's decision-making can be affected for one decision, for a series of decisions or for decisions more generally.
- 1.3 We use the term 'affected decision-making' to refer to all these situations. While other terms, such as 'impaired decision-making' or 'diminished capacity' are sometimes used, we have heard those terms may not resonate with everyone and they can be stigmatising or perpetuate negative stereotypes. We think it is important to use language that people are comfortable with.
- 1.4 If a person's decision-making is affected, the current law may treat some or all their decisions differently to the way it otherwise would. It does this using the concept of 'decision-making capacity'.
- 1.5 Not everyone with affected decision-making will be considered to lack decision-making capacity. For those who **are** considered to lack decision-making capacity, there are significant legal implications. If a person is assessed not to have decision-making capacity for a decision, the decision might not have legal effect. Another person may be appointed to make the decision for them.
- 1.6 Medical or other expert advice will often be important to determining whether someone has decision-making capacity. However, what it means to have decision-making capacity, and what happens if a person does not, are **legal** questions, not medical ones.

## SCOPE OF OUR REVIEW

- 1.7 Te Aka Matua o te Ture | Law Commission is an independent agency that provides law reform advice to the government. We review the law and make recommendations to the government on how to improve it.
- 1.8 The scope of this review is set out in a document called our ‘terms of reference’. They are very broad. In short, we will consider how the law should approach issues relating to affected decision-making of adults. Our terms of reference are included as an annex to this paper.
- 1.9 A brief summary of the current law is set out in Chapter 4. Under the current law, decision-making capacity tends to be a yes or no concept. For any given decision, a person is either assessed as having, or not having, decision-making capacity. If they are assessed not to have decision-making capacity, the law may not give effect to their decision and may appoint someone else to make a decision instead.
- 1.10 This is not the only approach the law could take. In recent decades, there have been widespread calls for law reform. There has been increased recognition of the human rights of disabled people and a shift towards supporting people to make their own decisions. There has also been increased recognition that the law in this area does not adequately take into account te Tiriti o Waitangi, or te ao Māori and the multi-cultural nature of Aotearoa New Zealand. As well, our population is changing. Aotearoa New Zealand is an increasingly aging and culturally diverse population.
- 1.11 Against this background, our review will consider fundamental questions such as: What, if anything, should the law do when a person’s decision-making is affected? How should the law enable people to make decisions about their own lives, while protecting them from harm or abuse? How should the law reflect te ao Māori? How should other cultural perspectives be included?
- 1.12 Some areas of decision-making capacity are outside the scope of our review, even though they are important. We are not reviewing approaches to decision-making capacity under criminal law. We are also not reviewing decision-making capacity for children and young people.

## OUR REVIEW SITS ALONGSIDE OTHER WORK

- 1.13 Some of the calls for law reform have also led to other related projects and initiatives. Manatū Hauora | Ministry of Health is carrying out a ‘repeal and replace’ review of the Mental Health (Compulsory Assessment and Treatment) Act 1992. Our review is separate to the work the Ministry of Health is doing, but we will consider the Ministry’s work when we make our final recommendations.
- 1.14 Other initiatives include the establishment of a new ministry – Whaikaha | Ministry of Disabled People – and the introduction of the Accessibility for New Zealanders Bill. Te Rōpū Whakamana i te Tiriti o Waitangi | Waitangi Tribunal, as part of its Hauora inquiry, is also looking at the experiences of tāngata whaikaha Māori | disabled Māori. In addition, the Royal Commission of Inquiry into Abuse in Care is investigating abuse in State and faith-based disability and institutional care settings.

## PURPOSE OF THIS PAPER

- 1.15 This paper supports our first round of consultation. We want to learn about your experiences with current law and practice and what you think about the big issues and principles that should inform our review.
- 1.16 This paper does not focus in detail on issues with the current law. It also does not cover every area of law or issue that is raised by this review. Instead, the paper starts by setting out relevant context to this review (Chapters 2-5). We discuss the language we use, why reform is needed, the key legal concepts and law, and relevant tikanga and te ao Māori concepts. In Chapter 6 we discuss some principles we have developed to guide our review.
- 1.17 This paper then considers decision-making in practice. Chapter 7 looks at ways in which people can be involved in others’ decisions. Chapter 8 considers how the law can ensure people with affected decision-making are safe from harm, and people involved in the decision-making of others are accountable for their actions. Chapter 9 then provides an opportunity for you to tell us anything else you think we should know.
- 1.18 In developing this paper we received input from our two advisory groups: the Professional Expert Advisory Group and the Lived Experience, Family and Whānau and Carers Expert Advisory Group.

- 1.19 We will have a second round of consultation in 2023, supported by a longer consultation document that will address the current law in more detail and propose some options for reform. This will draw on the feedback we receive on this paper.
  - 1.20 After our second round of consultation, we will prepare our final report. This will recommend to the government how the law should be reformed in this area. We intend to provide our final report to the Minister of Justice by 30 June 2024.
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## CHAPTER 2

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# The language we use in our review

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## INTRODUCTION

- 2.1 The language we use in this review is important. Some words are understood differently by different people, there are differing views around preferred language, and these views can change over time. Sometimes language can be stigmatising or perpetuate negative stereotypes.
- 2.2 To ensure that our written work and publications are as clear as possible, we need to settle on some consistent language. In this section, we explain some key terms we propose to use and why. We acknowledge that people will have a range of views on our proposed terminology and are interested in your thoughts.
- 2.3 If we are communicating with you directly, we will seek to use the language you prefer to use, whether or not that is the same as the language we use in our written work.

## SOME KEY TERMS

### Disability and disabled person

- 2.4 We intend to take a broad and inclusive approach to defining disability to include disability resulting from any mental, cognitive, or sensory impairments. We also intend disability to include disabled people's experience of being excluded from full participation in society due to physical and societal barriers. This reflects what is called the 'social model' of disability. We discuss the social model of disability in Chapter 3.
- 2.5 We propose to use the term 'disabled person' to describe any individual who experiences disability. This term also reflects the social model of disability and is consistent with the New Zealand Disability Strategy 2016-2026, which was developed with advice from disabled people.

- 2.6 We acknowledge that not all people with affected decision-making will identify or agree with the term disabled person. Some people may prefer to use the term ‘person with a disability’. We have also heard that many Māori disabled people identify as Māori first, and that some people may not identify with the language of disability at all.

### **Learning disability**

- 2.7 In our research and early consultation, we have seen the terms ‘cognitive impairment’, ‘learning disability’, ‘cognitive disability’ and ‘intellectual disability’ used interchangeably. We propose to use the term ‘learning disability’, as we have heard this term is generally preferred.

### **Tāngata whaikaha Māori**

- 2.8 We intend to use the term ‘tāngata whaikaha Māori’ to refer to Māori disabled people.
- 2.9 The term tāngata whaikaha Māori was developed in 2018 in collaboration between Māori disabled people, their whānau, providers and officials. The word ‘whaikaha’ can be translated as to have strength, to have ability, and to be enabled.

### **Mental distress and person experiencing mental distress**

- 2.10 We intend to use the terms ‘mental distress’ and ‘person experiencing mental distress’ to refer to circumstances where a person’s mental health is negatively impacted in a way that affects their thoughts, feelings, or behaviour. We intend this term to cover a range of experiences, from mild or short-term mental distress to severe or long-term conditions. It includes experiences caused by or arising from mental illness. It also includes experiences of mental distress where a person is not ‘ill’ in a medical sense – for example, following a bereavement, losing a job or witnessing a traumatic event.
- 2.11 Our current law tends to use the term ‘mental disorder’, and we understand some people may prefer the language of ‘mental illness’ or ‘mental health challenges’. We also acknowledge that some people may find the term mental distress limiting or feel that it does not capture their experience. We will use more specific terms where we can. However, we think it is helpful to have a term that covers a broad range of mental distress experiences that can affect the way that people make decisions.

### **Lived experience**

- 2.12 We propose to use the term ‘lived experience’ when someone has directly experienced or is directly experiencing something themselves. It is important that we understand and appreciate the unique insight and perspective that people’s first-hand

experience may bring. The United Nations Convention on the Rights of Persons with Disabilities also requires that disabled people are involved in the development of relevant legislation and policies.

- 2.13 In our review, we intend to distinguish between different kinds of lived experience:
- (a) ‘Personal lived experience’ refers to someone with personal lived experience of affected decision-making.
  - (b) ‘Lived experience as family or whānau member, friend or carer’ refers to someone who is a family or whānau member, friend or carer of someone with personal lived experience.
- 2.14 Some people may have both personal lived experience and lived experience as a family or whānau member, friend or carer.

### **QUESTION 1**

Do you agree with the terms we propose to use in our review? If not, what changes should we make?

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## CHAPTER 3

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# Why is reform needed?

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## INTRODUCTION

3.1 There have been widespread calls for reform of the law relating to adult decision-making capacity. In this chapter, we set out what has led to the calls for reform.

These are:

- (a) Changes in the way we view disability.
- (b) Greater recognition of the legal significance of te ao Māori, tikanga Māori and te Tiriti o Waitangi.
- (c) Greater protection of human rights.
- (d) Changes to Aotearoa New Zealand's population.
- (e) Increased understanding about how people's decision-making can be affected.
- (f) Particular issues with current legislation.

## CHANGES IN THE WAY WE VIEW DISABILITY

3.2 Attitudes towards disability have shifted in recent decades.

3.3 For a long time in Western society, disability was viewed through the lens of a 'medical model'. The medical model views disability as an illness, condition or impairment requiring a medical intervention (sometimes without the individual's consent). Increasingly, this approach has been seen to ignore the extent to which disability results from the physical and societal barriers that affect how disabled people live their lives.

3.4 Alongside the medical model sits institutionalisation, where thousands of disabled people here and overseas were placed away from their family and whānau to live in institutions. Aotearoa New Zealand has undergone a process of deinstitutionalisation, closing such institutions and enabling disabled people to live in and as part of the community. Deinstitutionalisation reflects a greater understanding of the harm done by separating people from whānau, family and friends.

- 3.5 In response to the medical model of disability and institutionalisation, the disability rights movement began to emerge and alternative models of disability were developed. ‘Social models’ of disability do not focus on a person’s impairment. Instead, they focus on identifying and removing physical and societal barriers that prevent disabled people from being fully included.
- 3.6 In the decision-making context, this has led to calls for the law to provide support to people to make decisions instead of decisions being made for them.

### **TIKANGA MĀORI, TE AO MĀORI AND TE TIRITI O WAITANGI**

- 3.7 In recent decades, there has been greater recognition of the significance to law reform of tikanga Māori, te ao Māori and te Tiriti o Waitangi.
- 3.8 The current law relating to adult decision-making capacity does not generally take into account te Tiriti o Waitangi | Treaty of Waitangi. Neither does it generally take into account tikanga Māori, nor provide for Māori perspectives to be reflected. For example, the Protection of Personal and Property Rights Act 1988 (PPPR Act) makes no express reference to te Tiriti or to Māori concepts, values or processes.
- 3.9 As well, the medical and social models of disability discussed above are ‘Western’ models of disability and therefore focus on the individual and their individual experiences of disability. These models may not account for other world views, especially those that place greater emphasis on relationships and collective responsibilities. The same issue arises with the concept of ‘decision-making capacity’.
- 3.10 This means we will need to consider what decision-making looks like in te ao Māori and how tikanga is and should be understood and applied. We will also need to consider what the relationship between tikanga and state law should be in relation to affected decision-making.
- 3.11 We discuss the relevance of tikanga and te ao Māori more in Chapters 4 and 5.

### **GREATER PROTECTION OF HUMAN RIGHTS**

- 3.12 The main statutes relating to people with affected decision-making were enacted in the 1980s and 1990s. Since then, there has been increased protection of human rights generally and for disabled people specifically.
- 3.13 In the early 1990s, Aotearoa New Zealand passed the New Zealand Bill of Rights Act 1990 and the Human Rights Act 1993.

- 3.14 In 2006 there was an international shift towards greater protection of rights of disabled people, with the adoption of the United Nations Convention on the Rights of Persons with Disabilities (Disability Convention). The Disability Convention recognises that disabled people enjoy human rights on an equal basis with others. It also emphasises that disabled people must be involved in the development of relevant law and policies. Aotearoa New Zealand ratified (agreed to implement) the Disability Convention in 2008.
- 3.15 There have been significant calls for greater protection of human rights in this area. For example, the Mental Health (Compulsory Assessment and Treatment) Act 1992 has been criticised for being out of step with Aotearoa New Zealand's human rights commitments. The United Nations Committee on the Rights of Persons with Disabilities has also criticised Aotearoa New Zealand's 'guardianship regime', that exists under the PPPR Act. We discuss human rights more in Chapter 4.

## **CHANGES TO OUR POPULATION**

- 3.16 In recent decades, our population has changed. It continues to become more diverse. For example, the 2018 Census recorded 27.4 per cent of people counted were not born in Aotearoa New Zealand. This was up from 25.2 per cent in 2015. Our current law may not adequately accommodate the perspectives of people from different cultural backgrounds.
- 3.17 New Zealanders are also living longer, and the incidence of dementia is therefore predicted to rise. In 2020, the Dementia Economic Impact Report estimated that the number of people living with dementia would more than double by 2050. This means an increasing proportion of New Zealanders may need support to make decisions.

## **LIMITATIONS OF THE CONCEPT OF 'DECISION-MAKING CAPACITY'**

- 3.18 Under our current law, a person is either considered to have or not have decision-making capacity for a particular decision. If a person is assessed not to have decision-making capacity, the law may intervene in their decision-making. If a person is assessed to have decision-making capacity, the law has no role to play, whether or not the person would benefit from some decision-making support.
- 3.19 This does not reflect reality. The extent to which a person's decision-making is affected, and how much support they may need in decision-making, may vary. A person's decision-making may be more affected at some times than others, or more affected for some decisions than others.

## **PARTICULAR ISSUES WITH CURRENT LEGISLATION**

3.20 We are aware of several particular issues with some of the current legislation. We discuss some of these issues in Chapters 7 and 8.

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## CHAPTER 4

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# Legal concepts and context

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## INTRODUCTION

- 4.1 In this chapter, we set out the legal context to this review. We discuss:
- (a) Some underlying legal concepts that are relevant to this review.
  - (b) Some of the key current laws that regulate affected decision-making.
  - (c) The relevance of te ao Māori and, in particular, tikanga Māori.
  - (d) Domestic and international human rights commitments.

## SOME UNDERLYING LEGAL CONCEPTS

- 4.2 This section explains some of the underlying legal concepts that are relevant to this review. These are: ‘decision-making capacity’, ‘legal capacity’, ‘substituted decision-making’, ‘supported decision-making’, ‘best interests’ and ‘will and preferences’.
- 4.3 What these terms mean, and how they should be used, is often debated. Some people prefer different terms entirely. This section provides a high-level summary of each concept.

### ‘Decision-making capacity’

- 4.4 The law uses ‘decision-making capacity’ as a threshold. If a person is assessed to have decision-making capacity, the law has no role to play, and the person is free to make their own decision. If a person is assessed not to have decision-making capacity, the law may step in. The decision might not be given effect, or it might be overturned. Another person may be appointed to make the decision instead. When we use the term decision-making capacity, we are referring to this concept.

- 4.5 Decision-making capacity appears in many of our laws, although sometimes different terms are used. Other phrases used include ‘competence’, ‘mental competence’, ‘mental capacity’, ‘legal capacity’ and ‘capacity’. In this review, we think using different terms for the same concept will be unhelpful. We will use the term decision-making capacity unless the context requires a different term.
- 4.6 Generally, the law uses a ‘functional approach’ to test decision-making capacity. Broadly, this means the assessor must consider whether the person sufficiently understands the general nature and likely consequences of their decision and is able adequately to communicate the decision. The test is a legal one, but in practice, the assessment is often made based on the opinion of a doctor.
- 4.7 The functional approach has been described as a neutral way of testing decision-making capacity. However, this view is not shared by everyone. Some people argue that it is discriminatory or discriminatorily applied towards disabled people – particularly when assessments are made of the individual alone, without the supports they would normally have to assist their decision-making.
- 4.8 Other criticisms of the functional approach include:
- (a) Professionals assessing decision-making capacity may be informed by their own culture and beliefs. Language or cultural differences may also lead to misinterpretation or misunderstanding.
  - (b) The experience of being medically assessed may be alienating for some people, which may impact how they respond to the test.
  - (c) Testing mental functioning alone, and restricting a person’s ability to make decisions on that basis, may not align well with other worldviews such as te ao Māori. This is discussed more in Chapter 5.

### ‘Legal capacity’

- 4.9 The United Nations Committee on the Rights of Persons with Disabilities has explained that ‘legal capacity’ refers to two closely related concepts:
- (a) Legal standing: the ability of a person to hold rights and duties.
  - (b) Legal agency: the ability of a person to act on those rights and duties.
- 4.10 Legal capacity is related to decision-making capacity. If a person is assessed as not having decision-making capacity, the law may restrict their legal capacity. In particular, it may restrict that person’s legal agency by not giving effect to or by overturning their decision or by requiring someone else to make the decision for them.

### **‘Substituted decision-making’ and ‘supported decision-making’**

4.11 ‘Substituted decision-making’ involves one person making a decision on behalf of another person. It is often said to involve two other features:

- (a) The substitute decision-maker can be appointed by someone other than the person concerned, including against their will. For example, a court might appoint a welfare guardian, or a doctor might make a treatment decision for a patient.
- (b) Decisions made by the substitute decision-maker are based on the ‘best interests’ of the person concerned.

4.12 By contrast, ‘supported decision-making’ refers to supporting a person to exercise their legal capacity. As it is the person’s decision that is supported, it follows the decision should reflect their will and preferences, rather than someone else’s assessment of their best interests.

4.13 The terms ‘substituted decision-making’ and ‘supported decision-making’ are understood differently by different people. This is particularly so in the context of calls to shift from substituted to supported decision-making. However, as discussed in Chapter 7, there are various ways in which one person can be involved in another’s decision. Not all these can be categorised in ways that everyone would agree with. Therefore, in later chapters, we have tried to avoid using these terms. We have instead focused on exploring some practical ways in which a person can be involved in another’s decision-making.

### **‘Best interests’ and ‘will and preferences’**

4.14 Related to substituted and supported decision-making are the concepts of ‘best interests’ and ‘will and preferences’.

4.15 Typically, best interests refers to a substitute decision-maker making a decision about a person based on what they believe to be the person’s objective best interests. For example, in the context of medical treatment, a person’s best interests might be determined by what expert medical opinion accepts as appropriate treatment. A key objective of the best interests standard is to protect people who are considered unable to adequately decide for themselves.

- 4.16 The concept of will and preferences focuses on the wishes of the person with affected decision-making. This may be different from what someone else considers to be the person's objective best interests. Some commentary emphasises that this is the point of supported decision-making: people should be supported to make the decisions they want to, even if others would decide differently (and might even consider the decision unwise).
- 4.17 In practice the distinction between best interests and will and preferences is not always as stark as it may first appear. For example, in the United Kingdom, a deputy (the equivalent of a welfare guardian) must act in the best interests of a person. In determining the person's best interests, the deputy must consider the person's past and present wishes and feelings and their values and beliefs relevant to the decision. In other words, the person's 'best interests' are heavily dependent on what the person wants (or is understood to want). Some case law in Aotearoa New Zealand has been guided by this test.

## **CURRENT LAW**

- 4.18 In this section, we outline some of the key laws in Aotearoa New Zealand that regulate affected decision-making of adults.

### **Some key statutes**

#### ***Protection of Personal and Property Rights Act 1988***

- 4.19 The Protection of Personal and Property Rights Act 1988 (PPPR Act) is a key statute in this area. The focus of the PPPR Act is on what happens if an adult is assessed as not having decision-making capacity to make a decision, or decisions, about their personal care and welfare or their property.
- 4.20 Broadly, if a person is assessed to lack decision-making capacity:
- (a) Te Kōti Whānau | Family Court may make a range of decisions about the person's personal care and welfare, such as that a person live in a particular place or receive medical treatment.
  - (b) The Family Court may appoint a welfare guardian. A welfare guardian is someone who makes decisions for another person about their personal care and welfare. For this reason, the PPPR Act is sometimes said to involve an 'adult guardianship' regime.
  - (c) The Family Court may appoint a property manager. A property manager is someone who makes decisions about another person's property.

- 4.21 The PPPR Act also sets out a process for one person to grant another an ‘enduring power of attorney’ to act in their personal care and welfare and/or their property affairs at some time in the future. The enduring power of attorney will generally activate once a person is assessed as not having decision-making capacity.

### ***Mental Health (Compulsory Assessment and Treatment) Act 1992***

- 4.22 The Mental Health (Compulsory Assessment and Treatment) Act 1992 (Mental Health Act) sets out the circumstances in which a person may be subject to compulsory mental health assessment and treatment. A person must have a “mental disorder” as defined by the Mental Health Act before they can be subject to compulsory assessment or treatment. “Mental disorder” is defined to mean an “abnormal state of mind” that is of such a degree that it poses a serious danger to that person or others and/or seriously diminishes the capacity of that person to take care of themselves. The term ‘capacity’ is used in a different way here – it refers to the person's ability to take care of themselves. However, the Act still operates on the basis that a person subject to it is not able to make their own decision or decisions about treatment.
- 4.23 There has been extensive criticism of the Mental Health Act 1992. The government inquiry into mental health and addiction (*He Ara Oranga: Report of the Government Inquiry into Mental Health and Addiction*) found that the Act is out of date and does not reflect best practice or align with Aotearoa New Zealand’s international commitments. As noted in Chapter 1, Manatū Hauora | Ministry of Health is carrying out a ‘repeal and replace’ review of the Mental Health Act.

### ***Substance Addiction (Compulsory Assessment and Treatment) Act 2017***

- 4.24 The Substance Addiction (Compulsory Assessment and Treatment) Act 2017 provides for compulsory medical treatment in some circumstances. It can apply when a person is assessed as having a severe substance addiction and “impaired capacity” to make decisions about their treatment.

### ***Code of Health and Disability Services Consumers’ Rights***

- 4.25 The Code of Health and Disability Services Consumers’ Rights (the Code) outlines the rights of people using health and disability services, and the duties of health and disability providers. Under the Code, people generally have rights to make an informed choice about medical treatment and to give informed consent.

4.26 These rights may be limited if it is considered that a person has “diminished competence” and in some circumstances treatment can be provided without the person’s consent. For example, if a person is “not competent” to give informed consent, medical treatment may be provided if it is in the person’s best interests, reasonable efforts have been made to understand their views, and the medical provider believes treatment would be consistent with the person’s views if they were “competent”.

### The common law

4.27 Adult decision-making is also regulated through the common law (law that is found in court decisions rather than in statutes). This includes contract law and the law of testamentary capacity.

4.28 Under contract law, people can enter into legally binding agreements with each other. The law will not undo a contract solely on the basis that one of the parties did not have decision-making capacity. However, it may do so if that is something the other party to the contract knew or should have known.

4.29 The common law also regulates a person’s ability to make a will to dispose of property after their death. When a person dies, there will sometimes be a dispute about whether the person had ‘testamentary capacity’ to make the will and whether the law should recognise the will as valid. Broadly, if a will appears “rational on its face”, the court will presume that the will-maker had sufficient decision-making capacity. If the will appears irrational, the person seeking to uphold the will must show that the will-maker had decision-making capacity when the will was made.

### TIKANGA MĀORI

4.30 Tikanga Māori is significant to law review and reform in four mutually reinforcing ways, recently underscored by Te Kōti Mana Nui | Supreme Court in *Peter Hugh McGregor Ellis v the King* [2022] NZSC 114.

- (a) Tikanga is the first law of Aotearoa New Zealand. It is an independent source of rights, obligations and authority in te ao Māori.
- (b) Law should give effect to rights and obligations under te Tiriti o Waitangi as they relate to tikanga.
- (c) Tikanga can comprise a source of New Zealand common law. Tikanga can also be reflected in statute law and assist in the interpretation of statutes.
- (d) Aotearoa New Zealand has international obligations in relation to Māori as indigenous people.

- 4.31 There are various ways tikanga and the law relating to affected decision-making might relate to each other. To explore these possibilities, we need first to consider how decision-making is approached in tikanga Māori and te ao Māori. We discuss this further in Chapter 5.

## **HUMAN RIGHTS AND AFFECTED DECISION-MAKING**

- 4.32 A number of human rights, both domestic and international, are engaged by law on affected decision-making.

### **New Zealand Bill of Rights Act 1990**

- 4.33 The New Zealand Bill of Rights Act 1990 (Bill of Rights) protects and promotes human rights and fundamental freedoms in Aotearoa New Zealand. Among others, this includes the right to refuse medical treatment, the right not to be detained (held) without good reason and the right to freedom from discrimination. The rights set out in the Bill of Rights may only be limited by other laws where this is “demonstrably justified in a free and democratic society”.

### **International human rights instruments**

- 4.34 People with affected decision-making hold several relevant rights at international law. These rights include the right to freedom from discrimination, the right to liberty, dignity and security, the right to self-determination, the right to the highest attainable standard of health and the right not to be tortured or subject to cruel treatment.

### ***Article 12 of the Disability Convention – equal recognition before the law and legal capacity***

- 4.35 The Convention on the Rights of People with Disabilities (Disability Convention) is fundamental to affected decision-making laws. Article 12 affirms the right of disabled people to equal recognition before the law and recognises disabled people have legal capacity on an equal basis to others.
- 4.36 Article 12 signals a major shift in attitudes to how we think about the law in this area. It is generally agreed that Article 12 reflects the shift from a ‘medical model’ of disability to a ‘social model’ of disability. Article 12 recognises that there are barriers in society that may prevent or make it difficult for some people to make decisions.

4.37 There is also broad agreement that Article 12 signals:

- (a) A shift towards supported decision-making; and
- (b) A focus on respecting the person's "rights, will and preference", instead of what someone else thinks is their objective best interests.

4.38 Beyond that, there are different views on what Article 12 requires or does not permit. One area of debate is whether Article 12 ever permits substituted decision-making, even in 'extreme' cases. This is a matter we will need to consider in our review. At this stage, though, we think it more helpful to focus on some specific decision-making arrangements.

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## CHAPTER 5

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# Te ao Māori me ōna tikanga

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## INTRODUCTION

- 5.1 In this chapter, we discuss some tikanga Māori and Māori concepts that might be particularly relevant to decision-making.
- 5.2 There are various ways in which the law concerning adult decision-making and tikanga might relate to each other, and in which the law might reflect Māori perspectives. To explore those possibilities, we need to understand how decision-making is approached in tikanga and te ao Māori, and learn about those perspectives.

## DECISION-MAKING IN TE AO MĀORI

- 5.3 The idea of decision-making capacity in our current law might be said to reflect a ‘Western’ perspective, focused on individual autonomy and individual rationality.
- 5.4 Māori understandings of decision-making, based on whakapapa and whanaungatanga, may be less focused on the individual.
- 5.5 Whakapapa sees each person as part of an interconnected framework of intergenerational ‘layers’ connecting individuals to each other by descent from ancestors. Descent-based relationships are not limited in te ao Māori to human genealogy, but describe the association of individuals to waka, to atua | gods and to the natural environment.
- 5.6 Whanaungatanga can be described as the everyday social fabric or reality of kin-based relationships in te ao Māori. It is the sharing of experiences and the strengthening of bonds with others in recognition of whakapapa connections. Whanaungatanga has been described as a principle of kinship:<sup>1</sup>

[K]inship is the warmth of being together as a family group: what you can draw from being together and the strength of using all the resources of a family. ...

Whanaungatanga to me also means that whenever a person feels lonely he will go round and visit some of his kin and it is just as enjoyable for the kin to receive a visit as it is for the person to go.

- 5.7 Together, whakapapa and whanaungatanga locate a person within and by reference to their whānau and whakapapa. Individual identity cannot be separated from whānau and whakapapa, because whānau and whakapapa are fundamental to that identity. The decisions of an individual are therefore inherently connected to, and can have meaningful implications for, their whānau and whakapapa
- 5.8 Compared to some other cultures, decision-making in te ao Māori may therefore place less emphasis on individual autonomy and the rights, will and preferences of the individual. Whakapapa and whanaungatanga obligations may require someone making a decision to engage in more kōrero with whānau and hapū and give greater consideration to those wider interests.
- 5.9 Definitions of decision-making capacity that focus on specific tests of individual mental ability may not sit easily alongside this approach. Neither may the appointment of someone to make decisions on behalf of a person who has failed a capacity test, if the person appointed is not familiar with the significance of whakapapa, whanaungatanga and tikanga more generally, or does not have whanaungatanga obligations to the person.

## TIKANGA MĀORI

- 5.10 Tikanga is the first law of Aotearoa New Zealand. Tikanga includes a body of norms and values that guides and directs behaviour in te ao Māori. Tikanga governs relationships by providing a “koru ... of ethics” and a shared basis for “doing things right, doing things the right way, and doing things for the right reasons”.<sup>2</sup> Tikanga has evolved over time and continues to adapt to accommodate developments in society and technology.
- 5.11 At an initial wānanga we organised, six principles of tikanga were identified as particularly relevant to decision-making in te ao Māori: whanaungatanga, aroha, mana, tiaki, wairua and rongō. We discuss these briefly below.
- 5.12 We acknowledge that how tikanga values are applied may differ among different iwi and hapū. We also acknowledge that no aspect of tikanga can be properly understood in isolation from tikanga as a whole. Tikanga principles are intertwined and exist in “an interconnected matrix”.<sup>3</sup> Singling out specific principles, and briefly summarising them, cannot fully convey their significance or relevance. We intend it to be helpful, but are mindful of its limitations.

## Whanaungatanga

- 5.13 As discussed earlier in this chapter, whanaungatanga is fundamental in te ao Māori. It imports positive obligations on members of a whānau or hapū. Whanaungatanga recognises that personal decisions not only have personal implications, but are made in a collective context and so may involve whānau, hapū and iwi.

## Aroha

- 5.14 Closely related to whanaungatanga is aroha. Broadly, aroha can be described as a display of love, compassion, sympathy, empathy and concern for others.
- 5.15 Aroha is closely associated with kinship ties and the caring acts expected to be performed towards kin, especially in times of sickness, need or other trouble. Cleve Barlow has explained that a person who has aroha for another “expresses genuine concern towards them and acts with their welfare in mind, no matter what their state of health or wealth.”<sup>4</sup>
- 5.16 A recent study found that aroha, alongside manaakitanga (which encompasses notions of hospitality, kindness, generosity and support), had a role in the way people cared for their whānau members living with dementia. The study showed that many whānau were driven by the inherent, collective obligation to care for others with a sense of compassion and caring that “enables their acceptance and tolerance of changes brought about by illness and disease.”<sup>5</sup> At our initial wānanga we heard that, in the case of illness, it is aroha that drives people to look for solutions and to lessen the difficulties that might result from situations where a person’s decision-making is affected.

## Mana

- 5.17 Mana has been described as “a key philosophical concept combining notions of psychic and spiritual force and vitality, recognised authority, influence and prestige, and thus also power and the ability to control people and events”.<sup>6</sup>
- 5.18 Inherent in the notion of mana as ‘power’ or ‘authority’ is the responsibility to use that power for the welfare and wellbeing of an individual or a collective. Mana derives from the collective, and so carries with it an obligation to exercise it for collective wellbeing.
- 5.19 Māori Marsden has identified three aspects of mana: mana atua – god given power; mana tūpuna – power from the ancestors; and mana tangata – authority derived from personal attributes.<sup>7</sup>

- 5.20 Mana tūpuna means that those with the senior whakapapa lines have a ‘head start’ in the expectation of leadership positions. But because, in tikanga, descent can be traced through both male and female lines in every generation, there will generally be many potential leaders with significant mana tūpuna. Mana tangata is therefore also very significant.
- 5.21 Mana tangata underscores the obligations of those with authority to make decisions that have the support of the collective – because a decision-maker whose decisions are not supported will be corrected or replaced by others with sufficient mana whose decisions will have support.
- 5.22 Mana has wider dimensions beyond the purely personal, which can be relevant to decision-making. Personal decisions can affect the mana of the collective – the whānau, the marae, the hapū, the iwi and other broader collectives or groups with which the person is associated.
- 5.23 Mana is also relevant to Māori whose decision-making is affected – for example, in how their connections to whānau, marae and hapū are maintained, and in the deference shown to their decisions. The greater a person’s mana atua and mana tūpuna, the greater the deference and respect expected to be shown to them.

### Tiaki

- 5.24 Tiaki means to care for or support. It is most widely known in the term kaitiaki, which is generally described as stewardship or guardianship. It is concerned with providing care for and preserving taonga or precious things. While the act of tiaki is often expressed in relation to the environment, it also relates to a social context – that is, caring for and looking after other people.
- 5.25 In relation to the care of people with dementia, for example, kaitiakitanga (the exercise of kaitiaki) has a critical role in the health and wellbeing of whānau. In the context of adult decision-making more generally, tiaki is relevant to providing foundational support to a person with affected decision-making. Tiaki, in this context, is therefore also closely tied to aroha. In the context of decision-making support, it could be thought of as a manifestation of aroha.

### Wairua

- 5.26 Wairua can be defined as the inherent spiritual essence of a person. The existence of wairua does not depend on the physical form of a person but describes a state of being beyond consciousness and even death. For example, when a person dies, they are said to travel ‘te ara wairua’ or ‘te rerenga wairua’, which describes the pathway of spirits someone follows to their final resting place.

- 5.27 The wairua of a person, however, can be affected by external forces or individuals. For example, traditionally the wairua of a person could be diminished by makutu or sorcery performed by tohunga, by transgressing a tapu, or by particular events or experiences.
- 5.28 The concept of wairua is relevant to the intervention and care that needs to be shown towards someone with affected decision-making capacity. They have wairua, which can be positively or negatively affected by others.
- 5.29 A related concept is ‘mauri’ or the life force of a person or an object. A mauri stone, for example, would traditionally be imparted with wairua through karakia, and buried beneath a whareniui to contain and symbolise the health and wellbeing of the whareniui. Mauri as it relates to a person symbolises their wellbeing, or ‘mauri-ora’. Protecting and enhancing the mauri-ora of a person whose decision-making is affected may be a key consideration.

## Rongo

- 5.30 In the context of this review, the notion of rongo as a state of internal balance and peace may also be relevant. A person’s decision-making might be affected by their spiritual and mental balance. Rongo might be considered to emphasise the importance of restoring that balance.
- 5.31 In tellings of the separation of Papatūānuku and Ranginui, Rongo-mā-Tāne is said to have been hidden within his mother, Papatūānuku. From there, he listened in safety and silence to the turmoil and violence of the world above. “In this way, Rongo gets to know silence, and internal peace from external violence. When Rongo emerges, peace prevails in the external world.”<sup>8</sup> Rongo is said to guide activities relating to knowledge and knowing, peace and peacemaking, healing, intent listening and silence.
- 5.32 In stressing the significance of balance, rongo might be seen to point away from a binary approach to decision-making that sees a person as either having, or not having, decision-making capacity. Dr Tākirangi Smith has explained:<sup>9</sup>

In traditional Māori narratives, light and dark are different states of being, both with aspects of well-being and healing. In Māori knowledge systems, the atua all had a place and it was the balance between these atua that was important, as well as rebalancing when there was disruption through trauma.

## NGĀ ARIĀ MATUA E TORU | THREE KEY CONCEPTS

5.33 In this section, we outline three Māori concepts we have encountered in our research that may be relevant to Māori perspectives on adult decision-making. While we understand that these are not tikanga principles, they may be significant to the operation of tikanga.

### Hinengaro

5.34 Hinengaro is sometimes given as a translation for mind, but this is not a perfect translation. Te Aka Māori Dictionary defines hinengaro more broadly, as “mind, thought, intellect, consciousness, awareness”. Dr Hinemoa Elder has explained that Māori have “distinct concepts of the mind as a system within a wider body of knowledge called mātauranga”. Dr Elder identifies the concept of hinengaro as being the Māori concept of “mind, the seat of thoughts and emotions”.<sup>10</sup>

5.35 One of the four dimensions in the Māori model of health developed by Tā Mason Durie, ‘Te Whare Tapa Whā’, is te taha hinengaro. Dr Elder has observed that te taha hinengaro is “often translated as the aspect of psychological health and well-being, or as emotional health”.<sup>11</sup> It encompasses how a person communicates, thinks and feels. It also encompasses spiritual wellbeing. When te taha hinengaro is strong, people are likely to be better able to cope with stress and challenges.

5.36 The concept of hinengaro may therefore not map easily onto Western conceptions of mind that view it as primarily about thinking and separate from emotions. In the context of affected decision-making, it may encourage approaches that focus on the person as a whole, rather than solely or primarily on their thought processes.

### Wairangi and pōrangi

5.37 Two other concepts we have encountered in our research are wairangi and pōrangi.

5.38 At our preliminary wānanga, wairangi was explained as describing someone who is confused or troubled such that their decision-making is affected. Wairangi is defined in the Māori dictionary Te Pātaka Kupu as “Kāore e āta whakaaro, kāore rānei e mātau ki te mahi tika”, meaning someone who “does not comprehend, or does not understand the correct thing to do”. The concept of wairangi not only describes affected decision-making capacity in a ‘cognitive’ sense, but also a state of intense emotion and despair.

5.39 At the same wānanga, the concept of pōrangi was described as referring to someone who is permanently in a state of deep unrest and trouble, and who therefore cannot make decisions for themselves or their whānau.

- 5.40 The causes of both pōrangī and wairangī will be varied. A person may be in a state of wairangī due to a specific event or situation that causes a severe emotional response, such as a bereavement. This will generally be temporary, but not always. Wairangī in the sense of general forgetfulness might also occur as someone ages. A state of wairangī might develop into a state of pōrangī caused by mate wareware (dementia).
- 5.41 Pōrangī may be considered by some to result from the person affected committing of a form of hara (spiritual infringement). Pōrangī resulting from a hara implies a moral judgement on the actions of the individual:<sup>12</sup>
- Some Māori may feel they are unwell because they have breached certain cultural protocols, and they may describe their illness as mate Māori, or mākutu, and their whānau may describe their behaviour as disturbing or pōrangī.
- 5.42 On the other hand, pōrangī and wairangī might also result from causes such as ageing. When this occurs, a kuia or kaumātua might be described as becoming more tapu, as they journey from te ao mārama (the current world) to te ao wairua (the realm of spirits). In that situation, there is no implied moral judgement under tikanga Māori. Rather, kuia and kaumātua continue to hold an important role as keepers of knowledge and wisdom.
- 5.43 As with hinengaro, neither pōrangī nor wairangī map easily onto similar Western terms. For example, both terms can encompass aspects of what, from a more Western perspective, might be separated into concepts relating to mental distress, to emotion and to cognition/thinking. As with hinengaro, in the context of affected decision-making, wairangī and pōrangī may encourage approaches that focus more on the whole person than solely or primarily on their thought processes.

### QUESTION 2

Have we identified the tikanga principles and concepts most relevant to decision-making? If not, what changes should we make?

## DECISION-MAKING BY MĀORI TODAY

- 5.44 We understand that, while some Māori may primarily live according to tikanga, this is not the case for all Māori. Some may feel different degrees of connection to te ao Māori, or find that there are other factors that prevent them from practising tikanga on an everyday basis. Some might find that it is hard to act consistently with tikanga given current law.

5.45 We are interested in how relevant tikanga is to Māori today when it comes to decision-making and, in particular, when someone’s decision-making is affected. We are also interested in how the current law affects the ability to live in accordance with tikanga Māori, and how the law could be changed to address this.

### QUESTION 3

How is tikanga Māori relevant to you in relation to decision-making, and to affected decision-making?

### QUESTION 4

In situations when someone’s decision-making has been affected, have you and your whānau/hapū/iwi been able to act in accordance with tikanga Māori in the way you would want? If not, how could this be improved?

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- <sup>1</sup> John Rangihau “Being Māori” in Michael King (ed) *Te Ao Hurihuri: The World Moves On – Aspects of Māoritanga* (Hicks Smith & Sons, Wellington, 1975) at 222.
  - <sup>2</sup> Bishop Manuhua Bennett “Pū Wānanga Seminar” (presented with Te Mātāhauariki Institute) as cited in Richard Benton, Alex Frame and Paul Meredith *Te Mātāpunenga: A Compendium of References to the Concepts and Institutions of Māori Customary Law* (Victoria University Press, Wellington, 2013) at 431.
  - <sup>3</sup> *Ellis v the King* [2022] NZSC 114, appendix “Statement of Tikanga” at [30].
  - <sup>4</sup> Cleve Barlow *Tikanga Whakaaro: Key concepts in Māori culture* (Oxford University Press, Melbourne, 1991) at 8.
  - <sup>5</sup> Margaret Dudley and others “Mate wareware: Understanding ‘dementia’ from a Māori perspective” (2019) 132 NZMJ 66 at 69.
  - <sup>6</sup> Richard Benton, Alex Frame and Paul Meredith *Te Mātāpunenga: A Compendium of References to the Concepts and Institutions of Māori Customary Law* (Victoria University Press, Wellington, 2013) at 154.
  - <sup>7</sup> Māori Marsden “God, Man and Universe: A Māori View” in Michael King (ed) *Te Ao Hurihuri: The World Moves On – Aspects of Māoritanga* (Hicks Smith & Sons, Wellington, 1975) at 194.
  - <sup>8</sup> Tākīrangī Smith “He Ara Uru Ora: Traditional Māori understandings of trauma and well-being” (Te Atawhai o Te Ao, Whanganui, 2019) at 3.
  - <sup>9</sup> Tākīrangī Smith “He Ara Uru Ora: Traditional Māori understandings of trauma and well-being” (Te Atawhai o Te Ao, Whanganui, 2019) at 4.
  - <sup>10</sup> Hinemoa Elder “Te Puna a Hinengaro: he Tirohanga ki a Āheinga The Wellspring of Mind: Reflections on Capacity from a Māori Perspective in Iris Reuecamp and John Dawson (eds) *Mental Capacity Law in New Zealand* (Thomson Reuters, Wellington, 2019) 29 at 32.
  - <sup>11</sup> Hinemoa Elder “Te Puna a Hinengaro: He Tirohanga ki a Āheinga: The Wellspring of Mind: Reflections on Capacity from a Māori Perspective” in Iris Reuecamp and John Dawson *Mental Capacity Law in New Zealand*, at 33, citing Mason Durie “Is there a distinctive Māori psychology?” (paper presented to the National Māori Graduates of Psychology Symposium, Hamilton, 2002).
  - <sup>12</sup> Louise Ihimaera “He Ara ki te Ao Mārama: A pathway to understanding the facilitation of taha wairua in mental health services” (MA theses, Massey University Palmerston North, 2004) at 108.

## CHAPTER 6

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# Principles for our review

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## INTRODUCTION

- 6.1 In this chapter, we discuss some principles that we have developed to guide our thinking in this review.
- 6.2 These principles will help us identify core values, interests or objectives that need to be considered in affected decision-making law reform. This will help us identify what is important and what good law concerning the affected decision-making of adults looks like. We will use these principles to guide our analysis of the issues and options for reform.

## OUR PROPOSED GUIDING PRINCIPLES

- 6.3 We have developed seven guiding principles for our review. We think the law relating to affected decision-making should:
- (a) Respect and uphold the human rights of people with affected decision-making.
  - (b) Uphold the Crown's obligations under te Tiriti o Waitangi.
  - (c) Recognise and provide for tikanga Māori.
  - (d) Empower people with affected decision-making to live flourishing lives.
  - (e) Recognise and facilitate relationships built on trust.
  - (f) Keep people safe from abuse and neglect and promote accountability.
  - (g) Be accessible and strike an appropriate balance between flexibility and certainty.
- 6.4 We developed these principles by considering what other people, laws and organisations have identified as important values and interests in this area. We also asked our advisory groups what important values, concepts or ideas our guiding principles should include.
- 6.5 We discuss each of these principles below.

### **Principle 1: the law should respect and uphold the human rights of people with affected decision-making**

- 6.6 Human rights help to underpin Aotearoa New Zealand's democratic society, and good law should seek to respect and uphold these rights.
- 6.7 As discussed in Chapter 4, many human rights are engaged in this review. Fundamental to these, and all human rights, is the inherent dignity of all people.
- 6.8 Some human rights that we think are engaged by this review include the rights to:
- (a) Equal recognition before the law.
  - (b) Freedom from arbitrary detention.
  - (c) Non-discrimination.
  - (d) Highest attainable standard of health.
  - (e) Refuse medical treatment.
  - (f) Self-determination.

### **Principle 2: the law should uphold the Crown's obligations under te Tiriti o Waitangi**

- 6.9 Te Tiriti o Waitangi | the Treaty of Waitangi is a foundation of government in Aotearoa New Zealand. Good law should uphold the Crown's obligations under te Tiriti o Waitangi.
- 6.10 There is a te reo Māori text and an English text and there are differences between the two texts. For reasons discussed in our recent reports, our view is the te reo Māori text should be regarded as the primary record of the commitments made in 1840.

### **Principle 3: the law should recognise and provide for tikanga Māori**

- 6.11 As we explain in Chapter 4, tikanga Māori is relevant to law review and reform. We think the law should recognise and provide for tikanga Māori.
- 6.12 In Chapter 5 we outline six tikanga principles that appear to be particularly relevant to decision-making in te ao Māori. There are various possible ways in which tikanga Māori and the law relating to affected decision-making might relate to each other. For example, the law might reflect tikanga values that resonate widely with all New Zealanders. It might also respect the operation of tikanga amongst Māori who wish to live in accordance with it.

#### **Principle 4: the law should empower people with affected decision-making to lead flourishing lives**

- 6.13 We think empowering people with affected decision-making capacity should be a guiding principle for this review. Empowerment is one way the law can contribute to the wellbeing of people with affected decision-making.
- 6.14 We have heard that the voices of people with affected decision-making can be lost or ignored. When decisions are made for a person with affected decision-making, they may feel disregarded or disempowered. We think it is important the law's role in promoting wellbeing and good outcomes for people with affected decision-making is deeply rooted in empowerment.

#### **Principle 5: the law should recognise and facilitate relationships built on trust**

- 6.15 We think the law should recognise and facilitate relationships built on trust. We have heard that trusting and supportive relationships are fundamental to promoting positive decision-making and outcomes for people with affected decision-making. These relationships include those between the person with affected decision-making and their family and whānau. They also include those between professionals and people affected and their family and whānau.
- 6.16 We have heard concerns that the current law is too focused on the individual making the decision and does not sufficiently allow for family and whānau involvement. For example, many submitters in the 'repeal and replace' review of the Mental Health (Compulsory Treatment) Act 1992 (Mental Health Act) shared that family and whānau are essential to the wellbeing of people experiencing mental distress and hold significant knowledge and understanding of their needs. We have heard that the formality of many decision-making arrangements, in particular the adversarial nature of the court system, can also damage relationships.
- 6.17 We have also heard that the law does not provide enough avenues for people to make decisions collectively or together as a family or whānau. This may be particularly relevant for Māori and other cultures, where more collective or group-based decision-making arrangements may be preferred. The tikanga principle of whanaungatanga, discussed in Chapter 5, may be particularly relevant here.
- 6.18 It is important to note that some people do not have positive relationships with all their family or whānau or may not wish them to be involved. This was raised by submitters in the 'repeal and replace' review of the Mental Health Act. While we think the law should facilitate family and whānau involvement in decision-making, individual preferences should also be respected.

### **Principle 6: the law should keep people safe from abuse and neglect and promote accountability**

- 6.19 We think the law has a role to play in ensuring that people with affected decision-making are safe from abuse and neglect. We have heard that people with affected decision-making can be vulnerable to abuse and neglect. This can sometimes involve family and whānau or people in their wider support system. For example, a significant proportion of elder abuse cases involve family members. The United Nations Convention on the Rights of Persons with Disabilities requires that laws concerning affected decision-making provide for appropriate and effective safeguards against abuse.
- 6.20 The law can also promote accountability. We have heard that it is important that people involved in decision-making arrangements are held accountable for doing things properly.
- 6.21 We think this principle will also allow us to think about safety more broadly. For example, we have heard that those involved in supporting a loved one with affected decision-making do not always feel safe and supported in their role. This principle could also include concepts like cultural safety. This is the concept of ensuring a service, like a health care service, reflects the cultural values and practices of those using it.

### **Principle 7: the law should be accessible and strike an appropriate balance between flexibility and certainty**

- 6.22 We think a legal framework for affected decision-making should be accessible. It is important that people who are affected by the law can access and understand it. We have heard that people do not always understand what the law requires of them or what they may or may not do. We have also heard that legal processes can be confusing to navigate.
- 6.23 The law also needs to be responsive to the circumstances, values and cultural considerations of the people interacting with it. Affected decision-making laws are relevant to a wide range of people in Aotearoa New Zealand, in all different walks and stages of life. We have heard that every experience is different. We have also heard that people have different approaches and values when it comes to decision-making and how they want others to be involved. People can have very different views about what 'good' decision-making looks like. For all these reasons, we think the law will need to be flexible and avoid a 'one-size-fits-all' approach where possible.

- 6.24 However, we will need to balance flexibility with certainty. We think it is important there is clarity and transparency about what the law requires.

**QUESTION 5**

Do you agree with the seven guiding principles we have developed? If not, what changes should we make?

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## CHAPTER 7

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# Decision-making arrangements

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## INTRODUCTION

- 7.1 When a person's decision-making is affected, the law can permit or require a decision-making arrangement to be used for some or all decisions. In this chapter, we:
- (a) Explain what we mean by 'decision-making arrangement'.
  - (b) Discuss some different decision-making arrangements that are used in our law or used in other countries' laws. These are: decision-making supporters, advance directives, enduring powers of attorney and court ordered decision-making. We also discuss the idea of collective or group-based decision-making arrangements.
  - (c) Discuss some ways the law might make decision-making arrangements work better for people.

## DECISION-MAKING ARRANGEMENTS

- 7.2 We use the term 'decision-making arrangement' to mean a process or arrangement that may be used when a person's decision-making is affected. The arrangement determines or guides how others may be involved in the decisions of a person with affected decision-making.
- 7.3 Many decision-making arrangements do not require the law to operate, such as when a parent supports an adult child with affected decision-making to make a decision. Sometimes these informal arrangements will involve family, whanau and friends. Other times they may involve care workers. We do not think new law should undermine any decision-making arrangements that are already working well.

- 7.4 However, some of these informal decision-making arrangements may be improved by new law. For example, a new law might enable a decision-making supporter to be more effective by giving them easier access to relevant information.
- 7.5 Other decision-making arrangements can only be used if they are set out in law, such as a welfare guardian.
- 7.6 In the rest of this chapter, we discuss some decision-making arrangements that might be improved by or included in law. These are not the only decision-making arrangements that could be included in our law, but they are some of the key ones.
- 7.7 We think it is likely our law will need to address a range of decision-making arrangements. People's decision-making can be affected in a variety of ways, for different amounts of time, and for different decisions. Not all decision-making arrangements will work for everyone and people may use different decision-making arrangements for different decisions. A 'one size fits all' approach is unlikely to be appropriate.

## DECISION-MAKING SUPPORTER

- 7.8 As noted above, many people with affected decision-making are supported to make decisions by other people, such as friends or family members. We refer to these arrangements as 'decision-making support' or use of a 'decision-making supporter'.
- 7.9 Some of the ways a person might support another person to make a decision are:
- (a) Help the person to identify the decision that needs to be made. Sometimes only one decision may need to be made. Sometimes there may be more than one decision.
  - (b) Identify and access any relevant information, or assist the supported person to do this. Depending on the decision, this might include information on the person's medical history or finances.
  - (c) Help the person to understand information about the decision. For example, the supporter could help the person with online searches or to work through a document.
  - (d) Help the person to understand the consequences of the decision. For example, it may be helpful to discuss options and outcomes with the person and help them explore what is most important to them.

- (e) Help the person to communicate a decision, or even communicate the decision for them. This might include writing the decision down, discussing the next steps, and working out whether anyone else needs to be involved.

7.10 We have heard that decision-making supporters can be helpful. Many submitters in Manatū Hauora | Ministry of Health’s ‘repeal and replace’ review of the Mental Health (Compulsory Assessment and Treatment) Act 1992 (Mental Health Act) expressed a preference for a system where people are supported to make their own decisions. However, we have also heard that sometimes providing support can be difficult as supporters do not have legally recognised powers or duties.

*Hēmi is 25 years old. He likes watching football and playing Minecraft. He wants a job where he can work with lots of other people. He has a learning disability and lives at home with his mother.*

*Hēmi is offered a job at the supermarket near his house and his mum helps him read through the employment agreement and accept the job. Hēmi needs to provide his employer with his bank account number. His mum rings up the bank to get his bank account details, but the bank will not provide her with the information, saying it is Hēmi’s personal information.*

### What issues are we thinking about?

- 7.11 Decision-making supporters are not formally recognised in law in Aotearoa New Zealand.
- 7.12 We are thinking about whether and how the law in Aotearoa New Zealand could improve decision-making support. One way decision-making support could be improved by legislation is to give decision-making supporters power to access relevant personal information (subject to appropriate confidentiality obligations). In the Ministry of Health’s ‘repeal and replace’ review, many submitters said that, for support to be successful, whānau and family need to have access to relevant information.
- 7.13 We are also thinking about whether the law could clarify the scope and effect of a decision-making support arrangement. There may be cases where the role may need to be limited or support has not been (or cannot be) used. Some questions we are considering are:
- (a) How might a decision-making supporter provide support alongside other decision-making arrangements?

- (b) What should happen if a person would like a decision-making supporter, but they do not have family, whānau or friends who are able to assist them?
  - (c) Does the use of a decision-making supporter need to be limited in some situations? What should happen if the person's will and preferences are very difficult to work out or understand? What should happen if their proposed decision could harm them or someone else? Should the law require the supporter to take an action (for example, seek to use a different decision-making arrangement) or not provide support in such cases?
  - (d) What happens if a person makes a decision, such as entering into a contract, without the decision-making support they would otherwise use. Does the law need an ability to overturn the contract?
- 7.14 Some countries have tried to make decision-making support easier by creating a role of 'formal decision-making supporter'. This is a person legally recognised as a person supporting someone with affected decision-making. We are thinking about whether this is something which would be useful for the law in Aotearoa New Zealand to include and, if so, what it might look like. For example, should a formal decision-making supporter have any obligations? How should a person with affected decision-making appoint a formal decision-making supporter? How might the role accommodate different cultural perspectives?

### What is your experience with decision-making supporters?

- 7.15 To help us consider these issues, we are interested in your experiences with decision-making supporters.

#### QUESTION 6

Has someone supported you to make a decision, or have you been a decision-making supporter to someone with affected decision-making? If so, how well do you think that process worked? What could be improved?

### ADVANCE DIRECTIVES

- 7.16 Under an advance directive, a person may decide, in advance, what they want to happen when their decision-making is affected. Advance directives are typically used for health care decisions.

- 7.17 Advance directives are sometimes used in Aotearoa New Zealand. However, their legal status is unclear. It is uncertain when and whether other people (such as doctors) are required to follow them.

*Doug is in his mid-30s. He works at a bank and likes to play rugby in his spare time. He has been diagnosed with bi-polar disorder.*

*A few years ago, he made a written advance directive about the treatment he would, and would not, like to receive when he is experiencing mental distress. He has not reviewed the advance directive since it was written.*

*Doug becomes unwell and his decision-making becomes substantially affected. His family tells the doctor that there is an advance directive in place and it must be followed. Doug says he no longer wants to follow the advance directive. The doctor is uncertain about whether the advance directive should be followed, especially given it was made several years ago.*

### What issues are we thinking about?

- 7.18 As noted above, the legal status of advance directives in Aotearoa New Zealand is unclear. We will need to consider whether the status and scope of advance directives should be clarified in law.
- 7.19 Many submitters to the Ministry of Health's 'repeal and replace' review considered advance directives to be useful and important. Concerns raised included the absence of an easily accessible register of current advance directives, and the ability of clinicians and attorneys appointed under enduring powers of attorney to override advance directives.
- 7.20 Other issues we are thinking about are:
- (a) How should a person make an advance directive? Should it be in writing? Should they receive legal advice?
  - (b) What sorts of decisions can be covered by an advance directive? Should they be limited to health care decisions or can they include other types of decisions? Are there some decisions that should not be made with an advance directive, such as a decision under the End of Life Choice Act 2019 (as is currently the case)?
  - (c) What should happen if a person's decision-making is substantially affected when they make an advance directive? What should happen if later, when their decision-making is significantly affected, they want to change it or decide differently?

- (d) Should people, such as doctors, be required to follow an advance directive? If so, what happens if the advance directive is 10 years old and the person's circumstances have significantly changed? What happens if it does not specifically deal with the situation at issue? If advance directives are not binding, what effect should they have?
- (e) When should an advance directive take effect? Typically, an advance directive only becomes active once a person is assessed not to have decision-making capacity. However, there are possible variations on this, including 'self binding-directives'. These are similar to advance directives but operate in the mental health context. They do not require a loss of decision-making capacity and instead apply during periods of mental distress that the person knows ahead of time can significantly affect their behaviour and decision-making.
- (f) How can advance directives be accessed when they are needed? Should there be a central register?

### What is your experience with advance directives?

7.21 To help us consider these issues, we are interested in your experiences with advance directives.

#### QUESTION 7

Have you experienced making, or been involved in using, an advance directive? If so, how well did you think that process worked? What could be improved?

### ENDURING POWERS OF ATTORNEY

7.22 An enduring power of attorney (EPOA) is a decision-making arrangement where a person (the donor) gives another person (the attorney) the power to make a decision or decisions for them in the future. The attorney's powers typically only begin once the donor is assessed as not having decision-making capacity. An EPOA can cover decisions about personal welfare or about financial/property matters.

7.23 EPOAs currently are made possible by the Protection of Personal and Property Rights Act 1988 (PPPR Act).

*Priya is in her mid-60s and has just retired from being a school teacher. She enjoys spending time in her garden.*

*She is planning ahead and decides she would like to give one of her children the power to make personal and financial decisions for her, if her decision-making becomes seriously affected in the future.*

*Priya investigates how to make an EPOA and learns she needs a lawyer to witness it. The last time she used a lawyer was when she bought her house 20 years ago.*

*Priya contacts her lawyer and sets up her EPOA. It was a bit more expensive than she was expecting, but she decides it was worth it. Priya leaves the original EPOA at the lawyer's office, and takes a copy home and puts it in a drawer in her desk.*

**What issues are we thinking about?**

7.24 Some issues we are thinking about are:

- (a) How can the law ensure EPOAs are accessible? We have heard it is difficult for service providers and professionals to find out whether there is an EPOA in place, who the attorney is and how to get hold of them. One way to resolve these issues may be a register of EPOAs.
- (b) Can the process for creating an EPOA be improved? The current process for creating an EPOA is formal and prescriptive. It must be witnessed by a person who must explain the effects of the EPOA and answer any questions. We have heard that it is too expensive and inaccessible for many people. We have also heard it is difficult to change an EPOA easily if needed.
- (c) Is there a way to ensure that EPOAs remain up-to-date and accurate? We have heard that they are not often regularly reviewed by donors.
- (d) When should an EPOA come into effect? Should it come into effect when a person is assessed not to have decision-making capacity? Should some other threshold be used?

- (e) When an EPOA is activated, how should the attorney make decisions for the donor? Currently, the paramount consideration of the attorney is the promotion and protection of the welfare and best interests of the donor or the best interests of their property. As far as practicable, the attorney must consult with the donor. They are not required to follow any advance directive.

### What is your experience with an enduring power of attorney?

- 7.25 To help us consider these issues, we are interested in your experiences with enduring powers of attorney.

#### QUESTION 8

Have you made, or been involved in using, an enduring power of attorney? If so, how well did you think that process worked? What could be improved?

### MAKING DECISIONS FOR SOMEONE ELSE UNDER A COURT ORDER

- 7.26 Under this type of arrangement, a decision is made for a person with affected decision-making under a court order. This can occur without the person's consent. Such processes can apply to a single decision or can be ongoing.

*Hēmi, who we met on page 38, has made a friend online. His friend is older and lives in the United Kingdom. His friend has bought him a ticket to come and visit him. Hēmi's mother does not find out about the proposed trip until shortly before Hēmi is due to leave.*

*Hēmi's mother is very concerned about his safety and applies to Te Kōti Whānau | Family Court for an order that Hēmi cannot leave Aotearoa New Zealand. The Family Court is concerned it is unsafe for Hēmi to go to the United Kingdom, and decides it is in his best interests to remain in the country. The Court makes an order that Hēmi cannot leave Aotearoa New Zealand.*

- 7.27 Under our current law, there are many decision-making arrangements where decisions are made for someone under a court order. Some examples include:
- (a) An order under the PPPRA, such as an order that a person be given medical advice or treatment, or not leave New Zealand. These orders are made by Family Court.

- (b) The appointment of a person to make decisions for another person on an ongoing basis. This could be for personal matters (a welfare guardian) or financial and property (a property manager). These orders are made by the Family Court.
- (c) An order for compulsory mental health treatment under the Mental Health Act. These orders are made by the Family Court.
- (d) An order for compulsory treatment for addiction under the Substance Addiction (Compulsory Assessment and Treatment) Act 2017 (Substance Addiction Act). These orders can be made by the Family Court or Te Kōti-ā-Rohe | District Court.

- 7.28 With the exception of the Mental Health Act, the orders require a finding that the person lacks decision-making capacity. Under the Mental Health Act, orders are only made when a person has “an abnormal state of mind” that is of such a degree that it poses a serious danger and/or seriously diminishes their ability to take care of themselves.
- 7.29 When a decision is made for someone else, the decision is effectively guided by what the decision-maker believes to be in the person’s best interests. For example, in the case of compulsory treatment for addiction, the person must have a severe substance addiction, compulsory treatment must be considered necessary, and appropriate treatment must be available. When a welfare guardian makes a decision, their first and paramount consideration is promoting and protecting the welfare and best interests of the person for whom they are acting.
- 7.30 Determining what is in a person’s best interests will often require consideration of the views of the person affected and their whānau. Some processes aim to empower the affected person. For example, under the PPPR Act, a person acting as a welfare guardian must encourage the person with affected decision-making to act on their own behalf to the extent possible. In addition, some case law under the PPPR Act has interpreted ‘best interests’ to include substantial consideration of the person’s will and preferences. Another example is the Substance Addiction Act which provides the purpose of compulsory treatment is to “protect and enhance [the person’s] mana and dignity and restore their capacity to make informed decisions about further treatment and substance use”.

## What issues are we thinking about?

### *The key debate – should one person be able to make a decision for another person?*

- 7.31 There is significant debate about whether someone should be able to make a decision for a person with affected decision-making under a court order. Much of the debate is concerned with 'hard' cases, such as where:
- (a) The person's will and preferences are difficult to work out or understand, even after all available support has been provided and previously expressed wishes have been identified. An example is where a person is in a coma and does not have an advance directive or whānau who know the person's preferences for medical treatment.
  - (b) The person's decision could seriously harm them or someone else.
- 7.32 Article 12 of the United Nations Convention on Rights of Persons with Disabilities (Disability Convention) does not expressly state whether the law can permit someone to make a decision for someone else without their consent. However, it does state that legal measures should respect the rights, will and preferences of the person and apply for the shortest time possible. Views on whether the law can permit one person to make a decision for someone else without their consent therefore often depend on questions such as:
- (a) When is a person able to make a decision for someone else? Is it only in cases of last resort? Against this, some people have argued that it is very difficult to ensure this only occurs in the most extreme cases. This is especially so if it is quicker and cheaper to appoint someone else to make the decision, rather than support the person to make their own decision.
  - (b) How should the decision be made? There is a big difference between a simple 'objective best interests' standard and a standard that is required to take proper account of, or reflect, the person's rights, will and preferences.
  - (c) How long can the intervention last? Attitudes to the possibility of short-term 'emergency' interventions are likely to be different to attitudes to long-term ones.

- 7.33 The United Nations Committee on the Rights of Persons with Disabilities (Committee) has said it is not permissible to make an objective ‘best interests’ decision for someone else. In its view, if it is not practicable to work out a person’s will and preferences, the best interpretation of a person’s will and preferences must be used. Someone else will work out what the person would likely want based on what is already known about them, including preferences, values, attitudes, any advance directive (or other record of their values and wishes) and any physical and verbal communications. This is sometimes referred to as ‘facilitated decision-making’.
- 7.34 Some commentators disagree with the Committee’s approach. As explained in Chapter 4, the concept of best interests is nuanced. We have heard that it may be better viewed as a framework or process for reaching a decision, where the decision-maker is required to consider several matters, including the views of the person with affected decision-making.
- 7.35 In addition, the Committee’s view does not expressly address what should happen when a person’s decision could seriously harm them or someone else. Some people have told us the law should address situations where a person with affected decision-making wants to make a decision that places themselves or someone else at risk of immediate serious or irrevocable harm. According to this view, the law’s failure to respond in such situations would be inconsistent with the human rights of the person (and potentially others). Article 12(4) of the Disability Convention does not just refer to the “will and preferences” but to the “**rights**, will and preferences” of the person.
- 7.36 If someone is permitted to make a decision for another person, we have heard that great care is required to ensure it is only allowed in ‘serious’ cases. It should not be used where the decision the person wants to make is simply seen by someone else as imprudent or risky. It is often said that a key purpose of article 12 of the Disability Convention is to ensure the ‘dignity of risk’ – the right of disabled people to take risks in the same way that everybody else can.

### *How is the debate relevant to our review?*

- 7.37 In light of that debate, we are thinking about several issues.
- 7.38 We need to consider whether the law should ever permit someone to make a decision for a person with affected decision-making, including without that person’s consent.

7.39 If so, several other issues arise, such as:

- (a) When should the law permit someone to make a decision for someone else? Should it be when the person is assessed not to have decision-making capacity? Should it be because they or someone else is at risk of immediate harm? Should another test be used?
- (b) How should a decision be made? Should it be based on the person's best interests? If so, what account should be taken of the person's wishes? Should the decision-maker be required to decide solely based on the person's will and preferences (and what is known about their will and preferences)? What if these appear to conflict with each other, or with the person's rights? Should another standard be used?
- (c) Who should authorise the decision? For example, should an order be made by the Family Court or a specialist Tribunal? We have heard that access to the Family Court can be beyond the reach of many New Zealanders and not always possible in urgent situations. How long should the intervention last? Should it be just for one decision or for multiple decisions? As noted above, article 12 of the Disability Convention states any legal measures should be for the shortest time possible.
- (d) How can these arrangements accommodate different cultural perspectives?

### What is your experience with court ordered decisions?

7.40 To help us consider these issues, we are interested in your experiences with court ordered decisions.

#### QUESTION 9

Have you been involved in a process of making decisions for someone else under a court order, or having decisions made for you under a court order? If so, how well did you think that process worked? What could be improved?

## COLLECTIVE DECISION-MAKING ARRANGEMENTS AND COLLECTIVE DECISIONS

- 7.41 The decision-making arrangements discussed above generally reflect ‘Western’ understandings of decision-making which emphasise individual freedom and see decision-making primarily as a question of individual reasoning and thinking skills. However, it is easy to imagine all the scenarios in this chapter having significant impacts on the wider members of the person’s family or whānau. And, as discussed in Chapter 5, approaches to decision-making in te ao Māori may be less focused on the individual and reflect a more collective perspective based on whakapapa and whanaungatanga. Other cultures may also have a more collective approach.
- 7.42 As part of our review, we are considering whether the law should allow people to approach decision-making arrangements collectively or as a group. For example, a decision-making arrangement might allow multiple people to support a person to make a decision. The decision would still be made by the individual, but some or all of their wider family, whānau and significant others may be involved in providing support. Alternatively, an advance directive might record a wish that certain decisions are made after discussion among the family or whānau and that collective interests should be taken into account.
- 7.43 For some people, a collective arrangement might enable more effective decision-making support than using one decision-making supporter. It might better reflect how the person lives their life and avoid tensions in the wider group as to who should be singled out as the supporter.
- 7.44 Another way a decision-making arrangement could be collective is by allowing the decision itself to be made collectively. For example, some overseas jurisdictions permit an arrangement called ‘co-decision-making’. Under this arrangement, a person with affected decision-making has a ‘co-decision-maker’. Decisions are made jointly by the person with affected decision-making and the co-decision-maker.
- 7.45 We have also heard of interest, particularly amongst doctors, in models of ‘shared decision-making’. This is where a treatment decision is reached jointly, based on conversations between the patient and doctor.
- 7.46 While co-decision-making and shared decision-making focus on a decision made jointly between two people, they could be adapted to allow more than two people to make the decision.

### What issues are we thinking about?

- 7.47 Many of the issues we are thinking about for decision-making support arrangements are relevant here. Collective decisions also raise additional issues, such as:
- (a) Should a co-decision-maker owe obligations to the person with affected decision-making? If so, what should they be?
  - (b) What should the decision-making 'standard' be? Should collective decisions be reached based on the best interests of the person with affected decision-making, their will and preferences, or something else (for example, a balance of the wishes of the person and other members of the person's family, whānau and other group)?
  - (c) Can collective decisions be specified in an advance directive or similar document?
  - (d) Should a co-decision-maker be liable to third parties for any decision made collectively? If so, should that liability be the same as the person with affected decision-making or should it be different?
  - (e) How should disagreements be resolved? What happens if the joint decision-makers do not reach consensus? Could a process for resolving disagreements be addressed in an advance directive or similar document?

### What is your experience with collective decisions and decision-making arrangements?

- 7.48 To help us consider these issues, we are interested in your experiences with collective decisions and decision-making arrangements.

#### QUESTION 10

Do you think there should be more ways for other people to be involved, in a more collective way, in decision-making arrangements when a person's decision-making is affected? If so, how?

## OTHER DECISION-MAKING ARRANGEMENTS

7.49 We have discussed some core decision-making arrangements above. However, there are others, such as the ‘personal ombudsman scheme’ in Sweden. Under this scheme, people with affected decision-making can access a personal ombudsman, who provides them with professional decision-making and advocacy support on an ongoing basis. We are interested to hear about any other decision-making arrangements you think we should be aware of.

### QUESTION 11

Do you think there are any other decision-making arrangements we should explore? If so, what are they?

## WHAT WOULD MAKE USING DECISION-MAKING ARRANGEMENTS EASIER?

7.50 We are also thinking about what could make decision-making arrangements easier or more effective to use.

7.51 For example:

- (a) It may be helpful for a person with affected decision-making to write down their personal beliefs and values or record how they want people to communicate with them. This could then be used by a decision-making supporter, to inform how they support the person to make a decision. An example of this is My Health Passport developed by Te Toihau Hauora, Hauātanga | Health and Disability Commissioner. My Health Passport contains information about how to communicate with and support the person and can be taken along to health and disability services.
- (b) Some decision-making arrangements may benefit from template documents. For example, if a person is required to choose a decision-making supporter and set the boundaries of that arrangement in writing, it may be useful to have a template support agreement.
- (c) It may be helpful for people to receive guidance or training on what the decision-making arrangements are and how they are used. For example, it may be useful for a decision-making supporter to receive training on the scope of the role and ways to support a person to make a decision.

- (d) It may be helpful for some decision-making arrangements to be recorded in a central register. We have heard that advance directives and EPOAs can sometimes be difficult to find when they need to be used.
- (e) Decision-making is generally easier when the material relating to the decision is provided in an accessible or easy to understand way. Some initiatives are already happening in this space. For example, the government has introduced the Accessibility for New Zealanders Bill which aims to provide a new legislative framework for identifying, preventing and removing barriers to participation for disabled people, tāngata whaikaha Māori and others with accessibility needs.

### **QUESTION 12**

What things might make decision-making arrangements easier or more effective?

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## CHAPTER 8

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# Safeguards and accountability

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### INTRODUCTION

- 8.1 Much of the time, decision-making arrangements for a person with affected decision-making work well. However, sometimes things might go wrong or people's rights might need protecting.
- 8.2 We think the law has a role to play in keeping people with affected decision-making safe from abuse, neglect and being taken advantage of. The law might also be used to support others involved decision-making arrangements, such as decision-making supporters.
- 8.3 Which safeguards and accountability mechanisms are appropriate will depend on the decision-making arrangement being used. Because it is difficult to think about safeguards and accountability mechanisms out of context, this chapter focuses on five scenarios. The scenarios are intended to help you think about which safeguards and accountability mechanisms might be needed in different situations.

## SCENARIO ONE: THE ROLE OF A DECISION-MAKING SUPPORTER

*Hēmi (who we met in Chapter 7) has a learning disability and lives at home with his mum. His mum now has control of his money and how he spends it. Hēmi is getting older and wants to make more decisions about his own life. She uses some of it to cover Hēmi's house expenses and saves the rest for Hēmi. Hēmi would like to have some more control over his money. He would like to buy some expensive Minecraft collectibles. His mum does not think this is a good use of money and is worried about his budgeting skills. She is worried that if she gives more control to Hēmi he will not make 'responsible' decisions.*

### What safeguards and accountability mechanisms could be useful in this scenario?

- 8.4 As explained in Chapter 7, there is no specific legal framework for decision-making supporters. This means that there are no specific safeguard and accountability mechanisms to manage difficult situations, such as when a person with affected decision-making wants to do something and their supporter disagrees.
- 8.5 Some ways the law could provide safeguards and accountability mechanisms are:
- (a) **Formalising the relationship:** The law could allow, or require, the support relationship between Hēmi and his mum to be formalised and recorded.
  - (b) **Setting out duties:** The law could set out duties or responsibilities of decision-making supporters. For example, the law could require Hēmi's mum to respect his will and preferences.
  - (c) **Limits on the supporter:** The law could place clear limits on what the decision-making supporter can do. For example, the law could expressly prohibit Hēmi's mum from making decisions on his behalf. It could also set out a process for when the supporter has a conflict of interest in relation to a particular decision.
  - (d) **Protection of personal information.** If the law allowed a decision-making supporter to access the personal information of the supported person, the law might need to place limits on the access and use of that personal information. For example, the law might prevent a decision-making supporter from accessing the supported person's personal information without their knowledge or consent. It might prevent the decision-making supporter from using that information for any purpose other than providing support.

- (e) **Written agreement:** The law could require a formal written support agreement. This could ensure that Hēmi and his mum are clear on the scope of the relationship and there is something to refer to if there is uncertainty or disagreement. The law might set out minimum requirements for support agreements or require them to be reviewed by a lawyer for the person with affected decision-making.
- (f) **Independent body:** The law could require the support relationship to be disclosed or registered with an independent body. This could allow third parties to verify the relationship. The independent body could also have an education and/or oversight role.

### QUESTION 13

Do you think there needs to be safeguards or accountability mechanisms when a person with affected decision-making has an informal decision-making supporter? If so, what should they be?

## SCENARIO TWO: ENDURING POWERS OF ATTORNEY AND ELDER ABUSE

*Priya, who we met in Chapter 7, is now in her mid-70s and lives alone. Under the enduring power of attorney (EPOA) she made ten years ago, she appointed one of her adult children, Sam, as attorney for both her personal care and property.*

*Priya is diagnosed with dementia and assessed as no longer having decision-making capacity. The EPOA is activated, which means Sam has power to make decisions about Priya's personal care and welfare and property.*

*Sam moves in to live with Priya, rent free. All house expenses are coming out of Priya's bank account. Sam has been making a lot of cash withdrawals, which he says are for food, clothes and gifts for Priya, but there are no receipts or records. Sam recently bought himself a new car.*

*Sam's siblings don't know how Priya's money is being spent, but are concerned that she is not getting good care. They are worried she is not being properly fed and she is not allowed to leave the house.*

### What safeguards and accountability mechanisms could be useful in this scenario?

- 8.6 Some safeguards and accountability mechanisms for EPOAs already exist under the Protection of Personal and Property Rights Act 1988 (PPPR Act). For example:
- (a) There are strict requirements for making an EPOA. It must be in the prescribed form and witnessed by an approved person, such as a lawyer.
  - (b) Generally, an EPOA will only activate if a person is assessed as not having decision-making capacity.
  - (c) When acting under an EPOA, the attorney's paramount consideration is to promote and protect the person's welfare and best interests (or to use their property in the promotion and protection of their best interests).
  - (d) An attorney must keep records of each financial transaction.
  - (e) If an attorney is not acting in the donor's best interest, or has failed to comply with their other obligations, Te Kōti Whānau | Family Court may revoke their appointment.
- 8.7 It is not clear how effective these mechanisms would be in this scenario.

- 8.8 We have been told that applications to the Family Court can be expensive, time consuming, and are not always able to be heard promptly. In this case, Priya may be unaware of how Sam is using her money and (given her dementia) is likely unable to access the court without support.
- 8.9 We have also heard that there are insufficient monitoring processes for EPOAs. In Priya’s scenario, Sam’s siblings are concerned about Priya’s welfare, but might not notice the potential misuse of Priya’s money. One option might be to have a specific oversight or complaints body, that could monitor or investigate actions taken under EPOAs or respond to concerns. Oversight may increase the likelihood of issues being identified proactively, rather than reactively. Such a body could also have an ongoing educative function.
- 8.10 We have also heard that a central register of EPOAs may assist with transparency of actions taken by attorneys. A register may be unlikely to help in Priya’s scenario, but it would make interactions between third parties and attorneys more straightforward.

#### **QUESTION 14**

Do you think there needs to be safeguards or accountability mechanisms when a person uses an enduring power of attorney? If so, what should they be?

## SCENARIO THREE: MOVING TO A REST HOME OR CARE FACILITY

*Linda is in her mid-80s and has been diagnosed with dementia. She lives alone in the family home as her husband died five years ago. She has not made an enduring power of attorney.*

*Her family is worried it is no longer safe for Linda to live at home. They have come over multiple times to find the gas element left on. Linda has also started leaving her house and getting lost.*

*Linda's family and clinicians decide Linda should be in a secure care home environment. In practice, once in the rest home she will not be able to leave, and her personal choices will be limited. It appears the move to the care home will be permanent. Linda indicates to family members that she would prefer to live at home, but does not strongly say no to the move.*

### What safeguards and accountability mechanisms would be useful in this scenario?

- 8.11 Specific safeguards and accountability mechanisms for Linda's situation are missing from our current law. There is no specific legal process designed to approve Linda's move to the long-term residential care, nor any specific mechanism for monitoring her ongoing stay.
- 8.12 There have been calls for Aotearoa New Zealand to fill this gap. Ways to do this might include:
- (a) A clear and straight-forward legal process that can be used to authorise a move to long-term residential care. This could be a specialist court or tribunal, or an independent person.
  - (b) A process to monitor the continued stay in the care home.
  - (c) An independent oversight body, specifically established to monitor moves to rest care facilities and investigate concerns.

### QUESTION 15

Do you think there needs to be safeguards or accountability mechanisms when a person moves to a rest home or care facility? If so, what should they be?

## SCENARIO FOUR: WELFARE GUARDIAN'S DECISIONS MIGHT CAUSE HARM

*Deborah lives with her aunt, Lucy, and their two cats. She has had a traumatic brain injury and is assessed as not having decision-making capacity for a wide range of personal decisions. Lucy is appointed as a welfare guardian to make decisions about Deborah's personal care and welfare.*

*Lucy often rejects medical advice about Deborah's healthcare because Lucy does not trust doctors. As a result of the traumatic brain injury, Deborah sometimes has seizures and they are becoming more frequent. The doctor advises these can and should be treated with medication. Lucy does not accept the advice as she does not believe in medication. Lucy believes she can better manage Deborah's seizures with natural remedies.*

### What safeguards and accountability mechanisms would be useful in this scenario?

- 8.13 There are some existing safeguards and accountability mechanisms for welfare guardians under the PPPR Act. For example:
- (a) A welfare guardian can only be appointed by the Family Court.
  - (b) The appointment of a welfare guardian must be reviewed at least every three years by the Family Court.
  - (c) The welfare guardian's first and paramount consideration is promoting and protecting the person's welfare and best interests.
  - (d) Individual decisions made by welfare guardians may be challenged and reviewed by the Family Court, as can the appointment of the welfare guardian itself.
- 8.14 It is not clear how effective these mechanisms would be in a case such as Deborah's. There is no formal monitoring system in place for welfare guardians. The primary accountability mechanism is the Family Court which we have heard may not be accessible for some people. It is also a very formal response. Lucy may simply require some education or training. However, a formal response might still be necessary if Lucy continues to ignore medical advice.

8.15 Ways of providing improved safeguards or accountability could include:

- (a) An oversight and complaints body, which could help identify and resolve any issues that arise.
- (b) Accessible education and training about the welfare guardian's role and powers.
- (c) A requirement for welfare guardians to provide regular updates on the exercise of their powers.

### **QUESTION 16**

Do you think there needs to be safeguards or accountability mechanisms if a person has a welfare guardian? If so, what should they be?

## SCENARIO FIVE: SUPPORTING PEOPLE WHO PROVIDE SUPPORT

*Alex is looking after their elderly father, who has affected decision-making. Alex is trying to support their father to make decisions but finds the demands on them exhausting. There is no other support within the extended family. Alex has a very strained relationship with their siblings, who constantly demand explanations and regularly claim Alex is failing to provide proper care and support. Alex is also experiencing mental distress and is struggling to cope.*

### What safeguards and accountability mechanisms would be useful in this scenario?

- 8.16 We have heard that the safety and wellbeing of decision-making supporters is important in facilitating good outcomes for adult decision-making – both for the supporter, and for the person being supported.
- 8.17 Some mechanisms that might assist in Alex’s situation include:
- (a) Ensuring that legal frameworks consider or support the safety and wellbeing of decision-making supporters and those they are supporting.
  - (b) Easily accessible information and advice on the role of decision-making supporter.
  - (c) Access to support services. It may be helpful for Alex to have a space to raise concerns, explore options and seek guidance. Other support, such as counselling or respite care may be useful.
  - (d) An accessible resolution service. This could be used to resolve situations where there are challenges or breakdowns in the relationship between the decision-making supporter and the supported person.

### QUESTION 17

Do you think there needs to be safeguards or accountability mechanisms to help supporters? If so, what should they be?

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## CHAPTER 9

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# Is there anything else you would like to tell us?

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- 9.1 The focus of this paper has been on the big issues and principles that should inform our review. We have asked several questions about your experiences. We want to hear about what currently works, and what could be done better.
- 9.2 However, how the law should best address affected decision-making is a large and complex question. There are many possibilities and issues we have not been able to address in this paper. That does not mean they are not important.
- 9.3 We want to provide an opportunity for you to tell us anything else you think we should know. Your input will help us make recommendations on how the law should approach adult decision-making.
- 9.4 We also want to provide an opportunity for you to tell us how we could improve our consultation process. We will have a second round of consultation in 2023 and your feedback will help us improve that process.

### QUESTION 18

Is there anything else you would like to tell us?

### QUESTION 19

How easily could you access information about the review and how to make a submission? What could we do better?

### QUESTION 20

How easy did you find making a submission? What could we do better?

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## APPENDIX 1

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# Acknowledgements

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Te Aka Matua o te Ture | Law Commission gratefully acknowledges the contributions of the people and organisations that have shaped our Preliminary Issues Paper, especially those individuals who have generously shared their personal experiences with us.

We acknowledge the generous contributions and expertise from our Lived Experience, Family, Whānau and Carers Expert Advisory Group:

Jeanette Brunton, Gina Giordani, Matthew Innes, Cindy Johns, Kate Johns, Wiremu Kohere, Lisa Martin, Sir Robert Martin, Fiona Parrant, Gaylene Te Rauna

We also acknowledge the generous contributions and expertise from our Professional Expert Advisory Group:

Professor John Dawson, Alison Douglass, Dr Hinemoa Elder, Andrew Finnie, Dr Mark Fisher, Associate Professor Dr Ben Gray, Dr Huhana Hickey, Iris Reuvecamp, Dr Jeanne Snelling

We acknowledge the individuals who attended our wānanga to share their insights on adult decision-making in te ao Māori, including Tai Ahu, Tamati Cairns, Dr William Edwards, Dr Hinemoa Elder and Tā Hirini Mead.

Nō reira, ko tēnei mātou e mihi nei ki a koutou, kua whai wā ki te āwhina i a mātou. Tēnā koutou, tēnā koutou, tēnā koutou katoa.

We emphasise that the views expressed in this Preliminary Issues Paper are those of the Commission and not necessarily those of the people who have helped us.

The Commissioner responsible for this project is Geof Shirtcliffe. The legal and policy advisers who have worked on this paper are Megan Rae, Sarah Fairbrother, Rebecca Garden and Fiona Thorp. We thank Tai Ahu and Annelise Samuels from Whāia Legal for their considerable assistance, in particular with Chapter 5. The law clerks who have worked on this paper are Georgia Drummond and Jessica MacPherson.

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## APPENDIX 2

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# Select bibliography

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Below is a select bibliography. If you would like to learn more about the laws we are reviewing, you may find these texts helpful.

### AOTEAROA NEW ZEALAND LEGISLATION AND BILLS

[Accessibility for New Zealanders Bill \(153-1\)](#)

[Health and Disability Commissioner \(Code of Health and Disability Services Consumers' Rights\) Regulations 1996](#)

[Human Rights Act 1993](#)

[Mental Health \(Compulsory Assessment and Treatment\) Act 1992](#)

[New Zealand Bill of Rights Act 1990](#)

[Protection of Personal and Property Rights Act 1988](#)

[Substance Addiction \(Compulsory Assessment and Treatment\) Act 2017](#)

### OVERSEAS LEGISLATION AND INTERNATIONAL INSTRUMENTS

Adult Guardianship and Trusteeship Act 2008 (Alberta)

Assisted Decision-Making (Capacity) Act 2015 (Ireland)

Convention on the Rights of Persons with Disabilities 2515 UNTS 3

Guardianship and Administration Act 2019 (Vic)

Legislative Review No 1384 (Peru)

Mental Capacity Act 2005 (UK)

### CASES REFERENCED IN THIS PAPER

*Peter Hugh McGregor Ellis v the King* [2022] NZSC 114

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## TEXTS AND COMMENTARY

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Te Tari Mō Ngā Take Hauātanga | Office for Disability Issues *New Zealand Disability Strategy 2016 - 2026* (Te Manatū Whakahiato Ora | Ministry of Social Development, November 2016)

United Nations Committee on the Rights of Persons with Disabilities *General Comment No 1 (2014): Article 12 – Equal recognition before the law* UN Doc CRPD/C/GC/1 (19 May 2014)

United Nations Committee on the Rights of Persons with Disabilities *Concluding observations on the combined second and third periodic reports of New Zealand* CRPD/C/NZL/CO/2-3

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## APPENDIX 3

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# Terms of reference

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## PROJECT OVERVIEW

Te Aka Matua o te Ture | Law Commission (the Commission) will undertake a review of the law relating to adult decision-making capacity.

## THE CURRENT LAW

Under the current law, if a person is assessed as wholly or partly lacking decision-making capacity, their exercise of legal capacity may be limited. So, if a person is assessed as lacking the ability considered necessary to exercise legal rights and duties, their decisions may not be recognised as having legal effect. In these circumstances, another person can be given authority to make decisions on their behalf. This is commonly referred to as substituted decision-making.

The central statute that addresses adult decision-making capacity is the Protection of Personal and Property Rights Act 1989 (PPPR Act). Other law also addresses issues to do with decision-making capacity. Together these cover a wide variety of decisions we may all face over the course of our lives.

The current law regulating decision-making capacity affects a wide range of adults. Those particularly affected include people with dementia, people with acquired brain injuries, people with neurodisabilities (including learning/intellectual disabilities), people with mental health needs and people with other neurological or physical disability or health needs that affect their decision-making abilities. People sometimes fall into more than one of these groups. A person's decision-making abilities may be affected only some of the time, to differing degrees at different points in time or in relation to different types of decisions. Further, experiences of impairment are influenced by societal barriers and, frequently, by multiple forms of discrimination (such as race, gender and sexual orientation).

## SOCIETAL CHANGES AND THE NEED FOR REFORM

There have been significant developments since the PPPR Act was passed over 30 years ago.

Issues have arisen with the operation of the PPPR Act and other relevant law. Societal attitudes about disability have also shifted, and in 2008 Aotearoa New Zealand ratified (committed to implementing) the United Nations Convention on the Rights of Persons with Disabilities (Disability Convention). This has led to recognition that there are barriers in our society that disable people, which need to be removed to enable disabled people to participate equally in society. In addition, as our population ages an increasing proportion of New Zealanders will require support to make decisions about their lives. These developments have all contributed to widespread calls for reform of the law in this area.

Further, the PPPR Act may not be compatible with Māori perspectives, te Tiriti o Waitangi | the Treaty of Waitangi and the rights of tāngata whaikaha Māori (Māori disabled people), their whānau, hapū, and iwi.

The Disability Convention reaffirms existing human rights, the general human rights principles of equality and non-discrimination, and the specific right of disabled people to enjoy legal capacity on an equal basis. This specific right establishes obligations on government to provide the support required for people to exercise this right (commonly referred to as supported decision-making), and to provide associated safeguards. The Disability Convention also emphasises that disabled people must be involved in the development of law and policies that affect them.

The Disability Convention guides the New Zealand Disability Strategy 2016-2026. The Strategy is guided by the principles of te Tiriti o Waitangi, in particular partnership, participation and protection. Ensuring that disabled people are involved in decision-making that impacts them is also a guiding principle of the Strategy. In pursuing its vision of a non-disabling society, the Strategy recognises the need to provide appropriate support to those who require it to communicate or make decisions. The Strategy also recognises the need to put safeguards in place that protect disabled people in the exercise of their rights, regardless of whether they need support to make decisions.

## THE COMMISSION'S REVIEW

It is in this context that the Commission will examine the law and associated practice relating to adult decision-making capacity.

We will consider how issues relating to adult decision-making capacity should be regulated in Aotearoa New Zealand. In particular, we will consider whether our law and practice strike an appropriate balance between:

- enabling people to make decisions about their own lives (including with appropriate support from whānau, family, carers and caregivers, other professionals or the wider community); and
- safeguarding people from harm.

## A NOTE ON LANGUAGE

The language we use about disability is important. Some words are understood differently by different people, there are differing views around preferred language, and these views may change over time.

The language used in our law will be part of our review and we will be seeking disabled people's views on this matter.

We acknowledge the status of te reo Māori and New Zealand Sign Language as official languages of Aotearoa New Zealand and will seek to use these languages in appropriate ways in conducting our review.

## SCOPE OF THE REVIEW

The review will include (but not be limited to) consideration of:

- Ao Māori perspectives on decision-making capacity and its regulation, including how the law should address any matters of particular concern to tāngata whaikaha Māori, their whānau, hapū and iwi, and Māori more generally.
- How the law should recognise and provide for te Tiriti o Waitangi | the Treaty of Waitangi.
- How the law should protect and promote human rights, including consideration of:
  - Aotearoa New Zealand's international human rights commitments, particularly under the Disability Convention and the United Nations Declaration on the Rights of Indigenous Peoples; and
  - Domestic human rights laws, particularly the New Zealand Bill of Rights Act 1990 and Human Rights Act 1993.

- The language used in our law.
- How to assess a person’s ability to make decisions about exercising legal rights and duties.
- How the law should facilitate and regulate the provision of support to people who require support to be able to exercise legal capacity on an equal basis.
- How the law should recognise the role of whānau, hapū and iwi, family, carers and caregivers, and the wider community in the provision of such support.
- How the law should regulate the exercise of legal capacity in rare circumstances where decisions may need to be made on behalf of a person.
- What safeguards the law should provide around measures relating to the exercise of legal capacity.
- 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).

The review will consider various laws and legal instruments as they relate to the regulation of adult decision-making capacity, and how they interact.

In particular, this will include:

- Protection of Personal and Property Rights Act 1988
- Mental Health (Compulsory Assessment and Treatment) Act 1992
- Substance Addiction (Compulsory Assessment and Treatment) Act 2017
- Health and Disability Commissioner Act 1994 and the Code of Health and Disability Services Consumers’ Rights established under that Act

We are aware that the Mental Health (Compulsory Assessment and Treatment) Act 1992 and the Substance Addiction (Compulsory Assessment and Treatment) Act 2017 are the subject of separate reviews. We will consider these reviews and their implications for our work.

The Commission will not review capacity under criminal law (which includes the Intellectual Disability (Compulsory Care and Rehabilitation Act 2003)), but may however comment on the implications of our review for criminal law.

Similarly, we will not review capacity in relation to children and young people (as defined under the Oranga Tamariki Act 1989), but we may comment on the implications of our review for children and young people, their families, whānau, hapū and iwi, and carers and caregivers, particularly as young people transition into adulthood.

## REVIEW PROCESS AND TIMING

In addition to the Commission's general commitment to consulting the public on our reviews, the Disability Convention requires that disabled people are involved in the development of legislation and policies to implement the Convention.

We will work with disabled people, tāngata whaikaha Māori, and their representative organisations to facilitate accessible consultation processes and maximise the participation of those individuals and communities most directly affected by the laws relating to adult decision-making capacity.

Engagement will also include a public consultation process in 2022.

People can subscribe to updates on this review, including opportunities to be involved, on our webpage. Click [here](#) to subscribe for updates.

The Commission launched its review with the publication of these Terms of Reference in August 2021.

The Commission intends to report to the Minister Responsible for the Law Commission, the Minister of Justice by the end of 2023.

October 2021

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