HOW WILL YOU HEAR MY VOICE? THE DEVELOPMENT OF INDIGENOUS-CENTRED SUPPORTED DECISION-MAKING FOR MENTAL HEALTH SERVICE USERS IN AOTEAROA NEW ZEALAND

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ABSTRACT

There is an urgent need in the delivery of mental health services to incorporate a more human-rights oriented approach, and promote supported decision-making, whereby individuals make their own mental health decisions based on their will and preferences. Aotearoa New Zealand's current Mental Health Act enables the use of substituted decision making in treatment, which breaches both international obligations under the Convention of the Rights of Persons with Disabilities and the articles of The Treaty of Waitangi, the covenant between Māori and the Crown which demands partnership and equity and the principle of self-determination for Māori. Mental Health Advance Preference Statements (MAPS) have been identified as a tool to promote supported decision-making and ensure people have a voice in their own care. This paper explores the foundations of a new project that is Māori-centred. The project is being co-designed and co-produced with stakeholders, including experts with lived experience of mental distress (known as tāngata whaiora), as well as those who work and research mental health services. The aim of this project is to create and implement culturally appropriate and locally relevant MAPS-type tools and then evaluate the impact of implementation. In addition to compliance with rights' obligations, it is posited this will lead to improvements in health and equity, particularly for Māori.

1. INTRODUCTION

Compliance with the *Convention on the Rights of Persons with Disabilities* (CRPD) requires substitute decision-making being abolished and replaced with supported decision-making[1]. Substituted decision-making means that decisions about care for a person with significant mental health challenges are determined by others (e.g., clinicians, the courts), in the exercise of what they believe is in the 'best interests' of the person. By contrast, supported decision-making reflects a rights-based and person-centred approach to decision-making in the best interests of the person and

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[1] Gordon S, Gardiner T, Gledhill K, et al. From substitute to supported decision making: Practitioner, community and service user perspectives on privileging will and preferences in mental health care. 2022 Int J Environ Res Public Health; 19:6002 https://doi.org/10.3390/ijreph19106002.

shifts the locus of control to the recipient of service. This article examines how work from two separate research projects in Aotearoa New Zealand (Aotearoa)[2] has converged, spawning a new, in-depth study focused on creating the tools useful to facilitate supported decision-making in mental health care. This paper focuses on how the Indigenous voice is working to achieve a more inclusive and less discriminatory approach.

Supported decision-making is a key contemporary issue in mental health service and capacity law, with international and domestic agencies highlighting requirements to revise current legislation and service provision in line with human-rights obligations. From an Indigenous perspective, co-design and co-production are critical to be aspirational and reflect Māori interests and values. This entire project is Indigenously led. A combination of Māori-centred research and co-production ensures the collective includes the diverse voices of tāngata whaiora[3] (those with lived experience) and Indigenous peoples. Locating this research as a Māori-centred co-production project promotes the Te Tiriti o Waitangi/The Treaty of Waitangi (the Treaty) principles[4] of tino rangatiratanga (self-determination), pātuitanga (partnership), mana taurite (equity), and kōwhiringa (options) as well as championing tāngata whaiora as experts by experience, shifting the focus of research from 'doing to' to 'doing with' the people relevant to the study. By so doing, the project upholds a key aspect of the Treaty, that being the concept of partnership and equity in promoting Māori health and wellbeing. This is the cornerstone of partnership in Aotearoa.

2. BACKGROUND

International conventions and guidelines[5] and domestic codes of rights[6] require substitute decision-making to be replaced with supported decision-making (SDM), whereby individuals are supported to make their own mental health decisions based on their will and preferences. A move to SDM was recommended by the Aotearoa

[2] There has been a steady evolution to refer to New Zealand as Aotearoa, which was the Māori name for the North Island, and now generally refers to the country as a whole. As this project is co-designed, co-produced and co-governed by Māori, we have chosen to use the term Aoteoroa throughout this paper, except where the name of legislation includes the words New Zealand.

[3] All Te Reo Māori terms are defined in a glossary at the end of the paper.

[4] Waitangi Tribunal. Hauora: Report on Stage One of the Health Services and Outcomes Kaupapa Inquiry. 2019: Wellington Waitangi Tribunal:163–164. The five principles are 1) *tino rangatiratanga*, which provides for Māori self-determination in the design, delivery and monitoring of health and disability services; equitable health outcomes for Māori; 2) *whakamarumarutia*, active protection, by which the Crown must act proactively to achieve 3) *mana taurite*, equitable health outcomes for Māori; 4) *kōwhiringa*, options, which requires the Crown to provide culturally appropriate health and disability services; and *pātuitanga*, partnership, by which the Crown and Māori are to work together in the governance, design, delivery and monitoring of health and disability services.

[5] United Nations Convention on the Rights of Persons with Disabilities: resolution / adopted by the General Assembly, 24 January 2007, A/RES/61/106, available at: www.refworld.org/docid/45f973632.html [accessed 21 June 2023].

[6] Right 7(3). Health and Disability Commissioner (Code of Health and Disability Services Consumers' Rights) Regulations 1996, available at: www.hdc.org.nz/your-rights/about-the0code/code-of-helath-and-disabilit-services-consumers-rights/ [accessed 21 June 2023]

government inquiry into mental health and addiction, *He Ara Oranga*[7] and the Ministry of Health's most recent guidelines to the current legislation[8]. SDM requires understanding the person's background, acknowledging external environmental influences, and makes an ethically relevant approach critically important. This is especially valid when data indicate an overall increase in the use of coercive care, particularly on the basis of ethnicity[9].

There is overwhelming evidence that the prevalence of coercive care is increasing in Aotearoa. Since 2005, compulsory treatment has increased from 82 per 100,000 to 103 per 100,000 in 2020, both an absolute and a proportionate increase[10]. While Aotearoa has not seen as dramatic an increase in the use of involuntary hospitalisations as many other wealthy industrialised nations[11], the same cannot be said about the use of community treatment orders (CTOs) which in 2022 were 96 per 100,000[12], making the use of these orders amongst the highest in the world[13]. Importantly, Māori are approximately 3.5 times more likely to be subject to community treatment orders than non-Māori, and more than three times more likely to be subject to inpatient treatment orders[14]. One earlier study showed that some individuals who identified as Māori perceived CTOs as coercive and negative, others felt that they provided some safety, and thus provided a modicum of utility for them[15]. In a recent article highlighting the regional variability of the use of CTOs, the authors hypothesised that one variable contributing to the higher prevalence of CTOs amongst Māori might be inequities in access to healthcare[16].

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[7] *He Ara Oranga: Report of the government inquiry into mental health and addiction.* Wellington, NZ, Mental Health and Addiction Inquiry, New Zealand Government, 2018. www.mentalhealth.inquiry.govt.nz/inquiry-report/he-ara-oranga/. [Accessed June 19, 2023].

[8] Ministry of Health. *Guidelines to the Mental Health (Compulsory Assessment and Treatment) Act 1992*. 2022, Ministry of Health, Wellington.

[9] Faissner M, and Braun E. The ethics of coercion in mental healthcare: the role of structural racism. 2023 J Med Ethics. doi: 10.1136/jme-2023-108984. https://jme.bmj.com/content/early/2023/10/16/jme-2023-108984.abstract.

[10] Ministry of Health. *Office of the Director of Mental Health and Addiction Services 2020 Regulatory Report*; 2021, Ministry of Health, Wellington. https://www.health.govt.nz/publication/office-director-mental-health-and-addiction-services-regulatory-report-1-july-2020-30-june-2021 [accessed 11 July 2023].

[11] Rains LS, Zenina T, Casanova Dias M, et al. Variations in patterns of involuntary hospitalisation and in legal frameworks: an international comparative study. 2019 Lancet Psychiatr; 6:403-417.

[12] Ministry of Health. Office of the Director of Mental Health and Addiction Services: Regulatory report 1 July 2021 to 30 June 2022. 2023, Ministry of Health, Wellington. https://www.health.govt.nz/publication/office-director-mental-health-and-addiction-services-regulatory-report-1-july-2021-30-june-2022. [accessed 3 December 2023]

[13] O'Brien AJ. Community treatment orders in New Zealand: regional variability and international comparisons. 2014 Australasian Psychiatr; 22(4):352-356.

[14]Ministry of Health. *Office of the Director of Mental Health and Addiction Services: Regulatory Report 1 July 2020 to 30 June 2021.* 2022 Wellington: Ministry of Health. https://www.health.govt.nz/publication/office-director-mental-health-and-addiction-services-regulatory-report-1-july-2020-30-june-2021 [accessed 3 December 2023].

[15] Newton-Howes G, and Banks D. The subjective experience of community treatment orders: Patients' views and clinical correlations. 2014 Int J Soc Psychiatr: 60(5):474-481. doi:10.1177/0020764013498870.

[16] Lees, M, Newton-Howes, G, Frampton, C and Beaglehole, B. Variation in the use of compulsory community treatment orders between district health boards in New Zealand. 2023 Australasian Psychiatr; 31(3):349-352.

Aotearoa is often referred to as an example of a successful multicultural country with a co-governance model based on biculturalism[17]. Unlike the British adoption of *terra nullius* in Australia, Aotearoa was deemed to have an established social and cultural structure. As a result, the British entered into a declaration of confederation and independence in 1835, which culminated in 1840 with the signing of the Treaty of Waitangi (the Treaty), also known as te Tiriti o Waitangi[18]. The Māori version of the treaty (te Tiriti) was written in te Reo and signed by some rangatira or chiefs, while the English-language version was used by the Crown's representatives to establish the rights of Māori under Pākehā (European) laws. The Māori version, te Tiriti, differed in meaning from the English version, the Treaty. Māori signed te Tiriti with the expectation of retaining tino rangatiratanga or authority over their prized possessions, including their land and right to self-govern, as stated in Article Two. Article One of te Tiriti granted kawangatanga or governorship to British settlers by the Crown. Both versions of the treaty ensured that everyone, both Māori and Pākehā, were to be afforded oritetanga or equity and equality.

Although the Treaty promised some protections of the rights of Māori people, from a constitutional perspective, it was a revolutionary act that left Māori on the losing side[19]. The arrival of settlers, new technologies, ideologies, beliefs, disease, and the imposition of the Westminster legal system quickly diminished or completely banished tribal Māori lifestyles. Different interpretations of the Treaty articles, particularly regarding land ownership and sovereignty, have resulted in ongoing debates and legal challenges.

Over time, certain principles have emerged from the courts that have been incorporated into policy and legislation[20]. Additionally, treaty principles have been derived from the intentions, expectations, and spirit of the agreement[21]. These principles reaffirm the guarantee of Māori self-determination and mana motuhake (authority, sovereignty) as well as the obligations of the Crown towards equity, active protection, options, and partnership for, and with, Māori. However, despite their importance, the framing and application of these principles by the Crown in policy and law remain heavily criticised.

[17] Sibley CG, and Ward C. Measuring the preconditions for a successful multicultural society: A barometer test of New Zealand. 2013 Int J Intercult Rel; 37(6):700-713.
[18] Ward, C and Liu, JH. Ethno-cultural conflict in *Aotearoa*/New Zealand: Balancing indigenous rights and multicultural responsibilities, in Landis D and Albert RD (eds) *Handbook of Ethnic Conflict: International Perspectives*. 2012. Springer US: 45-69.
[19] Brookfield FM. *Waitangi and indigenous rights: Revolution, Law and Legitimisation*. 2023. Auckland: Auckland University Press.
[20] Came H, O'Sullivan D, Kidd J, and McCreanor T. Critical Tiriti Analysis: A prospective policy making tool from Aotearoa New Zealand. 2023 Ethnicities; https://journals.sagepub.com/doi/full/10.1177/14687968231171651.
[21] Te Puni Kōkiri/Ministry of Māori Development. He Tirohanga o Kawa ki te Tiriti o Waitangi. 2001. https://www.tpk.govt.nz/en/o-matou-mohiotanga/crownmaori-relations/he-tirohanga-o-kawa-ki-te-tiriti-o-waitangi.

Breaches of te Tiriti continue to have ramifications today. Māori are over-represented in negative social statistics[22]. In 2021, Māori made up approximately 17% of Aotearoa's population, yet they accounted for just over 28% of all mental health service users[23]. Health and outcome measurements show higher degrees of morbidity/dysfunction for Māori, who are under-represented on clinical domains of depression/self-harm and over-represented on domains of aggression, hallucinations, and problems with living conditions[24]. Tapsell and Mellsop[25] consider whether the reports of higher incidence of schizophrenia in Māori are biased by the use of a Western lens and interpretation of psychiatric phenomena to form clinically invalid opinions. Taitimu highlights current efforts to impose Western medical model concepts of treatment for psychological symptoms is endemic to colonialism and ignores Indigenous spiritual and cultural causal beliefs[26]. She cites the example of pōrangi, which refers to the sense of disconnection and darkness within the state of Te Pō, where individuals become withdrawn, lose a sense of self, time and space, and may hear and see things that are not physically present.

The risk for Māori within western-based mental health services is that assessment does not adequately attend to the cultural context of tangata whaiora. There are indications that inaccurate or inappropriate assessment of Māori can lead to misunderstanding, misdiagnosis and mistreatment. People who experience mental distress face multiple health, social, economic harm, and inequity[27]. These harms and inequities generally are amplified for people who are subject to compulsory treatment[28]. Compulsory treatment is largely experienced negatively by individuals, leading to long term traumatic impacts. *He Ara Oranga* reported that submitters[29]:

> *described the trauma of compulsory detention and treatment, the loss of their right to participate in decisions about their treatment and recovery, the adverse impacts of forced medication, and the harm and powerlessness they experienced through practices of seclusion and restraint and prolonged use of the Mental Health Act.*

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[22] Bennet ST, and Liu, JH. Historical trajectories for reclaiming an indigenous identity in mental health interventions for Aotearoa/New Zealand: Māori values, biculturalism, and multiculturalism. 2018 Int J Intercult Rel; 62:93-102.

[23] Ministry of Health. *Office of the Director of Mental Health and Addiction Services: Regulatory Report 1 July 2020 to 30 June 2021.* 2022 Wellington: Ministry of Health. https://www.health.govt.nz/publication/office-director-mental-health-and-addiction-services-regulatory-report-1-july-2020-30-june-2021 [accessed 3 December 2023].

[24] Tapsell R, Mellsop G. The contributions of culture and ethnicity to New Zealand mental health research findings. 2007 Intl J Soc Psychiat; 53(4):317-324.

[25] Tapsell R, Mellsop G. The contributions of culture and ethnicity to New Zealand mental health research findings. 2007 Intl J Soc Psychiat.; 53(4):317-324.

[26] Taitimu M, Read J, McIntosh T. Ngā Whakāwhitinga (standing at the crossroads): How Māori understand what Western psychiatry calls "schizophrenia". Transcult Psychiatry. 2018 55(2):153-177.

[27] Burns JK. Mental health and inequity: A human rights approach to inequality, discrimination, and mental disability. 2009 Health Hum Rights; 11(2):352-356.

[28] New Zealand Health Mental Health and Wellbeing Commission. *Te Huringa: Change and Transformation. Mental Health Service and Addiction Service Monitoring Report* 2022: Wellington. https://www.mhwc.govt.nz/news-and-resources/te-huringa-mental-health-and-addiction-service-monitoring-reports-2022/attachment/319/. [accessed 7 December 2023].

[29] *He Ara Oranga: Report of the government inquiry into mental health and addiction;* 2018, Mental Health and Addiction Inquiry, Wellington. www.mentalhealth.inquiry.govt.nz/inquiry-report/he-ara-oranga/ at 189. [Accessed June 19, 2023].

States which have confirmed, acceded to, or ratified[30] the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), which include Aotearoa, are obligated to enact *appropriate legislative, administrative and other measures for the implementation of the rights recognized in the present Convention*[31]. Article 12(3) of the UNCRPD requires States Parties to *take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity*. The expert committee that sits under the UNCRPD has recommended that Aotearoa take:[32]

> *immediate steps to revise the relevant laws and replace substituted decision-making with supported decision-making…(which) provide a wide range of measures that respect the person's autonomy, will and preferences, and is in full conformity with article 12 of the Convention*.

The UNCRPD partially defines persons with disabilities as those who *have long-term physical, mental, intellectual or sensory impairments*[33]*.* Bell et al note that these impairments are disabling because society fails to take account of or include people regardless of their individual differences, and it is incumbent on society to adapt to ensure respect and inclusion of persons with disabilities[34]. Aotearoa's Mental Health (Compulsory Assessment and Treatment) Act 1992 (MHA) has been identified as failing to meet the human rights' principles identified in the Convention, particularly with regard to compulsory mental health treatment[35]. The MHA enables a responsible clinician, usually a psychiatrist, to substitute their decision-making for that of a patient based on an assessment of mental disorder and risk[36]. Wharehoka (2020) argues that Section 59 of the MHA, which allows for compulsory treatment against an individual's consent, is a form of substitute decision-making and is inconsistent with the UNCRPD[37]. Aotearoa will continue to breach the CRPD and the principles of the Treaty, as well as connected conventions such as the United Nations Declaration on the Rights

[30] As of the time of writing this paper, this number was 186 countries, with 37 countries including a declaration or reservation to their ratification. Available at: https://treaties.un.org/pages/ViewDetails.aspx?chapter=4&clang=_en&mtdsg_no=IV-15&src=IND [accessed 21 June 2023].

[31] UNCRPD Art 4(2), available at: https://www.ohchr.org/en/instruments-mechanisms/instruments/convention-rights-persons-disabilities [accessed 21 June 2023].

[32] Concluding Observations of the Committee on the Rights of Persons with Disabilities (New Zealand), CRPD/C/NZL/CO/1, 12th sess, (15 September - 3 October 2014). Available at: https://tbinternet.ohchr.org/_layouts/15/TreatyBodyExternal/Download.aspx?symbolno=CRPD%2fC%2fNZL%2fCO%2f1&Lang=en at B.22 (3).

[33] Article 1. United Nations Convention on the Rights of Persons with Disabilities: resolution / adopted by the General Assembly, 24 January 2007, A/RES/61/106, available at: www.refworld.org/docid/45f973632.html [accessed 21 June 2023]

[34] Bell S, McGregor J, Wilson M. The Convention on the Rights of Disabled Persons: A remaining dilemma for New Zealand? 2015 NZJ Pub Intl Law; 13(2):277-296

[35] Concluding Observations of the Committee on the Rights of Persons with Disabilities (New Zealand), CRPD/C/NZL/CO/1, 12th sess, (15 September - 3 October 2014). Available at: https://tbinternet.ohchr.org/_layouts/15/TreatyBodyExternal/Download.aspx?symbolno=CRPD%2fC%2fNZL%2fCO%2f1&Lang=en

[36] MH(CAT) 1992, ss 58-59.

[37] Wharehoka T. Disability rights and compulsory psychiatric treatment: The case for a balanced approach under the Mental Health (Compulsory Assessment and Treatment) Act 1992. 2021 Victorian U Wellington L Rev; 52:221. https://heinonline.org/HOL/LandingPage?handle=hein.journals/vuwlr52&div=12&id=&page=.

of Indigenous People (UNDRIP)[38] if it continues to discriminate on the grounds of disability. A positive measure to address both the breach of the Treaty's principles of partnership and equity and the failure to meet the requirements of the UNCRPD to eliminate the use of substitute decision-making would be to implement supported decision-making across the mental health sector. Supported decision-making requires all forms of support, including the most intensive, to be based on the will and preferences of the person concerned. It will be difficult to operationalise this aspiration, until the initial draft of the MHA or its accompanying guidelines from the Ministry of Health are published.

He Ara Oranga recommended the repeal of the MHA and its replacement with legislation that reflects a human rights approach, promotes supported decision-making, minimises coercive treatment, and is consistent with national and international treaty obligations[39]. In its report on change and transformation in the mental health service, Te Huringa states:[40]

> *We call on the Government to be bold in its work to repeal and replace the Mental Health (Compulsory Assessment and Treatment) Act 1992. Restrictive practices should be minimised with a view to elimination. Tāngata whaiora must have autonomy to make decision about their care and have these decisions upheld, and have support to make decisions where their decision-making skills may be impaired.*

This, alongside the Treaty, demands tools that recognise the place of Māori in society. In response, the Ministry of Health has created recommendations to improve the way the MHA functions[41] such as abolishing indefinite orders, but has by no means met this end. There is still much work needed[42]. The Health and Disability Commissioner, whose function is to promote and protect people's rights as set out in the New Zealand Code of Health and Disability Services Consumers' Rights (the Code), emphasised the Code was "established to reinforce people's right to be partners in their own care"[43]. The Commissioner goes on to say:

> *(T)he current Mental Health Act devalues the perspectives of consumers and engenders an approach to their care that is heavily weighted towards risk-based, clinician-centric decision-making and coercion. Such an approach is not aligned with a recovery-centred philosophy, which stresses the importance of people exercising choice and autonomy and regaining a sense of control over one's life.*

[38] United Nations Declarations on the Rights of Indigenous Peoples: resolution / adopted by the General Assembly, 13 September 2007, A/RES/61/295, available at: www.refworld.org/docid/471355a82.html [accessed 21 June 2023].
[39] United Nations Declarations on the Rights of Indigenous Peoples: resolution / adopted by the General Assembly, 13 September 2007, A/RES/61/295, available at: www.refworld.org/docid/471355a82.html [accessed 21 June 2023].
[40] New Zealand Health Mental Health and Wellbeing Commission. *Te Huringa: Change and Transformation. Mental Health Service and Addiction Service Monitoring Report* 2022: Wellington: at 9.
[41] Ministry of Health; *Human Rights and the Mental Health (Compulsory Treatment and Assessment) Act 1992;* 2020, Ministry of Health, Wellington.
[42] Ministry of Health; *Transforming our Mental Health Law: A public discussion document*; 2021, Ministry of Health, Wellington.
[43] McDowell M (Health and Disability Commissioner). Consultation: Transforming mental health law in Aotearoa New Zealand. Email to Mental Health Act Review: 19 May 2022; Available at www.hdc.org.nz/media/6209/submission-transforming-mental-health-law-in-aotearoa-new-zealand-final-to-moh.pdf [accessed 23 June 2023].

Progress, however, has been slow. Responses have included academics instituting a court case against the Attorney General and the Ministry of Health to seek a more human rights' consistent interpretation of the MHA pending substantive law reform[44]. Further, the authors of an independent analysis of the status of the MHA from the perspective of compliance with the CRPD argue that substitute decision-making regimes being completely prohibited[45] requires that:[46]

> *Even where there is an assessment of perceived or actual impaired mental capacity / decision-making skills, it should result in the provision of the support necessary to enable the individual to make a decision in accord with their will and preferences…as opposed to this then resulting in a denial of legal capacity and justifying others making decisions on behalf of the individual.*

Irrespective of any new legislative regime, there needs to be systemic change, including culture change and provision of tools conducive to protecting personal autonomy and people making choices in accordance with their will and preferences.

3. GENESIS OF THE CURRENT PROJECT

This current project brings together two teams from Aotearoa that, for several years, have been working on projects to support systemic change that enable supported decision-making in mental health services. This included two previous projects on stakeholder priorities for supported decision-making and a pilot project on mental health advance preferences statements.

A. A SDM Approach to Mental Wellbeing

Gordon et al used a mixed-methods approach to explore how key-stakeholders identify and prioritise interventions that could best facilitate SDM in mental health[47]. Categories of intervention identified included proactive pre-event planning and post-event briefing, enabling options and choices, information provision, facilitating conditions and support to make a decision, and education. Allowing the necessary time to enable SDM was identified as critical[48], but something that the exigencies of delivering care in an over-stretched service, particularly in crisis situations, does not

[44] Newton-Howes G. We're taking the government to court to challenge New Zealand's outdated Mental Health Act – here's why. The Conversation 11 Nov 2022; https://theconversation.com/were-taking-the-government-to-court-to-challenge-new-zealands-outdated-mental-health-act-heres-why-191166 [accessed 23 June 2023].

[45] Schneller A, Thom K, Jenkin G, et al. *Privileging the focus and voices / voices and focus of tāngata whaiora: Mental Health Act review and replacement.* 2022 New Zealand Mental Health Foundation. Available at: https://mentalhealth.org.nz/resources/download/1943/moy0mfxjsh1f5v6w accessed 28 June 2023].

[46] Schneller A, Thom K, Jenkin G, et al. *Privileging the focus and voices / voices and focus of tāngata whaiora: Mental Health Act review and replacement.* 2022 New Zealand Mental Health Foundation, at 18.

[47] Gordon S, Gardiner T, Gledhill K, et al. From substitute to supported decision making: Practitioner, community and service-user perspectives on privileging will and preferences in mental health care. 2022 Int J Environ Res Public Health; 19:6002 https://doi.org/10.3390/ijreph19106002.

[48] Gordon S, Gardiner T, Gledhill K, et al. From substitute to supported decision making: Practitioner, community and service-user perspectives on privileging will and preferences in mental health care. 2022 Int J Environ Res Public Health; 19:6002, at 11.

allow for. Previous work has identified that the lack of time is a key barrier to applying SDM in practice[49]. The authors point out that SDM cannot occur unless options and choices are actually available[50].

Another key finding of Gordon's research was that tāngata whenua[51] who experience the most inequities and discrimination, as well as Pasifika and LGBTQIA people, all prioritised the intervention categories of proactive pre-event planning / post-event debriefing[52]. Gordon concludes that this highlights the need for culturally responsive and inclusive approaches to SDM[53].

B. MAPS and the Approach to Supporting Māori

Consumer engagement is well documented as a crucial step in facilitating mental health recovery[54]. A well-recognised tool for increasing service users' experience of involvement in decisions regarding their mental health care is an advance care plan. This is now common practice in mental health systems in the UK, many European countries, the USA, Australia and Aotearoa[55]. International research has advocated for interventions facilitative of pre-event planning as mechanisms of SDM[56, 57, 58]. Mental Health Advance Directives, also known as Psychiatric Advance Directives (PADs) or Mental Health Advance Preference Statements (MAPS), enable tāngata whaiora to make statements about their preferences for future mental health care and provide service providers with the means to understand these preferences. This form of advance planning relies on a sharing of healthcare decision-making between tāngata

[49] Every-Palmer, S Kininmonth L, Newton-Howes G, et al. Applying human rights and reducing coercion in psychiatry following service user-led education: A qualitative study. 2021 Health Hum Rights; 23: 239-251.
[50] Gordon S, Gardiner T, Gledhill K, et al. From substitute to supported decision making: Practitioner, community and service-user perspectives on privileging will and preferences in mental health care. 2022 Int J Environ Res Public Health; 19:6002, at 12.
[51] Loosely: 'people of the land' and refers to Māori as the Indigenous peoples of Aotearoa.
[52] Gordon S, Gardiner T, Gledhill K, et al. From substitute to supported decision making: Practitioner, community and service-user perspectives on privileging will and preferences in mental health care. 2022 Int J Environ Res Public Health; 19:6002 https://doi.org/10.3390/ijreph19106002, at 13.
[53] Gordon S, Gardiner T, Gledhill K, et al. From substitute to supported decision making: Practitioner, community and service-user perspectives on privileging will and preferences in mental health care. 2022 Int J Environ Res Public Health; 19:6002 https://doi.org/10.3390/ijreph19106002.
[54] O'Keefe D, Sheridan A, Kelly A, et al. 'Recovery' in the real world: Service user experiences of mental health service use and recommendations for change 20 years on from a first episode of psychosis. 2018 Admin Policy Ment Health Ment Health Serv; 45(4):635-648.
[55] Henderson C, Swanson JW, Smuckler G, et al. A typology of advance statements in mental health care. 2008 Psychiatr Serv; 59(1):63–71.
[56] World Health Organisation. Guidance on Community Mental Health Services: Promoting person-centred and rights based approaches. 2021. Geneva, WHO. https://www.who.int/publications/i/item/9789240025707
[57] Johnson S, Dalton-Locke C, Baker J, et al. Acute psychiatric care: Approaches to increasing the range of services and improving access and quality oc care. 2022 World Psychiatr; 21:200-236.
[58] Tinland A, Loubiére S, Mougeout F, et al. Effect of psychiatric advance directives facilitated by peer workers on compulsory admission among people with mental illness: A randomized trial. 2022 JAMA Psychiatr Online; 79(8):752-759. doi:10.1001/jamapsychiatry.2022.1627.

whaiora and providers[59]. MAPS are one tool that could assist Aotearoa to meet its obligations under UNCRPD, article 12.3, which requires "States Parties", such as New Zealand, to "*take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity*"[60]. MAPS support people to exercise their capacity to make decisions, in advance, when they might have difficulty formulating or articulating choices later[61]. Studies have shown that there is acceptance of MAPS amongst service users and providers, but service users report lack of information to support or collaborate in their care planning[62] and providers are not convinced that choices made by service users in MAPS will be consistent with the providers' perceived duty of care[63].

MAPS was piloted in a multi-year project in the southernmost region of New Zealand[64,65,66,67]. Findings from that work illustrated that the content of MAPS includes expressions of preferences which are personally meaningful for tāngata whaiora and provide practical guidance for clinicians[68]. Many of the preferences demonstrate a strong theme of procedural justice with tāngata whaiora wishing to have a voice, validations, and respectful engagement with mental health teams[69].

A limitation of this work was that it failed to consider cultural factors that may influence the creation and content of MAPS, and thereby fell short of the requirement to reflect the five principles of Te Tiriti o Waitangi recognised by the New Zealand Ministry of Health as a foundational document for public policy[70]. To achieve mana taurite (equity), which is the fifth principle of Te Tiriti o Waitangi, a Māori model of MAPS must support tino *rangatiratanga* (self-determination); whakamarumarutia, (active

[59] Lenagh-Glue J, Thom K, O'Brien A, et al. The content of Mental Health Advance Preference statements (MAPs): an assessment of completed advance directives in one New Zealand health board. 2020 Int J Law Psychiatr; 68:101537.
[60] UNCRPD, Art.12.3.
[61] Lenagh-Glue J, Dawson J, Potiki J, et al. Use of advance directives to promote supported decision-making in mental health care: Implications of international trends for reform in New Zealand. 2022 Australian NZ J Psychiatr; 57(5):636-641.
[62] Farrelly S, Brown G, Rose D, et al. What service users with psychotic disorders want in a mental health crisis or relapse: thematic analysis of joint crisis plans. 2014 Soc Psychiatry Psych Epidemiol; 49:1609-1617.
[63] Bee P, Brooks H, Fraser C, et al. Professional perspectives on service user and carer involvement in mental health care planning: a qualitative study. 2015 Int J Nurs Stud; 52:1834-1845.
[64] Lenagh-Glue J, O'Brien A, Dawson J, et al. A MAP to mental health: the process of creating a collaborative advance preferences instrument. 2018 NZMJ; 131(1486):18-26.
[65] Thom K, Lenagh-Glue J, Potiki J, et al. Service user, whānau and peer support workers' perceptions of advance directives for mental health. 2019 Int J Mental Health Nurs; 28(6):1296-1395.
[66] Lenagh-Glue J Potiki J, O'Brien A, et al. Help and hindrances to the completion of psychiatric advance directives. 2021 Psych Serv; 72(2): 216-218.
[67] Lenagh-Glue J, Dawson J, Potiki J, et al. Use of advance directives to promote supported decision-making in mental health care: Implications of international trends for reform in New Zealand. 2022 Australian NZ J Psychiatr; 57(5):636-641.
[68] Lenagh-Glue J, Thom K, O'Brien A, et al. The content of Mental Health Advance Preference statements (MAPs): an assessment of completed advance directives in one New Zealand health board. 2020 Int J Law Psychiatr; 68:101537.
[69] Lenagh-Glue J, O'Brien A, Dawson J, et al. A MAP to mental health: the process of creating a collaborative advance preferences instrument. 2018 NZMJ; 131(1486):18-26.
[70] Ministry of Health: *Whakamaua: Māori Health Action Plan 2020-2025* (Wellington, NZMoH, 2020).

protection) of Māori health; kōwhiringa, (options) for health care that reflect Māori models; and pātuitanga, (partnership)[71].

Potiki et al conducted a Māori-centred study to explore the experience of tāngata whaiora, whānau (kinship, extended family), and Māori clinicians in order to create a Māori-centred model of MAPS and ensure a pathway for its culturally safe implementation. The result was the creation of a process that focuses on the need to find a mooring place (*Pou Herenga*) that would allow tāngata whaiora and their whānau to focus on their wellbeing using Māori cultural options (*Te Ao Māori*). Unlike a western model of MAPS, which focuses on the individual's needs, will and preferences, Māori participants insisted that whānau be included in both decision-making regarding care and in the creation of any MAPS-type instrument, regardless of the requirements codified in current New Zealand legislation[72].

4. ENABLING SUPPORTED DECISION-MAKING THROUGH MAPS

Both the MAPS work and Gordon et al's work on SDM focussed on understanding the priorities of key stakeholders by engaging in a series of inclusive hui (workshops) with tāngata whaiora, whānau, peer support workers and service providers who worked collaboratively to inform the discussion and outcome. These hui were held in accordance with tikanga Māori (Māori protocol). Hui can be roughly translated to mean meeting, but this fails to elucidate its deeper meaning of collecting, generating and dispersing information to promote enlightenment[73]. Tikanga Māori reflects the inherited values and concepts that inform te ao Māori (Māori world view) and includes the importance of te reo (language), whenua (land), and in particular, whānau. Both projects were engaged in identifying vehicles to promote SDM by building relationships and fostering community awareness through education and outreach.

Given these commonalities, the two groups recognised the value of working together under an expanded, overarching structure. This unique structure informs all the various project sub-groups and all aspects of the methodology. This project adopts a bicultural approach that draws on human rights law, psychiatry, psychology, and *kaupapa Māori* principles and methodologies. *Kaupapa Māori* refers to a philosophical doctrine incorporating the knowledge, skills, attitudes and values of Māori society. Guidance is taken from Smith's[74] intervention elements in *kaupapa Māori* research: in particular (1) *Tino Rangatiratanga* - 'self-determination' (i.e., mental health and wellbeing will be informed by the participants), (2) *kaupapa* - 'collective philosophy' (i.e., collective sense-making of the process and execution of decisions concerning actions designed to restore mental health), and (3) *Taonga tuku iho* - 'cultural aspirations' (i.e., validation of positioning of Māori as legitimate and valid).

[71] Potiki J, Tawaroa D, Casey H, et al. Cultural influences on the creation and use of psychiatric advance directives. 2023 Psych Serv: appi-ps. Available at: https://doi.org/10.1176/appi.ps.20220565.
[72] Potiki J, Tawaroa D, Casey H, et al. Cultural influences on the creation and use of psychiatric advance directives. 2023 Psych Serv: appi-ps, at 3.
[73] O'Sullivan J, Mills C. The Māori cultural institution of hui: When meeting means more than a meeting. 2009 Commun J NZ; http://hdl.handle.net/10092/12788.
[74] Smith LT, *Decolonising Methodologies* (2nd ed.). 2012 Dunedin, NZ: Zed.

The project is guided by the constitutional model set out in *He Puapua*[75], thus ensuring research which is Te Tiriti o Waitangi-led, upholds UN treaties, and is in step with co-governance for the health sector. *He Puapua* provides a roadmap for Aotearoa to fully realise the UNDRIP, particularly with regard to Articles 18, 23 and 24(2)[76]. *He Puapua* draws on *Matike Mai*[77] to conceptualise Te Tiriti o Waitangi relationships in constitutional terms, outlining three spheres of influence over decision-making: Tino Rangatiranga, Kāwanatanga, and Relational. The Tino Rangatiratanga sphere, which refers to the principle of self-determination, includes Māori governance over people and places. The Kāwanatanga sphere, which translates to governorship, represents Crown governance. An overlapping and larger Relational sphere reflects the space where Māori and the Crown join in decision-making over mutual concerns. This Te Tiriti o Waitangi-led constitutional model is informed by the innovative anti-racism research programme developed by Came et al[78]. To apply this Te Tiriti o Waitangi-led approach, the design is multidimensional, being a combination of Māori-centred according to Te Ara Tika guidelines[79] and co-designed and co-produced by tāngata whenua who have experienced mental distress, and those who work and research mental health services[80] (see Figure 1). Sitting outside this structure is a governance committee, whose membership comprises Māori academics and leaders in the public sector - inclusive of tāngata whaiora, which acts to provide additional checks and balances to ensure that the research holds true to the three spheres of influence.

[75] Charters C, Kingdon-Bebb K, Olsen T, et al. He Puapua: Report of the working group on a plan to realise the UN Declaration on the rights of indigenous peoples in Aotearoa/New Zealand. 2019 Beehive, New Zealand Parliament; available at https://www.tpk.govt.nz/en/a-matou-whakaarotau/te-ao-maori/un-declaration-on-the-rights-of-indigenous-peoples. It is important to note that subsequent to the New Zealand general election of November 2023, the incoming government has stated it intends to cease all work on He Puapua. For more information, see: https://www.nzdoctor.co.nz/sites/default/files/2023-11/NZFirst%20Agreement%202.pdf

[76] UNDRIP. Article 18: *Indigenous peoples have the right to participate in decision-making in matters which would affect their rights, through representatives chosen by themselves in accordance with their own procedures, as well as to maintain and develop their own decision-making institutions.*
Article 23: …*indigenous peoples have the right to be actively involved in developing and determining health, housing and other economic and social programmes affecting them…*
Article 24.2: *Indigenous peoples have an equal right to the enjoyment of the highest attainable standard of physical and mental health. States shall take the necessary steps with a view to achieving progressively the full realization of this right.*

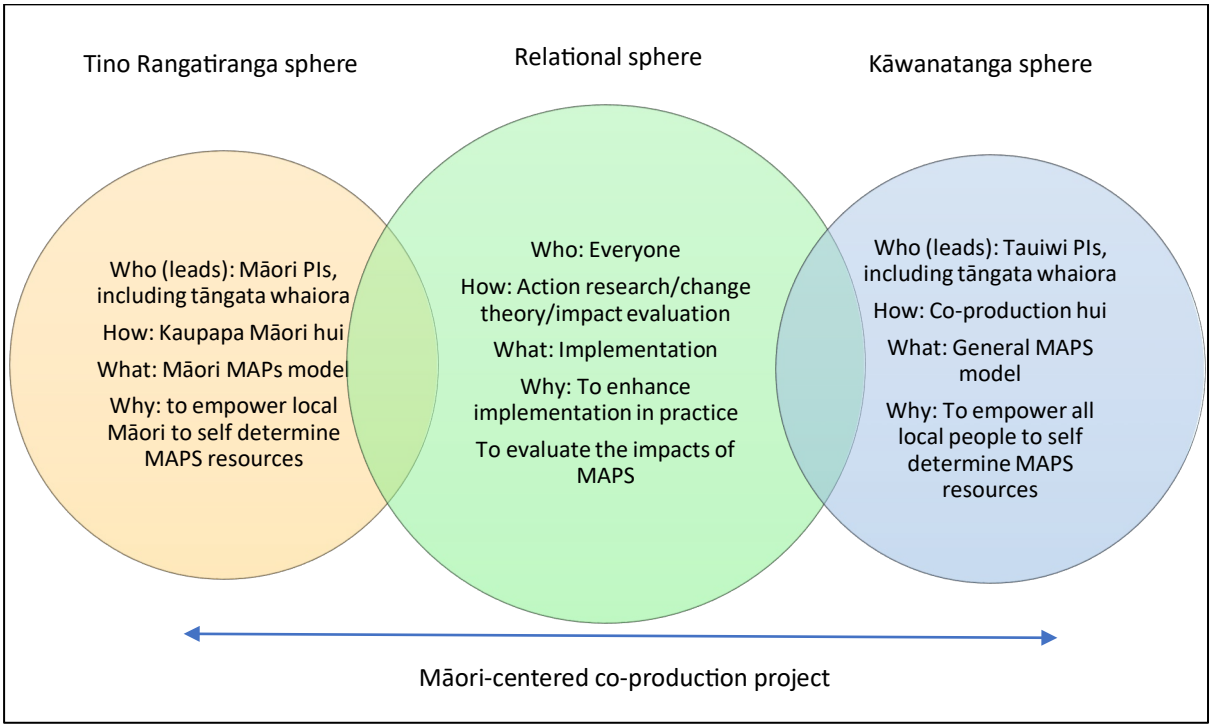
[77] Matike Mai Aotearoa. *He whakaaro here whakaumu mō Aotearoa: The report of Matike Mai Aotearoa.* 2016; New Zealand: Matike Mai Aotearoa. Available at: https://nwo.org.nz/wpcontent/uploads/2018/06/MatikeMaiAotearoa25Jan16.pdf.

[78] Came H, Kidd J, McCreanor T. Re-imagining anti-racist theory for the health sector. 2022 NZMJ; 135(1554): 105-110.

[79] Hudson M, Milne M, Reynolds P, et al. Te ara tika guidelines for Māori research ethics: a framework for researchers and ethics committee members. 2010; Wellington, Health Research Council.

[80] Roper C, Grey F, Cadogan E. Co-Production: Putting principles into practice in mental health environments. 2018. Available at https://healthsciences.unimelb.edu.au/__data/assets/pdf_file/0007/3392215/Coproduction_putting-principles-into-practice.pdf [accessed 24 July 2023].

Figure 1: *Overarching Approach, Governance Structure and Research Plan*



Hence, all the various sub-groups involved in the research – the Principal Investigator group, the academic group, the Governance Group, the project management teams in the two regions where the research is occurring – all have a foundation of Māori and Tauiwi (non-Māori people of Aotearoa), both as tāngata whaiora and providers, with those team members and others enhancing the research team with expertise in te ao Māori, and as legal and social science scholars, and clinicians. The regions that have chosen to be engaged in the research, Te Whatu Ora Lakes and Te Whatu Ora Waikato, have a high percentage, relative to the overall population in Aotearoa, of individuals who identify as Māori. They also have a relatively high proportion of people in the most deprived section of the population and evidence a significant number of eligible referrals across mental health services. Privileging Māori preferences and interests promotes a social justice view of wellbeing given the over-representation of Māori in compulsory treatment coupled with the high rate of mental illness within this population.

The goal is to create a toolkit which will inform changing the way mental healthcare is practiced in Aotearoa by facilitating pre-event planning as a SDM mechanism. There are three main objectives of the work:

(1) To create resources that are informed by community knowledge and preferences (a.g., MAPS-type);
(2) To implement the co-developed local resources; and
(3) To evaluate the impact of implementation.

It is posited this will lead to compliance with Aotearoa's human rights' obligations and improvements in health and equity, particularly for Māori.

Reflecting the co-governance and co-design of this work, the research project was bestowed a Māori name, *Te Kete Rongomau*. Kaumātua (respected leaders) Hori Kingi and Wi Huata, composed the name and presented it at a hui to research team members and regional partners. The name refers to a carrier (*Te kete*) of a taonga – or precious resource. In this sense, the taonga represents advanced preference statements which are seen as an agreement or settlement of autonomy, control and rights (*rongomau*). Like other Indigenous cultural traditions, Māori naming practices are reflective of deep personal, historical or cultural connections. The choice of name was made because the aim of the research is to champion the self-determination of tāngata whaiora by privileging the voice, experience and expertise of service users.

The transition from substitute to supported decision-making in Aotearoa reflects human rights concerns and international trends in privileging the autonomy, will and preferences of mental health service users. The development of tools to facilitate supported decision-making in mental health care holds promise to extend the frontier of socially just health care by operationalising and measuring appropriate decision points that will aid in upholding our obligations to some of our most vulnerable citizens. The use of applied tools as part of establishing and nurturing a systemic culture of change that prioritises personal autonomy is a significant condition necessary to enable the tools, and the intended outcomes, to be effective. In this regard the work described in this paper provides an agenda for an approach that is informed by (and for) tāngata whaiora which not only affords respect and dignity to those persons, but also promotes the focus on broader notions of culture and recognises that the experience of disability and health is shaped by the social context surrounding the person. Drawing on a dual-worldview paradigm, the co-designed/co-produced model invokes several key elements that can be distilled to inform future directions of SDM in practice, as well as guide the current reform of the Mental Health Act. Specifically, this is comprised of a *relational* view of inclusive participation (whanaungatanga; manākitanga), a *process* of validating the will and preferences (MAPS), and *practices* of upholding a person's mana (tikanga Māori).

GLOSSARY OF TE REO MĀORI TERMS

Aotearoa – the Māori name for New Zealand, translated meaning Land of the Long White Cloud.
He Puapua – "a break" is a report commissioned by the government in 2019 to inquire into and report on appropriate measures to achieve the goals set out by the UNDRIP.
Hui – a meeting or workshop
Kaumātua – a respected elder in the Māori community. Male elders are also known as *koroa* or *koro* and female elders as *kuia*.
Kaupapa Māori – Māori customary approach or philosophy, incorporating the knowledge, skills, attitudes, and values of Māori society.
Kāwangatanga – governorship, the authority of the governor.
Kōwhiringa – selection, options. The principle of kōwhiringa acknowledges Māori rights to pursue their own personal direction.
Mana taurite – the principle of equity, equal status
Manākitanga – expressing kindness and respect for others, emphasising responsibility and reciprocity.

Māori – the Indigenous people of Aotearoa.
Mana Motuhake – the right or condition of self-government.
Matike Mai – The independent Māori working group on constitutional transformation with a commitment to human values such as the value of place and belonging, of community, of tikanga, and of balance.
Oritetanga – the right of tāngata whenua to be treated equitably in all aspects of life governed by the Crown.
Pākehā – European or white inhabitants of Aotearoa.
Pātuitanga – the principle of partnership, working together.
Pōrangi – to be insane, mentally ill.
Rangatira – A Māori chief holding authority.
Rongomau – peace, peace settlement or a settlement of control and rights.
Te Whatu Ora – the current name for Health New Zealand, which represented the abolition of the 20 District Health Boards into a centralised national health system.
Tāngata whaiora – "people seeking wellness" or people with lived experience of mental distress.
Tāngata whenua – "people of the land", indigenous people of Aotearoa.
Taonga – treasure.
Taonga tuku iho- an heirloom, something precious handed down.
Tauiwi – non-Māori New Zealanders.
Te Ao Māori – Māori world view emphasising the importance of relationships between nature and people. A holistic worldview that focuses on interconnectivity and is grounded in tikanga values.
Te Ara Tika – "to follow the right path" – a set of Māori ethical research principles that draws on a foundation of tikanga.
Te Kete – a carrier or a basket.
Te Pō – the perpetual night, the door of the world of death. This is part of the Māori creation story whereby *Hine-nui-te-pō* ("Great woman of night") is a goddess of night and she receives the spirits of humans when they die.
Te Tiriti o Waitangi – The Treaty of Waitangi, the founding document signed by the Crown and Māori in 1840.
Tikanga Māori – Māori protocols and practices.
Tino rangatiratangai – self determination.
Whakamarumarutia – the principle of active protection.
Whānau – kinship group or extended family. This can include people other than blood relations; it is who individuals self-determine to be their 'family'.
Whanaungatanga - forming and maintaining relationships between kin and communities. It is the value that binds people together and provides the foundation for unity and a sense of belonging.
Whenua – land, including territorial rights, power from the land and authority over land or territory.