MENTAL HEALTH LAW PROFILE

Use of advance directives to facilitate supported decision-making in mental healthcare: learnings from Aotearoa New Zealand

Giles Newton-Howes,[1] Jessie Lenagh-Glue,[2] Katie Thom,[3] Sarah Gordon,[4] Paul Glue[5] and Armon Tamatea[6]

[1] Professor, Department of Psychological Medicine, University of Otago, New Zealand

[2] Senior Research Fellow, Department of Psychological Medicine, University of Otago, New Zealand, Email: jessie.lenagh-glue@otago.ac.nz

[3] Associate Professor, AUT School of Law, Auckland Institute of Technology, New Zealand

[4] Senior Lecturer, School of Health Equity and Innovation, University of Waikato, New Zealand

[5] Professor, Hazel Buckland Endowed Chair, Department of Psychological Medicine, University of Otago, New Zealand

[6] Associate Professor, Psychology, University of Waikato, New Zealand

Keywords. Mental health law; ethics; advance directives; New Zealand; UNCRPD.

First received 12 May 2025
Final revision 18 Dec 2025
Accepted 30 Jan 2026

doi:10.1192/bji.2026.10097

Mental health advance directives are one mechanism to enable individuals to have a voice in their treatment at a time when most legislative systems would consider them to lack the capacity to make informed choices. This honours their will and preferences while at the same time recognising the difficulties of the legislative framework. In this review we consider the use of such advance directives in New Zealand, in the form of a specialised advance agreement known as a mental health advance preference statement (MAPS). By evaluating their development and considering their ethics and cultural components we offer insights into one approach to the creation and implementation of MAPS for other jurisdictions.

> 'Our current Mental Health Act is outdated. Forcing people into mental health treatment regardless of their rights and preferences unjustifiably breaches their autonomy, freedom and tino rangatiratanga [Māori: self-determination, independence, autonomy], and can contribute to mental illness prejudice and discourage people from seeking help.'[1]

Enabling individuals to have an active voice in treatment choices is acknowledged as important in facilitating recovery.[2] Advance care planning or advance directives have gained currency in many health systems worldwide.[3] The driving force behind the use of advance directives is their ability to promote autonomy by honouring an individual's will and preferences when that person is unable or unwilling to express them in a future context. This has been contentious, with some arguing that the beliefs and desires of a future self are unknown to the present self, and thus negate the autonomy of the future self.[4] Others, however, propose that the concept of precedent autonomy allows for the use of an advance directive based on inherent moral values that the individual held when the directive was made.[5]

In this article, we explore elements related to mental health advance directives (MHADs) with reference to New Zealand-based research on a specialised advance agreement known as a mental health advance preference statement (MAPS). We will give an overview of MHADs from an historical and legal perspective, taking the New Zealand point of view, and examine how their use might help facilitate a step-change by supporting people with psychosocial distress[a] to receive mental healthcare that meets their individual needs.

Uptake of advance directives for end-of-life care has been slowly gaining traction,[6] but there are still substantial barriers to their use in mental health contexts.[7] Advance directives can facilitate supported decision-making and are endorsed as best practice for nations to comply with their obligations under the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD). The use of advance directives is being integrated, in many jurisdictions, into reformed mental health law.[8]

MHADs enable individuals to make statements about their preferences for future mental healthcare. They are designed to record peoples' choices, so that clinicians are aware of them when they later provide care and treatment. Traditionally, MHADs have been based on the concept that healthcare decision-making is shared between patient and provider.[9] A 'shared' approach implies a symmetric distribution of power between patient and clinician that, in practice, may weigh in favour of clinicians and negate the patient's preferences. This approach falls short of the responsibilities of signatories to the UNCRPD, which states that people should be given the support needed to enable them to make their own decisions regarding their care. The distinction between legal capacity to make one's own decisions under the law and mental capacity, which has often been interpreted as the cognitive ability to make such a decision, is discussed in more depth in the next section. In its General Comment to Article 12 of the UNCRPD, the Committee on the Rights of Persons with Disabilities states:[10]

> 'For many persons with disabilities, the ability to plan in advance is an important form of support, whereby they can state their will and preferences which should be followed at a time when they may not be in a position to communicate their wishes to others. All persons with disabilities have the right to engage in advance planning

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[a] This is the term used by the Committee on the Rights of Persons with Disabilities and it encapsulates those often described as having a mental illness or mental disorder in other contexts.

> and should be given the opportunity to do so on an equal basis with others. States parties can provide various forms of advance planning mechanisms to accommodate various preferences, but all the options should be non-discriminatory' (para. 17).

Use of MHADs reflects the principle behind supported decision-making: people should be supported to make their own decisions in advance if they might have difficulty making or articulating them at a later time. To be in compliance with Article 12, when an MHAD enters into force, or ceases to have effect, should be decided by the person and included in the text of the directive; it should not be based on an assessment that the person lacks capacity.[b] A pertinent question, then, is how can MHADs be used most effectively to that end?

Paternalism versus empowerment

General principles of mental healthcare law

Traditionally, MHADs are documents that are designed to convey an individual's healthcare preferences or designate a surrogate decision-maker when the individual is deemed to lack capacity to make their own care decisions.[11] This is consistent with common law principles governing consent, which determine that the standard for informed consent is the information that a person, in that person's circumstance, deems important.[12] Similarly, common law deems that every competent adult has the right to refuse any medical treatment, even where death is the inevitable consequence.[13] King & Moulton's[14] analysis revealed that patient preferences that reflect their lifestyle, values and personal preferences are often the best indicator for appropriate treatment, but clinicians are rarely well-placed to take these values into consideration when making treatment decisions, given the pressures on health systems and the fact that often clinical presentation is in an emergency setting.

Mental health legislation

These general principles of healthcare law are not fully reflected, however, in many countries' mental health legislation. In New Zealand, for example, the Mental Health (Compulsory Assessment and Treatment) Act 1992 (NZ MHA)[c] fails to give effect to this premise. When a person meets the criteria for civil commitment under that Act, they come under a model of substitute, rather than supported, decision-making. The NZ MHA authorises a responsible clinician to provide compulsory treatment 'for mental disorder' regardless of any preference or refusal the person may have previously stated in a valid MHAD. Compulsory treatment under the Act requires the person to have a clinically assessed 'mental disorder' that poses a serious danger to the health or safety of that person or others, or seriously diminishes their capacity to care for themselves, but there is no requirement that the person lacks capacity to consent. There is no need for the person's mental condition be present constantly: its 'intermittent' presence is enough to meet the criteria for compulsory treatment. If the person meets these criteria, any advance refusal they have issued may be overridden or disregarded, provided that their responsible clinician considers the treatment proposed to be clinically indicated, and a second psychiatric opinion concurs that it would be in the person's best interests. Although compulsory treatment is generally concerned with persons experiencing mental distress, legislation permitting compulsory treatment for certain contagious communicable diseases exists in different jurisdictions, such as US federal quarantine orders for certain infectious diseases.[15] In the USA, the Supreme Court has ruled that involuntary confinement is justified only when three conditions are satisfied: (a) the individual is truly dangerous; (b) confinement is the least restrictive alternative to protect from the danger; and (c) the individual must be afforded procedural due process.[15] In situations where individuals fail to consent to treatment or are non-compliant with restrictions,[15] the Court may order them to remain in confinement. In these cases, the determination has been that the risk to the public outweighs the individual's right to make their own healthcare decisions. Although the ethics of this approach may be debatable, we would argue that as long as there remain compulsory regimes, the onus is on the legislation and medical practitioners to find the least restrictive option,[16] and MHADs have an important role to play.

Committee on the Rights of Persons with Disabilities

These general principles of healthcare law are also not reflected in the implications of the UNCRPD for mental health law. The Committee on the Rights of Persons with Disabilities, which sits under the UNCRPD and monitors compliance, has directed countries that have ratified the convention to abolish substitute decision-making and replace it with supported decision-making.[10] The Committee has repeatedly criticised New Zealand for failure to uphold its obligations under international law, assumed on ratifying the UNCRPD in 2008, and has highlighted New Zealand's failure to revise its laws that permit substitute decision-making for people with disabilities.[17] They have also remonstrated with New Zealand over its failure to respect every individual's right to give and withdraw informed consent to healthcare, in compliance with Article 12 of the UNCRPD.

Not everyone accepts the UN Committee's interpretation of the implications of the UNCRPD for mental health law. Dawson has pointed out ambiguities in the language of the UNCRPD, which leaves some matters unclear. He suggests that the Committee's interpretation of

[b] The important point to note here is the MAPS is not based on a medical capacity assessment.

[c] It is important to note that this 1992 Act is in the process of being repealed and replaced with a new Mental Health Act in New Zealand. The Bill is currently awaiting its second reading in Parliament. Part 2 of the Bill provides for the making of advance directives but the Bill's purpose, as set out in clause 3, is to provide for compulsory mental health

assessment, and clause 7(1)(c) states that the impaired mental health causes the person to lack capacity to make decisions about their mental healthcare. The 'intermittent presence' clause regarding the person's mental condition remains under clause 9(2)(b).

Article 12 could have 'affirmed the need to recognise the legal capacities of persons with disabilities wherever possible, and the need to support them, on occasion, to exercise those capacities and formulate an authentic expression of their views, while reserving the possibility that a person may be found to lack capacity in a certain domain'[18] and therefore require substitute decisions to be made for them, on occasions, in that domain. Paragraph 14 of the General Comment on Article 12 details two reasons why the capacity approach is problematic. First, it is discriminatorily applied to people with disabilities, and second, it presumes to be able to accurately assess the inner workings of the human mind and, when the person does not pass the assessment, it then denies them a core human right – the right to equal recognition before the law.[10]

Article 12 refers to legal capacity, which has been defined as 'a person's power or possibility to act within the framework of the legal system'.[19] Thus, legal capacity reflects the individual's right to make their own decisions regarding how they live and interact in society. Mental capacity is often defined as the ability of an individual to understand information relevant to a decision and its effect; to retain that information to the extent necessary to make the decision; and to use or weigh that information as part of the process of making the decision (Mental Capacity Act 2005 (England and Wales), section 3). The concept of mental capacity is highly controversial in and of itself. Mental capacity is not, as is commonly presented, an objective, scientific and naturally occurring phenomenon. Mental capacity is contingent on social and political contexts, as are the disciplines, professions and practices that play a dominant role in assessing it.

Under a supported decision-making model, individuals accessing healthcare and disability services would be provided the support and resources needed to articulate their will and preferences. Use of MHADs can be one critical means promoting that aim. There have been developments in some jurisdictions, such as England and Wales, Scotland, the Canadian provinces and certain states of Australia, that have recently reformed their mental health legislation to incorporate the use of advance directives. However, none of these changes fully reflect the obligations as stated in the General Comment, namely that:[10]

> 'States parties' obligations to replace substitute decision-making regimes by supported decision-making regimes requires *both* [emphasis added] the abolition of substitute decision-making regimes and the development of supported decision-making alternatives. The development of supported decision-making systems in parallel with the maintenance of substitute decision-making regimes is not sufficient to comply with article 12 of the Convention' (para. 28).

Use of advance directives for mental healthcare – Aotearoa New Zealand

International research has advocated for interventions facilitative of pre-event planning, including MHADs, as supported decision-making mechanisms.[20]

Recent New Zealand research has explored the creation and promotion of the use of MHADs using online surveys[9] and hui (focus groups) with *tāngata whaiora* (Māori: 'people seeking wellness') and *whānau* (Māori: family and wider kinship group) to ascertain what they would want to see in such an instrument and their attitudes to its use.[21] The resulting instrument was called a mental health advance preference statement (MAPS), which reflected the desire for a clear and concise template that included diverse options expressing preferences.[21] A MAPS covers eight domains based on two categories: (a) treatment-related options and (b) personal support choices.[9] There was general agreement between service providers and *tāngata whaiora/whānau* that this was the right content for MAPS. There was less agreement concerning their perceived value and utility. Service providers doubted whether MAPS would help *tāngata whaiora* engage with mental health services or increase their self-management skills.[9]

Thematic analysis of the content of MAPS subsequently completed showed that they provide expressions of preferences that are both personally meaningful for *tāngata whaiora* and give practical guidance to clinicians.[21] Many preferences demonstrate a strong theme of procedural justice, with *tāngata whaiora* emphasising the desire to be listened to and respected during treatment or hospital admission. In many cases, preferences did concern the use (or not) of medication, but many advance refusals were mitigated by explanations or suggested alternatives. These findings are consistent with other reports.[22,23] This shows that, given the opportunity and the right support, people can create preference statements that both reflect their will and preferences and enable clinicians to support them in planning their care.

Culture matters

Further research in New Zealand has shown the importance of cultural considerations in both the creation and implementation of MAPS.[24] This is an area that has been ignored in MHADs.[25] One study reported strong support for family involvement in creating directives among Latinos in Florida, USA,[26] and a more recent study looked at whether advance choice documents improved the therapeutic relationship for Black people in England who had undergone compulsory mental health treatment.[27] These two studies are rare exceptions but do focus on ethnicity. These studies, however, did not focus on the cultural considerations of the instrument itself or the process of creating a person-centred and culturally relevant MHAD.

The New Zealand study demonstrated the importance of understanding cultural safety, strengths and resources that might reduce distress and provide support options for the patient.[24] Māori, the Indigenous people of New Zealand, emphasise the importance of the collective over the individual in making healthcare decisions, and the value placed by the collective on a holistic approach to health and well-being. This means that due consideration needs to be afforded to Māori patients whose world is comprised of a network of familial and tribal relationships that draw on heritage and ancestral ties to the land as meaningful cultural resources. Responses to decision-making about health are not so easily addressed by laws and conventions that assume a natural science view of the universe where personhood privileges individual autonomy over obligations to *whānau* and community. Further, approaches to healthcare that do not account for the patient's cultural world appear incomplete and uninformed and risk overlooking a rich repository of pro-health resources and pathways. Last, Māori, like many Indigenous peoples, are over-represented in mental health statistics, disproportionately committed under the NZ MHA[28] and experience differential access to healthcare services as a consequence of socioeconomic disparities. In this regard, the UNCRPD – in particular Article 12 – highlights the importance of 'equal recognition before the law', which may serve to do little more than offer lip service to real-world disparities in health in the absence of applied policies, practices and tools to meaningfully promote *tino rangatiratanga* for chronically disadvantaged patients. Culture matters.

Although it is not possible to extrapolate these findings to other Indigenous cultures, socioeconomic disparities and the flow-on effects on health and mental well-being (and responses to these) are, among other things, shared concerns for Indigenous people worldwide. It is likely that the traditional Western paradigm whereby the individual is the primary driver of personal health decisions may not be culturally valid and alternatives need to be examined.

Conclusion

Health is more than the absence of disease. When a person presents to mental health services they come as a whole person with a wide range of life experiences and a life in context. Satisfying the preferences identified in their MHADs can support their return to health. It helps identify what will make a difference to them if they present again.

Although this may make people's experiences with services less traumatic and less disruptive to their lives, it will also meet the requirement under the UNCRPD to enable patients to direct the care and treatment they receive.

In our view, an MHAD instrument should be offered to all who experience mental health distress, including people who have been admitted under compulsory treatment orders. An MHAD is created by the person to express their voice. It can cover broader matters than health-related preferences. A member of our team who has used mental health services said: 'It is often our personal choices that will help us to move out of hospital quicker, and when our priorities are listened to, even if not followed, this can have a positive influence on our behaviour in distressing times'.

To fully meet the requirements outlined in Article 12 of the UNCRPD, that 'the human rights-based model of disability implies a shift from the substitute decision-making paradigm to one that is based on supported decision-making' (para. 3),[10] would require a legislative change moving away from judging a person's mental capacity to make a decision to a situation where the individual's will and preferences as stated in their MHAD informs clinical practice and enables the person to retain and exercise their legal capacity. Perceptions of risk with potential serious consequences cause some to argue that there should be exceptions available that enable clinicians to override the will and preferences in some situations. Various criteria are proposed in terms of what would be required for such an exception to be available. One of the concerns with an exception is that it can very easily become routine practice. The General Comment on Article 12 is clear that the development of supported decision-making systems in parallel with the maintenance of substitute decision-making regimes is not sufficient to comply with Article 12 of the Convention. The only exception considered acceptable is where, after significant efforts have been made, it is not practicable to determine the will and preferences of an individual, the 'best interpretation of will and preferences' must replace the 'best interests' determinations. As the evidence that supported decision-making in the absence of any substitute decision-making is growing,[29] the challenge is to focus our efforts on creating and using MHADs that enable individuals' right to have their will and preferences followed in order to facilitate their recovery journey.

Author contributions

First draft: J.L.-G., G.N.-H. and A.T.; revisions: all authors; drafting of final version and approval for submission: all authors.

Funding

This work was supported by a New Zealand Health Research Council Health Delivery Research Project Grant (ID# 22/670).

Declaration of interest

None.

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