Supported Decision-Making: An Alternative to Guardianship in New Zealand Dementia Care

Andy Hipkiss

15887070

Dissertation submitted towards a Master of Human Rights

Auckland University of Technology

School of Culture & Society

19 December 2024

Co-Supervisors:

Dr Jane Verbitsky

Dr Camille Nakhid

Abstract

Global trends indicate that the prevalence of dementia is expected to increase from 57 million cases in 2019, rising to more than 150 million cases by 2050 (Nichols, et al., 2022). It has been argued that a model of supported decision-making is ideal for those who suffer from cognitive and functional impairments who might struggle with their personal autonomy at varying levels from time to time (Peterson, Karlawish & Largent, 2020). New Zealand ratified the Convention on the Rights of Persons with Disabilities and its subsequent optional protocol in 2008 and 2016 respectively (Ministry of Justice, 2020). Article 12 of the Convention grants persons with disabilities, including mental health disabilities, the right to equal recognition before the law and legal capacity on an equal basis with all people. New Zealand has a Code of Health and Disability Services Consumers' Rights, which establishes the rights of health service users and the obligations of providers. The code is provided for under the Health and Disability Commissioner Act 1994. This code also applies to those responsible for providing residential care for people living with dementia (HDC, 2023). The code, specifically at Right 7, states that health services may be provided to the recipient only if they have made an informed choice and have freely given their informed consent. On 12 May 2014, the United Nations Committee on the Rights of Persons with Disabilities asked Aotearoa New Zealand to explain whether there were initiatives being taken to replace the current system of substituted decision-making (guardianship) with one of supported decision-making as required by Article 12 of the Convention on the Rights of Persons with Disabilities (CRPD) (UN, 2014). Prior to the combined second and third periodic review on the CRPD, New Zealand was asked to report on progress made to change laws on supported decision-making, specifically to conform fully with the requirements of Article 12 and empower people with intellectual disabilities to give and withdraw informed consent (UN, 2019). Obviously from this request for information, New Zealand had failed to make progress on the recommendation of the 2014 report to replace substituted decision-making with a supported model (UN, 2018).By September 2022, on publishing the conclusions of the combined second and third periodic reviews, the Committee observed that there remained a lack of progress in replacing the guardianship model of substitute decision-making with a supported decision-making model making for people with intellectual disabilities (UN, 2022). From 2014 through to 2022, the issue of New Zealand not having a system that allows supported decision-making has

persisted. This dissertation aims to examine models of supported decision-making available and the benefits and drawbacks of each, as well as what possible alternatives might be on offer. It will look at legislation and regulations from around the world where supported decision-making has been adopted to examine how difficult it might be for New Zealand to adopt a similar regime to comply fully with Article 12 of the CRPD.

The Author

I came to this research from a long and winding path. As an able bodied, white, middle-class pākehā, I have no connection to disability research as such. I am by profession an advocate for social justice, which includes all human rights. I am currently employed by the New Zealand Nurses Organisation as an Industrial Advisor. I started university very late in life, at age 49, and completed this project at age 59 having studied at both under- and post-graduate level in that time. I took up this research simply because it took my interest during other reading undertaken during the course of my study. With an ageing population and in New Zealand's case a privatised aged-care sector, it seemed appropriate to examine whether the market is providing fully for those in their care to live their best lives and exercise all their rights.

Contents

"I hereby declare that this submission is my own work and that, to the best of my knowledge and belief, it contains no material previously published or written by another person (except where explicitly defined in the acknowledgements), nor used artificial intelligence tools or generative artificial intelligence tools (unless it is clearly stated, and referenced, along with the purpose of use), nor material which to a substantial extent has been submitted for the award of any other degree or diploma of a university or other institution of higher learning."

19/12/2024

Part 1

Introduction

Human rights are inalienable rights that we each have simply because we exist. They are not granted by states but are considered universal regardless of nationality, colour, sex, religion or any other defining characteristic. Universality is the cornerstone of human rights law and means that every person is equally entitled to all rights. Human rights are also considered inalienable, which means they cannot not be taken away except in very specific circumstances and situations. There are many conventions, declarations and covenants on human rights, some of which are repeated, defined and expanded for certain groups, such as disabled people under the Convention of the Rights of Persons with Disabilities (CRPD). Despite there being multiple written sources of human rights, they are considered to be both interdependent and indivisible, meaning one specific set of rights cannot be fully exercised without another. For example, the rights granted under the CRPD expand and better define rights granted under other documents such as the Convention on Economic, Social and Cultural Rights (1976) and the Universal Declaration on Human Rights (1948) Human rights also describe obligations for states that have joined as state parties by ratifying or acceding to a treaty to respect the rights contained therein, to protect those rights for individuals, and take positive actions to incorporate the rights into their own domestic legislation.

The right to exercise one's legal capacity as contained in Article 12 of the Convention on the Rights of Persons with Disabilities (CRPD) is a frequently discussed and debated subject on what is meant by the rights defined within the CRPD. Views differ between legal, medical and social sciences, and social work academics and experts who have written on the subject. If fully and properly implemented, as recommended to the New Zealand government by the Committee on the Rights of Persons with Disabilities, supported decision-making might bring about positive change for the lives of persons with cognitive decline and intellectual disabilities by expanding on their right to exercise their legal capacity. Yet its implementation in Aotearoa New Zealand has been hindered by inaction and lack of progress, despite issues being recognised by governmental, legal and medical experts alike.

Nations across the globe are struggling with the problem of how guardianship sits alongside the CRPD where Article 12 grants the inalienable right to legal capacity. Many states are struggling to introduce supported decision-making, and the majority of people still have guardianships in place (Pogach, 2020). Concerns remain that proponents might use a supported decision-making framework to exploit and abuse those they are supposed to be supporting and assisting to make their own decisions. Guardianships usually provide safeguards for those placed under such an order, but no such checks and balances exist for supported decision-making.

Dementia can be described as a long-term disorder affecting the brain and leading to changes in memory retention, personality, problem-solving and the ability to undertake daily tasks. Although associated with many neurological conditions, Altzheimers Disease being the most common, dementia might also be a stand-alone condition (Mayo Clinic, 2025). Global trends indicate that the prevalence of dementia is expected to increase from 57 million cases in 2019, rising to more than 150 million cases by 2050 (Nichols, et al., 2022). It has been argued that a model of supported decision-making is ideal for those who suffer from cognitive and functional impairments who might struggle with their personal autonomy at varying levels from time to time (Peterson, Karlawish & Largent, 2020). Dementia is defined by the Aged Care Association (ACA) (2023) as a generic term for impaired ability to remember things, have coherent thought or make decisions, rather than a specific disease in and of itself. It is commonplace for patients admitted to an aged care facility to arrive with an enduring power of attorney and staff at the facility rely on the advocates' ability to act in the patients' best interests when called upon (ACA, 2023).

Article 1 of the Universal Declaration of Human Rights stated that every person deserves equal dignity and respect in realising their human rights. The concept of dignity has evolved over time, originally not being connected to a persons' value but rather to one's merit, or social status (Soken-Huberty, n.d.). If a person was described as having dignity, they were considered to have a high social status. In 1948, the Universal Declaration of Human rights changed the meaning of dignity to a concept of something that all people are born with, regardless of their social class, race or other factor. Simply by being a person, being human, a person deserves respect, and human rights find the dignity of a person at their source (Soken-Huberty, n.d.). This dissertation will explain and define both substituted decision-making and supported decision-making and how both of these systems interact with the human rights of the person living with dementia, or any of the other conditions that might cause cognitive decline to an extent where decision-making capacity is brought into question. It will examine jurisdictions, such as Australia, including specifically their First Nations people, and Ireland where progress has been made towards supported decision-making. It will look at how this might be applied to New Zealand in general and, recognising Te Tiriti o Waitangi as a founding document of the state, will look specifically at how each model sits within a Te Ao Māori[1] lens. The dissertation will also detail the questions currently being asked by the New Zealand Law Commission's examination of the legal framework around decision-making from a human rights perspective.

The second part discusses guardianship, or substituted decision-making, including a discussion of the rights of persons considered in New Zealand to lack decision-making capacity. A similar discussion and definition of supported decision-making will follow, including a review of legislatures where supported decision-making has been introduced, the status of supported decision-making in New Zealand and a comparison of supported decision-making and Te Ao Māori, to give an inclusive New Zealand context.

The final section examines the second Law Commission report (2024) on decision-making legislation in New Zealand. The second Law Commission report specifically discusses what would need to change in a legislative sense in New Zealand with respect to decision-making support for those with lowered mental capacity and their ability to exercise their legal capacity.

A comprehensive literature review has been undertaken to define and discuss the decision-making models that are being recommended by The United Nations Committee on the Rights of Persons with Disabilities (The Committee) and the decision-making processes used in Aotearoa New Zealand. Both substituted and supported decision-making will be defined and the two models discussed from a human rights perspective, discussing how each format interacts specifically with the rights to exercise legal capacity granted by Article 12 of the CRPD.

---

[1] Te Ao Māori describes the world of Māori, including concepts such as Māori language (te Reo Māori), customs, protocols (Tikanga) and Te Tiriti o Waitangi. (University of Otago, https://www.otago.ac.nz/maori/world).

Literature has been systemically searched and assessed using Rapid Evidence Assessment[2] by deciding on appropriate search strategies, searching both relevant academic and grey literature and then assessing their relevance to the theme of this dissertation. Searches were conducted initially in both the university (AUT) library to access online databases such as Wiley, SocIndex (EBSCO), JSTOR, and SAGE as well as the United Nations Document library, with a focus on the Committee on the Rights of Persons with Disabilities and New Zealand as a State Party. The search was then widened to include resources made available through the New Zealand Government, including the Ministry of Social Development, the Ministry of Justice, Office for Disability Issues and the New Zealand Law Commission. Articles were assessed for relevance to decision-making in a New Zealand and international contexts. Key search terms used in searches for relevant articles included Supported Decision-Making, Guardianship, Dementia, CRPD, New Zealand, legal capacity and Human Rights.

Information from multiple specialities, including academic writers using a human rights perspective, social sciences, legal academics as well as various medical professional sources (nurses, doctors, bioethicists, social workers) have been drawn upon to provide differing perspectives outside of the human rights context. Literature searches commenced using grey literature made available through the United Nations digital repositories and various sources from New Zealand. These were used to form a timeline and to describe the issue that is at the heart of the exchanges of information between the UN and Aotearoa New Zealand through various reports, assessments and responses.

The Convention on the Rights of Persons with Disabilities

The Convention on the Rights of Persons with Disabilities (CRPD) was adopted by the General Assembly of the United Nations in 2006 through resolution A/RES/61/106 and was fully ratified with no reservations recorded in May 2008 by Aotearoa New Zealand (Ministry of Justice, 2020). In addition to this, the CRPD Optional Protocol was added to the CRPD in 2006 by the UN and was likewise adopted by Aotearoa New Zealand in late 2016. In Aotearoa New Zealand, the Office for Disability Issues[3] (ODI) is responsible for administering the CRPD. The CRPD provides for regular reports to be made to the Committee on the Rights of Persons with

---

[2] Undertaking a short and systematic assessment on a narrow topic using the research question and keywords as focus.

[3] ODI was integrated into Whaikaha Ministry of Disabled People in 2023, but still exists as a stand-alone policy team within Whaikaha, so will be referred to as ODI throughout this work.

Disabilities at Article 31, expanding this to include an obligation on States Parties to establish a framework to monitor and promote the CRPD. The Optional Protocol, also accepted and ratified by Aotearoa New Zealand, allows for an individual to report any violation of the CRPD by a State Party[4] via the Committee (Article 1). Guidelines on how States Parties report their CRPD monitoring and implementation progress for the Committee's Periodic Reports have been published by the United Nations and adopted by States Parties in order to simplify periodic reporting to improve participation and thus monitoring and reporting (UN, 2016).

Article 1 of the CRPD describes a person with a disability as including "those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others" (Article 1, CRPD), and states its purpose as promotion and protection of the dignity and right of all persons to equal enjoyment of their rights and freedoms (UN, 2006). While much of the literature on the subject of disability deals with specific physical and mental conditions or impairments, dementia is a quite broad heading under which we might find many different conditions. Dementia is also a progressive and dynamic condition, the presentation of which might change from time to time for an individual. The CRPD does require that supports, accommodations and rights should be applied to all persons equally and with dignity, taking into consideration their unique circumstances, conditions and preferences. Thus, this dissertation will include literature that covers a variety of conditions which might fall under the general heading of disability, and apply it to dementia in general and decision-making specifically.

Whilst the CRPD does not necessarily grant additional rights, it does rephrase rights already enshrined in various UN treaties and applies them specifically to persons with disabilities. The CRPD places these extant rights in the context of persons [5]with disabilities, taking into consideration the obstacles they might face in their interactions with society and the additional barriers in being able to exercise their rights. States Parties are required by the CRPD to promote disability rights, using all legislative tools at their disposal to fully implement

---

[4] According to the Law Insider dictionary, States Parties means states who have ratified or acceded to a treaty or protocol (https://www.lawinsider.com/dictionary/state-parties).

[5] Rights were originally set out in the 1948 Universal Declaration on Human Rights; it is from this basis that other treaties build on rights and frame them for specific groups. Examples include the right for all persons to be treated equally in Article 1 of the UDHR and to live free of discrimination in Article 2 which is repeated in context for disabled persons in Articles 5 of the CRPD (UN, 2006).

those rights, and are also required to ensure full participation in society, including training of professionals who work with disabled persons in the various support services they might require (UN, 2006).

Disabled persons must also have their right to equal recognition before the law fully realised and cannot be the subject of medical treatment without informed consent (UN, 2006). It should be noted, however, that although the CRPD was written using inputs from a variety of sources, including advocacy groups for persons with disabilities, both physical and mental, it excluded dementia patients, their supporters and advocacy groups (Cahill, 2018).

Article 12 of the CRPD states that persons with disabilities must be granted equal recognition before the law, including equal legal capacity and must be given appropriate supports to exercise this right. States Parties are required, also by Article 12, to safeguard persons with disabilities, ensuring they are protected from abuse by ensuring those providing support to persons with disabilities are free from undue influence or conflicts of their interests, and that the care and support being provided is subject to review by the courts from time to time. (UN, 2006).

Dementia

Finding a single definition of dementia is very difficult. The Dementia Alliance International (DAI) has four different definitions which vary to cover several progressively degenerative conditions that affect the brain and how the world is experienced, including through cognition and memory loss and behavioural changes (Cahill, 2018; DAI, 2021). Dementia is also closely linked to ageing and is also subjected to an increased degree of social stigma and misunderstanding (Alzheimers NZ, 2020; WHO, 2021). The World Health Organisation reported in 2021 that over 55 million people worldwide were living with some form of dementia and it was the 7th most common cause of death worldwide, with 65% of those deaths being women (Alzheimers NZ, 2020; WHO, 2021). While there is an extensive volume of medical, pharmacological and therapeutic research on how to treat or slow the progress of dementia, there remains a problem with persons living with dementia being able to exercise their full rights and legal capacity as described in the CRPD (Alzheimers NZ, 2020; UN, 2018, 2022(a)).

Penhale (2014) acknowledges a perceived increase in public concerns regarding the abuse and neglect of the elderly and disabled by caregivers but also recognises that the phenomenon is both complex and difficult to investigate well. Elder abuse is seen as taboo in many cultures, which has contributed towards the difficulties in gathering accurate data and undertaking research. Abuse of this type can also take many forms, including financial, sexual and physical abuse as well as neglect (Foster, Herring & Doron, 2014). Penhale also notes that the abuse of elderly and disabled persons is a relatively recent phenomenon for researchers to investigate, with little or no research conducted before the 1970's. Because of this, there is limited knowledge and understanding of elder abuse, and further research into the nature and prevalence of the abuse is required to develop more effective responses. These responses, Penhale goes on to suggest, should be individually tailored to meet the specific needs of the person with the disability or impairment (Penhale, 2014).

There is an assumption amongst many that dementia and associated conditions alter mental capacity to the point that it is necessary for the courts to appoint a guardian (Nakki et al, 2024; Cahill, 2018). Nakki states that accepted medical wisdom says that as dementia progresses, it deteriorates a person's cognition and capacity. This is shown by memory loss, language confusion, including loss of ability to communicate verbally or in writing, inability to undertake daily living tasks, paranoia and impulsivity (Nakki et al., 2024(a)).

The Code of Health and Disability Services Consumers' Rights

It is worth examining the Code of Health and Disability Consumers' Rights, as these form the basis of the rights granted to those using health care services in New Zealand (consumers) and the obligations of the institutional providers of care. The Code is a set of 10 rights and obligations set out under the Health and Disability Commissioner Act in New Zealand (HDC, 2023).

The very first right in the Code very simply states that every consumer has all the rights in the Code and that every institutional provider is subject to the duties in the Code to inform consumers of and allow them to exercise the rights granted therein (HDC, 2023).

Right 3 grants the right to dignity and independence for consumers. Right 5 grants the right to effective communication in a form, language and delivered in a manner and environment promoting open, honest and effective communication. Right 6, part 1, provides the right to be fully informed, including an explanation of the consumer's condition, options open to them for treatment as well as the risks and benefits of the treatment and other information required by legal, professional and ethical standards. Part 2 of Right 6 states "Before making a choice or giving consent, every consumer has the right to the information that a reasonable consumer, in that consumer's circumstances, needs to make an informed choice or give informed consent" (HDC, 2023, Right 6(2)).

It appears on first reading that Right 6, when read alongside earlier rights such as Rights 1, 3 and 5, requires all health care providers to provide, considering all the circumstances of the consumer, full and clear information in a manner that the consumer understands in order to receive informed consent prior to any treatment being decided upon and undertaken. This is further reinforced by Right 8 which allows a consumer to have support persons present, which includes interpreters and would also extend to supporters for decision-making purposes if required.

Combined, Rights 3, 5, 6 and 8 all comply well with a plain meaning reading of the CRPD. Issues begin to arise with Right 7. It could be interpreted that in not granting full rights to informed consent, it contravenes Article 12 of the CRPD. This interpretation can be further supported by reading through Right 7, quoted below in part, where we start to see a deviation from the requirements of the CRPD.

> **Right 7**
>
> *Right to make an informed choice and give informed consent*
> (1) Services may be provided to a consumer only if that consumer makes an informed choice and gives informed consent, except where any enactment, or the common law, or any other provision of this Code provides otherwise.
> (2) Every consumer must be presumed competent to make an informed choice and give informed consent, unless there are reasonable grounds for believing that the consumer is not competent.
> (3) Where a consumer has diminished competence, that consumer retains the right to make informed choices and give informed consent, to the extent appropriate to his or her level of competence.
> (4) Where a consumer is not competent to make an informed choice and give

> informed consent, and no person entitled to consent on behalf of the consumer is available, the provider may provide services where—
>
> > (a) it is in the best interests of the consumer; and
> >
> > (b) reasonable steps have been taken to ascertain the views of the consumer; and
>
> (c) either,—
>
> > (i) if the consumer's views have been ascertained, and having regard to those views, the provider believes, on reasonable grounds, that the provision of the services is consistent with the informed choice the consumer would make if he or she were competent; or
> >
> > (ii) if the consumer's views have not been ascertained, the provider takes into account the views of other suitable persons who are interested in the welfare of the consumer and available to advise the provider.
>
> (5) Every consumer may use an advance directive in accordance with the common law.
>
> (6) Where informed consent to a health care procedure is required, it must be in writing if—
>
> > (a) the consumer is to participate in any research; or
> >
> > (b) the procedure is experimental; or
> >
> > (c) the consumer will be under general anaesthetic; or
> >
> > (d) there is a significant risk of adverse effects on the consumer.
> >
> > (7) Every consumer has the right to refuse services and to withdraw consent to services (HDC, 2023; Right 7(1) to Right 7(7))

Rights granted under the Code grant not only the right to give informed consent, but to communication in a manner the consumer can understand, and given consideration of the consumer’s circumstances and considering their condition. This extends to the right to have support if required, so one should ask if there is an inherent contradiction contained within the Code at Right 7(4) Rights 7(2) and (3)? Both require providers to presume competence to make informed decisions but Right 7(4) then grants the provider the ability to make a decision as to whether the consumer is competent to make informed decisions. If the provider then thinks that the consumer is not competent to make their own decision, they then have the ability to take away the consumer's rights and make a decision for them "in the best interests of the consumer" (at 7(4)(a)) and if such a decision would be "the informed choice the consumer would make if he or she were competent" (at 7(4)(c)).

From a human rights perspective, Right 7 fits very smoothly with the expectations granted by the CRPD in Article 12. However, as you read through Right 7 to 7(4), those human rights are then taken away by a health provider based on their perception of competence, the measure for which is not clearly defined beyond what is considered in the consumer's best interests as decided by the clinician. Right 7(4) gives the power to the provider to decide not only on the competence of the consumer but also what is in the consumer's best interests without setting clear standards for the level of training and knowledge required to make that decision. Statistics show that in New Zealand, senior doctors are predominantly male (59%) (Te Whatu Ora, 2024), meaning women are underrepresented compared to the general population, leaving open the question of gender bias since women are more affected by dementia than men (WHO, 2021; Alzheimers NZ, 2020).

Further research might be suggested as to who is able to make the competence decision and what training they have received in order to reach their conclusion on competency. Certainly, Wright and other ethicists have already touched on this very subject, but without highlighting the intersectionality between medical ethics and the dignity and rights of those in the provider's care (Wright, 2021).

The Committee on the Rights of Persons with Disabilities

The Committee on the Rights of Persons with Disabilities has a mechanism requiring each member state to report on its implementation of the CRPD every four years (Committee on the Rights of Persons with Disabilities, 2016). Under this process, the Committee prepares and presents a list of issues prior to the review date to the member state. The responses to these issues by the state is considered by the Committee to be the state's report. This process simplifies older reporting conventions to better facilitate state participation in the reporting process. The CRPD Periodic Review process invites input and commentary not only from states, but also from other stakeholders, including, for example, non-governmental organisations and advocacy groups.

The 2nd and 3rd Periodic Review of New Zealand, at recommendation 22 refers to the UN Committee on the Rights of Persons with Disabilities' General Comment No. 1 entitled "What it means when everyone must be equal under the law" (UN, 2014(a)). The Committee paraphrased the General Comment, quoting that "no-one can take away a person's legal capacity because they think they do not have the mental capacity to make a decision. The person should have as much support as they need to use their right to legal capacity" (UN, 2022(a), page 5).

The Committee went on to recommend that State Parties repeal any laws and policies and end practices or customs that have the purpose or effect of denying or diminishing the recognition of any person with disabilities as a person before the law. States must then implement a nationally consistent, research-based supported decision-making framework that respects the autonomy, inherent dignity, and preferences of persons with disabilities. (UN, 2022(a)).

Given that New Zealand recorded no objections or reservations to the provisions of the CRPD in 2008, it should be asked why The Committee continues in 2022 to make the same recommendation regarding New Zealand's compliance with Article 12 of the CRPD, or lack thereof. To begin to answer this, a timeline (Table 1) can be established showing the steps between the 2008 ratification of the CRPD by New Zealand through to the 2022 combined second and third Periodic Review.

The Timeline

In order to understand the issues observed by the United Nations in monitoring New Zealand's compliance with the Convention on the Rights of Persons with Disabilities (CRPD), and establish a robust timeline, it is necessary to examine in some detail the grey literature made available through the United Nations and also by the New Zealand government and Non-Governmental Organisations (NGOs) that have contributed to the periodic reviews and the exchanges between them.

It is important to understand in doing so, that grey literature is commonly produced with a particular purpose in mind, such as government reports, working papers, technical papers or evaluations, etc. This is not to suggest that the grey literature may be any less accurate or reliable than peer-reviewed scientific literature. Indeed, it is often vital in providing background and context to a research project and might often contain raw data to which a researcher might not otherwise have access.

Table 1: Timeline

Year	Event	Note
2006	CRPD adopted by the United Nations General Assembly	
2008	New Zealand adopts the CRPD and the Optional Protocol	No reservations recorded by New Zealand (essentially, the CRPD is accepted in full)
2013	Initial report submitted by New Zealand on the CRPD	Refers to the Protection of Personal and Property Rights Act as the primary mechanism to safeguard the interests of persons with disabilities
2014	New Zealand Disabilities Action Plan 2014-18	ODI responsible for administering and progressing the plan
2014	Concluding observations on the initial report of New Zealand	The Committee recommends that the New Zealand take immediate steps to revise the relevant laws and replace substituted decision-making with supported decision-making
2018	List of Issues prior to the combined 2nd and 3rd Periodic Review	The Committee requests a report on measures taken to comply with Article 12 consistent with general comment No.1 (2014)
2019	New Zealand responds in writing to the Committee to the issues raised prior to	In response, Aotearoa New Zealand quotes the Protection of Personal and Property Rights Act as the primary safeguard for a person with disability's rights through welfare guardianship; no further relevant progress on the

	the combined 2nd and 3rd Periodic Review	Disabilities Action Plan or replacing existing legislation to implement supported decision-making
2022	Concluding observations on the combined 2nd and 3rd Periodic Review	Notes the Committee is "concerned about the lack of progress made in abolishing the guardianship system and substituted decision-making regime, and the lack of a time frame to completely replace that regime with supported decision-making systems."
2022	NZ Law Commission begins review of adult ("Adult" is defined as anything starting from 12 to 20 in New Zealand, depending on circumstances) decision-making capacity law in NZ.	Open to public commentary

Aotearoa New Zealand and the CRPD

A useful repository of grey literature on the topic of guardianship, supported decision-making and compliance with Article 12 of the CRPD is the United Nations' digital library (UN, n.d.) and the various documents stored and accessible to scholars and the public therein. Attention should also be given to the Office for Disability Issues (ODI), alongside its parent ministry Whaikaha, the Human Rights Commission and Ombudsman's Office, who together form the Independent Monitoring Mechanism, has been tasked with implementation and monitoring of New Zealand's implementation of Article 12 of the CRPD and releases regular reports to the minister responsible for Disability Issues.

The earliest documentation held by the UN subsequent to New Zealand adopting the CRPD is a 2013 report submitted by New Zealand on the implementation of the CRPD to the Committee on the Rights of Persons with Disabilities. In this report, New Zealand stated that,

> equality before the law is a fundamental principle of the New Zealand justice system. Disabled people enjoy equal recognition in the law, including protection of civil and other rights and legal capacity to manage their own affairs (para. 65, U.N., 2013).

New Zealand continued their response by stating that the primary mechanism under the law for safeguarding these rights is contained within the Protection of Personal and Property Rights Act 1988, which grants courts the right to determine capacity to manage one's own affairs and, if found incapable of doing so, to appoint a guardian to manage that person's affairs and welfare (U.N., 2013).

In 2014, the United Nations Committee on the Rights of Persons with Disabilities posed a question to New Zealand in direct response to the initial report. New Zealand was asked to explain what initiatives they were taking to move away from substituted decision-making, or guardianship towards a supported decision-making model for people who were living with dementia (UN, 2014; para. 13). The rationale for this was that supported decision-making complies better with Article 12 of the CRPD, whereas substitute decision-making removes some rights from those subject to such orders issued by the courts in New Zealand, as explained in greater detail later. New Zealand responded by highlighting the New Zealand Disability Action Plan 2014-2018 and the Disability Commissioner's annual reports on progress with implementing this strategy (ODI, 2014).

Progress was being made on implementation of the Plan, though this was slow. Priority 5 of the Strategy's Action Plan aimed to reduce barriers to disabled people being able to exercise their legal capacity in line with Article 12 of the CRPD to better comply with the 2014 (April) request of the United Nations (ODI, 2014) but this priority was not approved until over 6 months later in November of that year. The first action was described as the work being led by the Office for Disability to ensure that disabled people can exercise their legal capacity through the recognition of supported decision-making (ODI, 2014). In the 2015 report on the Disability Strategy, no further progress was reported beyond the commitment in the plan to recognise supported decision-making (ODI, 2019).

Progress on the issue was reported on once more in 2016, with information having been gathered on supported decision-making by the ODI. This was supplied by Auckland Disability Law, an NGO offering free legal services to people with a disability in relation to disability issues, and a literature search had been completed by the Donald Beasley Institute, a non-government disability research organisation (ODI, 2018).

A report on progress in the ODI's work towards disabled persons being able to exercise their legal capacity in decision-making was submitted to the Minister for Disability Issues in 2017 (ODI, 2017). The report acknowledged that other countries, such as Ireland, had already taken steps to improve and modernise their legislation to ensure greater consistency in using a rights-based approach. It further acknowledged that that New Zealand was becoming out of step with comparable jurisdictions in supporting disabled persons to have better control over decisions affecting their welfare. The report contains a section which discusses the need to support persons with disabilities to overcome the barriers to them exercising their right to make their own decisions, recognising they may require accommodations or changes in environment when making decisions. The ODI recognises that some disabled people must have support in decision-making, accepting that, of these, some are unable to make independent decisions without support, even if reasonable accommodation is made. The report states (ODI, 2017: page 12, paragraph 11) "It is important to be clear that supported decision-making is different from "support for decision-making", which may apply to anyone including disabled people (as we often make decisions by consulting with others)". This distinction does not reduce the requirement in the UNCRPD, however, to ensure support is provided to any disabled people so they can exercise their legal capacity. This statement recognises the U.N.'s recommendation that New Zealand move away from the guardianship model towards supported decision-making. It does not, as the report was intended to do, mark any progress beyond recognising that there is an issue to be addressed that was recommended 3 years previously by the Committee (U.N. 2014(a)). New Zealand employed very little supported decision-making at the time of the report and allowed the courts to have great leeway in their ability to appoint guardians. This led to the periodic review recommending that New Zealand take steps to move away from the guardianship model of substitute decision-making and adopt supported decision-making.

The next communication from the United Nations came in 2018 with their list of issues provided to New Zealand by the Committee on the Rights of Persons with Disabilities (U.N. 2018). It asked, in relation to Article 12 of the CRPD, for New Zealand to list measures taken to revise legislation on supported decision-making to allow persons with disabilities to exercise their right to equal recognition before the law, particularly in managing their affairs. The United Nations also requested numbers from New Zealand on how many persons with disabilities had regained their legal capacity since ratification of the CRPD and the number of persons with disabilities who had been the subject of new guardianship orders in the same period (U.N. 2018, para. 11).

New Zealand responded to the ongoing concerns with guardianship by referring the United Nations to the Protection of Personal and Property Rights Act 1988 for guidelines on how guardianship may be ordered through the courts (UN, 2019), and that persons subject to guardianships are considered by the courts to lack capacity to communicate their decisions regarding their welfare. New Zealand also stated at the time that "There are no measures currently underway or plans to revise laws to recognise supported decision-making consistent with the CRPD" (UN, 2019; para. 111) but in the next paragraph stated that "The Code of Health and Disability Services Consumers' Rights provides for people to make informed choices and give informed consent. This includes the right to effective communication in a form, language and manner that enables them to understand the information provided when accessing health or disability services" (UN, 2019, para. 112). This might raise the question of whether paragraphs 111 and 112 of the response to the initial concerns contradict each other. The first paragraph states there are no plans to recognise supported decision-making, but the next described the right to make informed choices, consent and decisions. If supported decision-making provides the right to informed choice and consent and is recommended by the Committee as compliant with Article 12, is New Zealand contradicting itself by stating that they support the right to informed choices, but persists with the use of guardianships as the preferred and legislated system for decision-making in cases of reduced capacity?

New Zealand reported an increase of guardianship orders from 743 in 2008 to 1525 in 2017, an increase of approximately 205% (UN, 2019, para. 118) but did not record the numbers on who retained or regained their legal capacity. In the 2019 New Zealand Government response submitted prior to the publication of the combined 2nd and 3rd periodic reviews, New Zealand reported that they had requested that the NZ Law Commission undertake a review of the law relating to supported decision-making, with a report due after public consultation in 2022 (UN, 2022).

The New Zealand Law Commission, part A

Two papers have been produced by the New Zealand Law Commission (NZLC) - a preliminary issues paper for public consultation in 2022 looking at options to reform current laws and a second paper issued in 2024 with more specific questions pertaining to a proposed new law (NZLC, 2022; 2024). The Law Commission recognised a need for a greater focus on the protection of an individual's human rights as well as a need in Aotearoa New Zealand to meet obligations under Te Tiriti o Waitangi and to provide for the observance of Te Ao Māori. They set out to review and report what people, laws and organisations have identified as important aspects of these principles and protections (NZLC, 2022) using seven guiding principles to determine how the different perspectives and obligations might intersect. These are:

> (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.
>
> (NZLC, 2022, page 31)

The review takes a purely legal perspective on decision-making and capacity, rather than having a focus on human rights. The terms of reference for the review begin with a very simple description of the current status of the law in Aotearoa:

> 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. (NZLC, 2022, Page 67)

This reflects the history of decision-making laws in New Zealand, which evolved from the legal doctrine of ‘parens patriae[6] which is underpinned by the assumption that some adults are unable to manage their own affairs and, therefore, require the state to act as a parent might act on their behalf with full authority to take over decision-making and the managing of their affairs. As law making has progressed, the state has delegated parens patriae to the courts. The courts, in turn, have adopted the practice of appointing decision-makers to people viewed as lacking the capacity to do so themselves (NZLC, 2024).

The review also recognises that the Protection of Personal and Property Rights Act 1988 (PPPR Act) might not reflect Māori perspectives. The rights of tāngata whaikaha Māori (disabled Māori persons), might not be compatible with the accepted interpretation of Te Tiriti o Waitangi and largely ignores connections to whānau, hapū and iwi (NZLC, 2022).

The NZLC acknowledged in their first consultation paper that those who provide support for decision-making to another person are not recognised under the current legislation when supporting a person (NZLC, 2022). The Law Commission asked for commentary from the public via feedback submitted to questions in their preliminary issues document relating to multiple impaired decision-making scenarios. The scenarios included supporting someone to make decisions for themselves, advanced directives for care when the person changes their mind whilst impaired, enduring powers of attorney, collective decision-making under Te Ao Māori and, finally, guardianships ordered by the courts.

Although the start of the NZLC’s work to review decision-making legislation was welcomed by the United Nations, the Committee on the Rights of Persons with Disabilities noted a lack of progress by New Zealand in repealing substituted decision-making legislation as was recommended in the first periodic review (UN, 2022(a)). The recommendation with regards to decision-making, under Article 12 of the CRPD, from the combined 2nd and 3rd periodic reviews for New Zealand in 2019, repeated that of earlier recommendations. The Committee has consistently since 2014 recommended that Aotearoa New Zealand adopt supported

---

[6] According to Legaldictionary.net, “The “father of the country,” as in the responsibility of the state (government) to protect its citizens, or those who are unable to protect themselves.” Parens patriae commonly refers to the duty of the courts or government as the ultimate guardian of children, mentally ill adults, and any people who are considered to be legally incompetent by the courts. (https://legaldictionary.net/parens-patriae/)

decision-making to replace laws providing for substituted decision-making as under the PPPR Act.

The Issue

The Committee’s latest recommendation, issued in 2022, some 8 years after their initial question regarding substituted decision-making, still expresses a desire to see supported decision-making implemented in Aotearoa New Zealand. This recommendation was given despite an ongoing legislative review by the Law Commission and yearly progress reports by the Office for Disability Issues on the issue of supported decision-making as the issue remained fundamentally unresolved. Overall, this could suggest that there is a CRPD compliance problem that the United Nations Committee for the Rights of Persons with Disabilities sees as in urgent need of correcting, but that remains one which successive New Zealand governments have not prioritised.

Questions need to be asked as to whether the recommendations being made to Aotearoa New Zealand by the United Nations Committee on the Rights of Persons with Disabilities to adopt supported decision-making better match the requirements described in Article 12 of the CRPD. It should also be asked where the current guardianship model fails in ensuring the right of those living with dementia to equal recognition before the law. The New Zealand government should undertake a robust examination of the effect on Māori in Aotearoa New Zealand of substituted decision-making and guardianships. Given the context of Te Tiriti o Waitangi as a founding document of the nation, and requirements in cabinet decision-making requiring consideration of Te Tiriti (Department of the Prime Minister and Cabinet (2023), we should ask whether supported decision-making would better fit with Māori needs and worldview, adopting a human rights research-based person-focused approach to ensuring rights and dignity of Māori are protected and promoted.

Part 2

Substituted Decision-Making: a discussion

There might be considered two main substituted decision-making models. The first of these is a court-ordered guardianship, the legal, court-enforced nature of which might also include the legal contract setting out an enduring power of attorney granted to another person to make decisions on the beneficiary's behalf when certain conditions are met, such as a perceived loss of competence. The other is an advance directive or care plan, which is common amongst people entering aged care facilities and has been advocated as essential by the Aged Care Association (New Zealand Aged Care Association, 2023). Both guardianship and power of attorney assign decision-making capacity directly to another person. Advanced care directives operate where a person, while still considered mentally competent, make orders as to their care should they lose capacity to communicate such decisions themselves, but then rely on others to adhere to their wishes.

Guardianship and Enduring Power of Attorney

According to the Legal Dictionary (2015), guardianship is defined as

> a legal relationship established by the court in which a person is given legal authority over another person when he or she is unable to make safe and sound decisions regarding his or her person, or property. Legal guardianships commonly involve minor children, but may also be ordered for developmentally disabled adults, or incapacitated adults.
>
> (Legal Dictionary, 2015. Guardianship https://legaldictionary.net/guardianship/)

The stated intention of guardianship is to protect the rights of persons deemed to have lost mental capacity, ensuring they receive the correct support and treatment they need. However, the actual effect of guardianship is to remove the right to self-determination, that is, to exercise one's right to equal recognition before the law. It also removes the right to give fully informed consent prior to undergoing medical treatment contained in the New Zealand's Code of Health and Disability Services Consumers' Rights (HDC 2023). It might seem obvious that the removal of self-determination under a court-ordered guardianship does not comply with the requirement of Article 12 of the CRPD.

In New Zealand, guardians can be appointed under the Protection of Personal and Property Rights Act 1988 (section 6) (PPPR Act) by the Family Courts (Parliamentary Counsel Office, 1988). The Act states:

> (1) Subject to subsection (2), a court shall have jurisdiction under this Part in respect of any person who is ordinarily resident in New Zealand and who—
>
> > (a) lacks, wholly or partly, the capacity to understand the nature, and to foresee the consequences, of decisions in respect of matters relating to his or her personal care and welfare; or
> >
> > (b) has the capacity to understand the nature, and to foresee the consequences, of decisions in respect of matters relating to his or her personal care and welfare, but wholly lacks the capacity to communicate decisions in respect of such matters.
>
> (Parliamentary Counsel Office, 1988. Protection of Personal and Property Rights Act (1988) at s6(1)).

The Act grants the ability to judges to make the decision that a person lacks capacity and to appoint a guardian to act in that person's interests. Guardianship is a form of substituted decision-making whereby a person is determined by the judge to lack capacity to understand or communicate decisions, as described in the Act above. The judge may then use the legal tools at their disposal under the Act to protect the interests of that person by appointing a guardian to make decisions on behalf of the person (Karp & Wood, 2008).

Whilst legislation between countries might differ on detail, guardianship is a commonly used process whereby courts are authorised to appoint a guardian once a person is deemed to have lost the mental capacity to make decisions for themselves. This is true even in countries where the CRPD has been fully ratified.

According to Nakki (et al., 2024(a)), the appointment of a guardian is viewed by the medical profession as being in the best interests of their patient when signs of dementia become too difficult for them to manage alone. Legal experts hold the belief that if a person is disorientated and struggling to make their own decisions, then there is a strong argument for the appointment of a guardian over financial and personal affairs. There are noted differences between the views of medical professionals and legal experts as to the importance of factors in determining the need for a guardian to be appointed. Medical practitioners emphasise decline in ability to, for instance, assimilate information, communicate decisions, perform daily tasks and the loss of coordination, as paramount. Differing slightly from the medical view, legal experts prefer memory impairment and dyscalculia (difficulty in understanding arithmetic) to be prime factors in measuring competence (Nakki et al., 2024).

In 2023, the New Zealand Aged Care Association (ACA) submitted to the NZ Law Society's initial issues paper in their review of adult decision-making capacity laws. They advocated for the increased use of enduring power of attorney over other supported decision-making structures. The ACA suggested that enduring power of attorney should be a compulsory requirement for an older person seeking admission to an aged care residential facility (NZ Aged Care Association, 2023). Enduring power of attorney is another form of substituted decision-making whereby the power to make decisions is granted to another person by the person experiencing decline prior to the loss of competency to make decisions, coming into effect on the loss of competence, decided jointly by carers and those granted the power of attorney. This person might be a family member or someone who has known the person well over a substantial period. There are standards to meet to be granted power of attorney, including on age (over 20), and a holder of power of attorney cannot be a bankrupt or under a personal or property order from the family courts. It differs from guardianship only in so much as the person granted power of attorney is chosen by the person themselves and not ordered by the courts.

The Human Rights Council of the United Nations in 2017 appointed Catalina Devandas Aguilar as a Special Rapporteur on the rights of persons with disabilities to undertake a study on the rights of persons with disabilities to exercise their right to equal recognition before the law. The Special Rapporteur undertook several country visits, engaged with stakeholders via conferences in the USA and Pacific region, and took part in the 2017 Conference of States Parties to the CRPD. She stated in her report published in 2018 that legal capacity is restricted for persons with disabilities on three grounds: that of medical conditions or impairment, such as dementia, which she calls the 'status approach'; where a person has made a decision deemed to be a poor one, termed the 'outcome approach'; and, finally, where the person in question has reduced decision-making skills which she calls the 'functional approach' (UN, 2018(a)). However, the Special Rapporteur emphasised the right of all persons to equal recognition before the law and their right to exercise their legal capacity as a person. Once a person is deemed to have reduced decision-making capacity - a decision in New Zealand that is made through the courts - their right to equal recognition is taken away from them through use of guardianship where decision-making powers are granted to medical personnel or by the courts.

The Special Rapporteur's report states that women and older persons are disproportionally affected by guardianships being imposed on their lives, restricting their right to exercise legal capacity before the law (UN, 2018(a); WHO, 2015, 2021; Alzheimers NZ, 2020). The Special Rapporteur argues that it is important to adopt a more human rights-based approach to decision-making and move away from guardianships as a solution. She stated that legal capacity is restricted, usually on medical advice, and that this results in the person deemed to lack capacity losing access to almost all their rights to exercise control over decisions that affect their lives. This statement is supported by the World Health Organisation who had reported in 2015 that people who live with dementia are often denied their human rights and are commonly either physically or chemically retrained by carers, such as through medicinal sedation or being kept in closed wings of a care facility (WHO, 2015).

The Special Rapporteur's findings are also supported by work undertaken by Bedson, Chesterman & Woods (2018) who found in Victoria, Australia, that following case file reviews from the Office of the Public Advocate, high levels of abuse of persons under guardianship orders existed, with an increase from 13% in 2014 to 21% in 2017. They also found that elder abuse, while subject to guardianship orders, affected women disproportionately and that dementia, in particular, was identified as a factor in higher levels of abuse. Their conclusions suggest that guardianship is over-used in responding to diminishing capacity (Bedson, Chapman & Woods, 2018).

However, not all agree with the Special Rapporteur, as guardians appointed by the courts are expected to protect the interests of and provide decision-making in the best interests of the person deemed to lack capacity to exercise their rights (Karp & Wood, 2008). Karp and Wood go on to stress the importance of constant monitoring by the courts to ensure there is no abuse by appointed guardians and the need for courts to impose sanctions where deliberate malfeasance is found. The New Zealand courts are required by section 12 of the Act to review guardianships at intervals not exceeding three years (Parliamentary Counsel Office, 1988).

Advance Directives/Advance Care Plans

An advance care directive, or advance care plan, is a document recording how a person would prefer to be treated. An advance care plan can include many aspects, including health related decisions as well as religious and cultural beliefs and might extend as far as end-of-life decisions including, commonly, donor decisions and resuscitation directives. It was found by Zhang (2021) that awareness of the option to construct advanced care plans was quite low in their China-based study and this low awareness led to reluctance, though those with better awareness and understanding were positive about advanced care planning (Zhang, et al. 2021).

Huang suggested that advance directives are of great importance to older people in residential care who are experiencing dementia as they provide guidance for those making care decisions on their behalf (Huang et al., 2017). However, their study did find that a very high percentage (96.4%) of advance care directives had been completed on the person's behalf by family surrogates with limited knowledge of illness trajectory, meaning many directives did not consider all treatment options available at the time of making the directive. This draws into doubt the decisions made while writing the care directive if they have not been made with full knowledge or with the preferences and wishes of the person under the directive considered fully by those preparing the directive. Such decisions might directly contradict the right (granted under the CRPD and the HDC Code of Rights in New Zealand) to the assumption of capacity, to receive support and accommodation, information given in an understandable manner, and informed consent.

Yuen-Sim considers advance care plans to be of great benefit to older persons who might be experiencing any degenerative condition, recognising in her case studies that there was limited knowledge of advance care planning in Australia (Yuen-Sim et al., 2010). Effective care planning is dependent upon a number of factors when developing the plan, including input from an expert nurse able to educate patients and relatives, being involved in discussions during the development of the advance plan, and the use of a person-centred approach to the development.

In the case of advance care directives, McGee asks the pertinent question as to what level of influence should a person be granted to determine the type of care they wish to receive following loss of mental competence? He argues that the “person” might have changed to such an extent because of their disability or impairment, that they can no longer be considered the same person, thus potentially invalidating any advance decisions or care orders in place prior to the loss of capacity (McGee, 2014).

Writing from a bio-ethics perspective, Wright agrees that there is a significant philosophical issue with advance directives, particularly given that evidence has shown that clinicians have a tendency to ignore them when they go against their medical opinion (Wright, 2020). Wright, in examining various studies on advance directives, has suggested a legal response is required to clarify the position for clinicians where they believe their clinical opinion overrides the directive. However, she suggests that allowing dementia patients greater support and autonomy in decision-making is a far preferable response to the issue of clashes between clinical advice and advance directives as this approach imposes limits on clinician liability and provides better opportunity for patients to exercise their legal capacity.

Jox and his team found in a study of substituted decision-making in patients with end-stage dementia, differences in how patients were treated by family members and professional guardians. In their study, using hypothetical scenes featuring feeding tubes and cardiac pacemaker insertions, only 25% and 31% of family carers gave consent for feeding tube and pacemaker treatment respectively, compared to 56% and 81% of professional guardians (Jox et al. 2011). The study found that relatives made decisions more instinctively, referring decisions to their own preferences, whereas professionals relied much more on the advice of medical advice and patient directives. However, for both groups in the study, medical advice was preferred to patient advance directives or stated preferences (Jox et al., 2011)

The Arguments for Substituted Decision-Making

Writing in the World Alzheimer’s Report, Splaine recognises and raises concerns that medical and aged-care professionals have a tendency only to think in terms of the later stages of dementia, developing a bias towards considering guardianship prematurely (Splaine, 2022). O’Connor looks to extend discussions amongst health professionals looking after people living with dementia when she writes about the importance of relationships and social interconnectedness on the functioning of dementia patients (O’Connor, 2010). Näkki and team also found divergence in medical opinions when measuring capacity, with different weighting given to different criteria that varied with the medical practitioner (Näkki et al., 2024).

Referencing the Protection of Personal and Property Rights (PPPR) Act 1988, and writing from a purely legal perspective, Atkin (2013) describes the Act as filling gaps in provision for support for those who lack capacity to make their own decisions. He argues strongly that the Act has proven effective and contains mechanisms to provide protections and supports that did not exist prior to its passing with respect to personal matters. Atkin states that much was actually done to and for dementia patients without the person concerned granting consent under the previous legislation (Atkin, 2013). Atkin argues that the CRPD is biased towards those with physical disabilities while the PPPR Act fills a gap in providing additional protections for those with mental capacity degradation. He particularly focuses on cases where family conflict exists, causing disadvantage to the person requiring support, and the appointment of a welfare guardian by the courts has considerably improved their interests.

Also arguing in favour of the guardianship model, Karp and Wood (2008) point to studies by the Bar Association in the USA to advise on guardianship monitoring. Stating the need for robust training for court staff, including judges, they go on to emphasise the importance of rigorous monitoring of guardianship with transparent reporting on standards to allow courts to maintain oversight of guardianships ordered by them. With suitable and rigorous monitoring and high training standards for guardians and monitors, guardianship can and does work, they argue (Karp & Wood, 2008).

Näkki argues that if guardianship restricts a person's human rights, then there exists a need to establish strict guidelines and criteria before guardianship orders are issued. Variations seen in medical practitioners' assessment of decision-making capacity strengthens the arguments put forward by Karp and Wood for rigorous training and monitoring for those involved in making guardianship decisions at all points in the process (Näkki et al., 2024(a)).

Some Scandinavian and European countries, such as Sweden, Finland and Denmark in Scandinavia and Germany and Austria in Central Europe, have adopted legislation to allow guardians to be appointed in matters pertaining to property and financial management, through to consenting to medical treatment that the person is unable to understand themselves. Restrictions do apply to guardians in these jurisdictions, where they are excluded from providing consent to such important personal matters as marriages and making wills, thus building safeguards into the system of guardianship as advocated for by other authors on the subject (Näkki, 2024(a)). There are currently no such safeguards in place for supported decision-making arrangements, leaving it open for potential bias and abuse by supporters (Pogach, 2020).

Part 3

Supported Decision-Making: a discussion

Article 12 of the CRPD requires informed consent be given to treatment, as does the NZ Code of Rights for Health and Disability Consumers (UN, 2006, HDC, 2023) One solution to the issue of denial of the right to provide informed consent to treatment and care planning, as well as other life decisions, is supported decision-making. This is the system that the Committee on the Rights of Persons with Disabilities has been recommending to Aotearoa New Zealand since 2014 and continues to do so (ODI, 2014, 2017; Peterson, Karawish & Largent, 2020).

It is accepted by the Office of Disability Issues, who are responsible for the administration of the CRPD in New Zealand, that we are lagging behind other states and jurisdictions in implementing strategies to address the requirement for persons living with dementia to access appropriate support systems in order to make their own informed decisions on issues that affect their care, in line with the requirements of Article 12 (ODI, 2017).

As already discussed, the right to provide informed consent to treatment is already contained in the Health and Disability Commissioner's Code of Health and Disability Services Consumers' Rights. Supported decision-making is a process by which people with dynamic cognitive impairment conditions, including dementia, are able to make informed decisions with the support of other people (Kohn, 2021). Supported decision-making is described as being an ideal system to assist persons with cognitive impairment who might be at the margins of autonomy, as opposed to substituted decision-making, as described in the previous part, which ignores a person's independence, negating their ability to self-determine and exercise their legal capacity (Peterson, Karlawish and Largent, 2021)

Three stages have been described as being required for the implementation of supported decision-making. These are: (a) identifying domains where assistance is required and desired (b) identifying the types of support that are needed and required by the decision-maker; and (c) formalising the decision-making relationship in a formal agreement (Peterson, et al., 2021). Nina Kohn, professor of law at Syracuse University who focuses her research on elder law, including advance planning and persons with cognitive capacity issues, argues that the third step of creating a formal agreement is not necessarily required to implement supported decision-making (Kohn, 2021). Kohn argues that a formal supported decision-making agreement should not be automatically assumed to be a superior arrangement than a person receiving informal support in decision-making. She goes on to state that there is no research to demonstrate that formal agreements enhance the quality of informal arrangements (Kohn, 2021).

How Does Supported Decision-Making (SDM) Work? A Very Simple Guide

Although supported decision-making might be different for each person based on their needs and preferences, certain tools are fundamental to the process. These include the use of plain language, sufficient time to discuss choices and their pros and cons, and note-taking during meetings to assist memory of decisions and discussions. These things, together with trusted friends, family and professionals, can assist someone with a disability affecting their decision-making capacity to reach their own informed decisions, as required by Article 12 and in New Zealand, the Code of Health Consumer's Rights (ACLU, 2024). This differs from substituted decision-making (guardianship, conservatorship, power-of-attorney) in that the decision-maker retains the right to make their own decisions. They are also able to change their supporters at any time or use multiple supporters of their choice, as opposed to a court-appointed guardian. Finally, the person can change their mind about the type of support or about any decision they have made with the expectation that this would be respected. Using the New South Wales Council for Intellectual Disability (CID) framework as a guide (New South Wales Council for Intellectual Disability, 2023), supported decision-making is an ongoing and developing relationship between somebody who might have a disability or condition that requires support to understand information and make decisions based on that, and their chosen supporter. The CID supported decision-making framework assumes, in line with the CRPD as well as the HDC Code of Rights, that everyone has decision-making capacity but might require support in reaching a decision (CID, 2023).

A supporter must recognise and accept the right for the affected person's decision-making and must be aware of their own influence, working actively to minimise any influence their support might have. It is important to ensure that the supporter spend time getting to know the decision-maker, what their goals and preferences are, and to explore options with them as to how they would like to make their decisions before embarking on the process.

Supporters must consider risks in making decisions and explore with the decision-maker the positive and negative results, exploring the ways they can reduce potential harm while acknowledging and understanding what is important to the decision-maker. The desires of the decision-maker for support and information must be central to the process and other supporters should be brought in to assist in the decision-making process if required by the decision-maker. The supporter should consider their primary role to be to respect and enforce the right to autonomy, to follow up to ensure decisions are respected and to uphold the rights of the decision-maker. Each decision should be followed by a period of reflection and a discussion on what the decision-maker would like to be done differently next time they require support (CID, 2023).

The Arguments for Supported Decision-Making

It has been argued that when a decision is made by a clinician to declare a patient incompetent and to impose treatment against their stated wishes, as can happen under Right 7(4) in the HDC Code, the clinicians are failing to fully differentiate between the perceived self-harm of a decision and the actual harm caused by the decision based on the patient's distinctive worldview and values (Earp et al., 2022). Such disregard might lead to genuinely unwanted treatments being unilaterally imposed on non-consenting patients, infringing on their bodily integrity and thus disregarding the universality and inalienability of their human rights. Pogach argues that supported decision-making cannot be considered as a 'one-size fits all' process. Each decision must recognise and meet an individual's needs and views, including stage of life as health care decisions gain importance to the point of palliative or end-of-life decisions (Pogach, 2020).

Supported decision-making provides a framework for patients to achieve autonomy in their decision-making which is in line with the requirements of Article 12 of the CRPD (Francis et al., 2023). Barriers do remain to full implementation from substituted decision-making through to shared decision-making models (whereby the clinicians and patients discuss options before a joint decision is reached), to fully autonomous decision-making, with supported decision-making sitting between shared and autonomous decision-making. The key to implementation lies in removing barriers and biases that remain to granting decision-making capacity to patients. Barriers include organisational barriers, such as barriers in processes used to reach decisions and relationship barriers. Considerations such as accommodation and support in communicating information necessary for the decision must be planned for and overcome, including providing information in a variety of ways and with enough time and space for the decision-maker to process the information (Francis et al., 2023).

Oregon law (House Bill 2105) requires that for disabled persons, less restrictive decision-making supports are considered before resorting to guardianships. For example, it is now compulsory that supported decision-making is taught at high school level in the context of decisions made by minors regarding post-secondary education goals. While this is very different to dementia care, research undertaken on decision-making in Oregon supporting the introduction of the new law in 2021 stated that the National Council on Disability reported in 2018 that best practice in decision-making was the use of supported decision-making. The supported decision-making format leads to affected persons becoming more independent, better integrated into the community, having improved employment prospects, and are better able to recognise and resist abuse and enjoy better health outcomes (Oregon Department of Human Services, n.d.).

How SDM fits with Te Ao Māori

Racism and discrimination are widely reported as having their source in unaddressed historical and systemic bias and the results of colonialism, resulting in disparities in health outcomes for indigenous people and, in New Zealand, worse outcomes for Māori specifically across a range of measures, including healthcare (Cowles, 2024; Reweti, 2023). The pākehā[7] system of 'same care for all' and the same rights for everyone regardless of outcomes, serves mainly to accentuate disparities in health outcomes and experiences for older Māori. In particular this system disregards differences in health and social outcomes for Māori, such as higher incidences of smoking, shorter life expectancy, higher incidence of mental health conditions, higher rates of food insecurity (Keelan et al., 2024; Minstry of Health, 2024). It has been reported that Māori patients often struggle to understand communication delivered using a pākehā perspective, which impacts their relationships with health professionals, lowers trust in a healthcare setting and leads to a negative experience of care services for

---

[7] Any non-polynesian New Zealander or more commonly a European New Zealand settler.

Māori (Cowles, 2024, Keelan et al, 2024). It is important to understand the Māori worldview when supporting them through any healthcare journey.

Cowles stated that in order to achieve good health outcomes for Māori, it is important to involve whānau decision-making, using a private space to discuss decisions and their outcomes with whānau present throughout, to deliver information through a variety of modes such as spoken and written communication, in both English and Te Reo, and the use of Māori staff in supporting the decision-making process (Cowles, 2024). Reweti points out that putting Māori values at the core of care, nurturing relationships and enhancing whānau mana and capability improves health outcomes for Māori by instilling a sense of self-determination for Māori (Reweti, 2023).

Reweti concludes by highlighting the ways in which mana enhancing, whānau-centred care delivered in a manner that is consistent with Māori worldviews and values increases Māori health and wellbeing (Reweti, 2023). She goes on to state that Māori health outcomes will be improved across the community if appropriate care is delivered, rather than the top-down, pākehā-based system currently being delivered. Certainly, Reweti’s view is largely supported by Jones who states that shared decision-making with Māori communities enables decisions to be made that draw on distinct Māori knowledge and experiences and enhance Māori rights under Te Tiriti o Waitangi (Jones, 2023).

From a human rights perspective, improved health experiences and outcomes for Māori is a desirable outcome, given the intent of human rights to be both universal and non-discriminatory. It would appear from the descriptions above that supported decision-making empowers Māori individuals, whānau and communities, as opposed to passing decision-making to others that might not have the same whanaungatanga (interconnectedness, relationships) and understanding of mauri (life-force, life-principle, vitality). While it should be acknowledged that courts ordering guardianships to be imposed, or health professionals deciding on competency, might believe themselves to be making decisions in a culturally appropriate way, social and health outcome disparities would suggest otherwise.

Part 4

Other Legislations

Since 2000, multiple jurisdictions have adopted legislative frameworks to address their laws around decision-making capacity and the need to replace substituted decision-making with supported decision-making systems (Davidson et al., 2015; Campbell et al., 2018). Human rights-based arguments in favour of supported decision-making are summarised as respecting the capacity to make decisions with appropriate supports where required and the decisions thus made being respected.

Thus, law changes away from substituted decision-making orders is in line with the rights granted under the CRPD. Studies have shown that in the UK, for example, 70% of patients under community treatment orders retained capacity to make their own decisions without the need for orders (Campbell, 2018). This section of the dissertation will examine some of the states where supported decision-making has been adopted and implemented.

Republic of Ireland

In 2015, the Republic of Ireland adopted the Assisted Decision-Making (Capacity) Act 2015. This new Act established the supported decision-making framework for Ireland, coming into effect in early 2023 for people aged over 18.

Established under the Act is the Decision Support Service, functionally a part of the Mental Health Commission, but with a separate role (Decision Support Service, n.d.). The Act replaced the ward-of-court[8] system previously in place under the Lunacy Regulation Act 1971. All Irish wards-of-court orders had a three-year lifetime, so between adoption of the new Act and the repeal of the old one, all adult wards would have ceased, and the new Act meant that no more wards would be established. The Decision Support Service (DSS) was established to assist decision-making for people who require assistance, and the legislation is supported by codes of practice (DSS, 2023). Quoted by the DSS in their code of practice, the Assisted Decision-Making (Capacity) Act 2015 states:

---

[8] Prior to 2023, any person who the Irish courts found was not able to look after their own affairs could be made a ward of court. Decisions were then able to be made on their behalf either by the court or somebody appointed by the court. (Citizens Advice, Ireland (https://www.citizensinformation.ie/en/health/legal-matters-and-health/wards-of-court/))

> - a relevant person is presumed to have capacity to make their own decisions unless the contrary is shown;
> - all practicable steps must be taken to help the relevant person whose capacity is being called into question to make their own decisions; and
> - the relevant person's capacity to make a specific decision must only be assessed if they are still unable to make the decision after such supports have been provided
>
> (DSS, 2023a, page 5)

The Irish legislation also sets out a functional test to assess capacity for decision-making and protects the right to independent decision-making but allows for support when required, now or in the future. The Irish Act presumes a person has decision-making capacity unless demonstrated otherwise, in line with the requirements of Article 12 of the CRPD. The functional test acknowledges that capacity for an individual might vary over time and that levels of support might also need to change to match variations in capacity. Capacity under the Act is defined as the capacity to understand information about a decision, to remember the information long enough to make a voluntary choice, to make use of the information in making the decision and the ability to tell others what decision has been made (DSS, 2023a). A capacity assessment can only be undertaken for a specific decision that needs to be made, when making or changing to decision-making support arrangement, when directed by the courts, or when a person has been appointed to undertake the assessment in the context of supervision of extant support arrangements, or in response to a complaint made about a support arrangement. The assessor must obtain consent for the assessment, which may be ended by the person undergoing assessment at any time (DSS, 2023a).

There are three different support arrangements for people who require support under the legislation. The lowest level of support is a decision-making assistance agreement described as support being provided by a trusted person, but decision-making remains with the relevant person (the person requiring assistance, as named in the Act). The second tier of support, co-decision-making agreement, also provides for the support of a person known and trusted by the relevant person, but decisions must be made jointly. The highest level of support is the decision-making representation order. A decision-making representation order is made by the courts who appoint a decision-making representative to act on behalf of the person. This appointee is usually a person who is known to the person they represent or may be a person chosen from a list of experts provided by the Decision Support Service in the case of more complex decisions.

Australia

In 2023, the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability (Royal Commission) made 222 recommendations to improve laws and practices to end abuse and exploitation of people with disabilities. A Royal Commission in Australia is independent of government and is the highest form of public enquiry in the country. For this report, they were asked to look at issues that affected vulnerable people with disabilities, such as exploitation, violence, neglect and abuse. The commission was also asked to specifically look at the effect on First Nation people who are defined in the final report as "both the Aboriginal people of mainland Australia, Tasmania and other islands off the continent, and the people of the Torres Strait Islands." (Royal Commission, 2023, Volume 9, page 1).

The investigation was framed with a consideration of the full realisation of rights and recognition of the dignity of all persons. This includes the right to equal enjoyment of all human rights which recognised, amongst others, the right to individual autonomy. The final report states that the recommendations they made are underpinned by Australia's obligations under the CRPD and the need to make these enforceable under Australian law. (Royal Commission, 2023).

The final report was delivered in 12 volumes, with volume 6 of the final report giving specific recommendations around enabling autonomy and access for persons with disabilities. Recommendation 6.4 recommends that Australian states and territories should take steps to amend legislation referring to guardianship and substituted decision-making, replacing references to guardianship, administration orders, financial managers and guardians with 'supporter', 'representative' and 'representative agreement'. This is in line with the Royal Commission's desire to see the creation of a supported decision-making framework for the country which includes CRPD obligations within legislation and retains a focus on a person's decision-making ability with a process for both supporters and decision-makers.

The Royal Commission's supported decision-making principles were listed in the final report as:

> Principle 1 – Recognition of the equal right to make decisions
>
> Principle 2 – Presumption of decision-making ability
>
> Principle 3 – Respect for dignity and the right to dignity of risk
>
> Principle 4 – Recognition of the role of informal supporters and advocates
>
> Principle 5 – Access to support necessary to communicate and participate in decisions
>
> Principle 6 – Decisions should be directed by a person's own will and preferences and rights
>
> Principle 7 – Inclusion of appropriate and effective safeguards against violence, abuse, neglect and exploitation
>
> Principle 8 – Co-design, co-production and peer-led design processes
>
> Principle 9 – Recognition of diverse experiences, identities and needs
>
> Principle 10 – Entitlement to culturally safe, sensitive and responsive decision-making support.
>
> (Royal Commission, 2023. Page 78).

The Royal Commission recommended that even guardianship orders should also include a requirement for the above principles to be observed by those who have power and functions under the guardianship orders. In practice, this would mean that guardianship frameworks must be modified to include robust tribunals who are able to adjudicate on or make determinations on disputes. These tribunal processes would ensure disabled persons are better able to participate to their maximum extent and provided with the accommodations and supports required to do so with representative decision-makers (guardians etc.) appointed only as an absolute last resort. The Royal Commission made their recommendations for supported decision-making to be adopted on the premise that Article

12 of the CRPD states that every person must be provided appropriate supports to be able to make decisions for themselves (Royal Commission, 2023).

The National Disability Insurance Agency (NDIA) has developed a policy for supported decision-making in Australia under the National Disability Insurance Scheme (NDIS) (NDIA, 2023). The purpose of the policy is to support people to make decisions for themselves, recognising their right to do so, and to have those decisions respected. It aims to achieve this by providing the support required for disabled persons to understand their rights and give assistance to those supporting the decision-makers. The NDIA approach to supported decision-making recognises each person as an individual, recognises the role of kinship, trust and relationships, sees decision-making as a process with a lifespan approach recognising transitions during an individual’s lifespan. The policy is guided by a need for effective safeguards against violence, abuse and neglect, in line with the Royal Commission’s intents. In determining the supports that are required for an individual to make an autonomous decision, the NDIA considers a number of factors, including culture and identity, fluctuations in their disability and the effect these might have as well as the person’s preferred communication style (NDIA, 2023).

To support the policy, the NDIA also has an implementation plan describing the steps required to fully implement the aspirations set out in the policy. The NDIA commenced the policy implementation plan in 2023 and planned for it to take 2 years to achieve full implementation by 2025 (NDIA, 2023a). Steps along the way include building opportunities to use supported decision-making, to develop the knowledge and skills required to use a supported decision-making framework for both decision-makers and their supporters as well as NDIA staff and community stakeholders and finally, to strengthen the process of appointment of nominee supporters (NDIA, 2023a).

First Nations People (Australia)

As with Māori in New Zealand, First Nations people in Australia suffer worse healthcare outcomes and experiences, especially those with disabilities, compared to the overall population (Royal Commission, 2023). First Nations people experience increased barriers to accessing the health system, in particular those with cognitive disabilities, with the symptoms and behaviours exhibited on first contact typically being attributed to the person’s cognitive disability or condition rather than any underlying physical health issue. This can result in a delayed or missed diagnosis, and when considered alongside any degree of institutional racism, points to a need for culturally safe assessment tools for First Nation people and especially those with cognitive decline or disability (Royal Commission, 2023). The Royal Commission also identified difficulties for First Nation people in accessing the NDIS, particularly in very remote or rural areas. They pointed out that the NDIS can be complex to navigate and that it lacks the family-centred approach better suited to First Nation people, meaning they often must move away from their Country[9] to gain any access to required support services, which is described as having a large impact on families and communities. Alternatively, First Nation people might have to rely on First People Community Controlled Organisations to provide support services for those with disabilities and these may not have the full range of services available in larger centres.

> "It would be better [to have] local services, yes. Because they would have an understanding of how we live and, you know, what we face day to day or, you know, monthly or seasonally. You know, it's just - yeah, just NDIS just doesn't understand what it's like to live remotely or on a dirt road that can be blocked off by water or by flood." Jazsikah, a First Nations mother of children with disability, at public hearing 25, 'The operation of the NDIS for First Nations people with disability in remote and very remote communities' (Royal Commission, 2023a, Page 13)

First Nations People say that when a person has to move away from Country and community, their engagement with services worsens and mental health conditions may become more exacerbated as a consequence of the disconnect (Royal Commission, 2023a). The First Peoples Disability Network reported to the Royal Commission that tools used to assess people's health conditions did not always easily translate across language and culture. This led the Royal Commission to recommend that NDIS tools and eligibility require some modification to allow First Nation people to thrive through provision of culturally appropriate assessment (Royal Commission, 2023a).

---

[9] The sense of belonging and identity of the Indigenous people of Australia and the Torres Strait. The connection to "Country" has a meaning that is deeply spiritual, formed by the footsteps of their ancestors. (https://www.evolves.com.au/connection-to-country/)

It should also be considered that the CRPD itself does not specifically identify rights for Indigenous people in a culturally appropriate context beyond reference in the preamble to indigenous status and the concerns in meeting their needs. This can be viewed as diluting CRPD obligations to meet the rights of indigenous people in a culturally appropriate manner, disregarding their need for dignity, treatment without discrimination and the equal worth of all people described in the CRPD preamble. This extends to recognising the contribution persons with disabilities might make to the well-being of their communities which is particularly important to First Nations people and other Indigenous groups. (UN, 2006). In saying this, consideration should be given to the status of the United Nations Declaration on the Rights of Indigenous Peoples (UNDRIP) adopted by the UN General Assembly in 2007 as a declaration of principles and rights rather than a legally binding treaty like the CRPD. UNDRIP was originally opposed by Australia and Aotearoa New Zealand, along with the USA and Canada, though the four states have since changed their position on the rights of Indigenous people and the declaration (UN, 2024a).

Similar to the Māori concept of taonga[10] and tina rangatiratanga[11], First Nation people connect deeply to their language, cultural worldview, Country, kin and community (Reweti, 2023, Royal Commission, 2023) . The lack of any indigenous voices in the drafting of the CRPD remains a serious shortcoming that has not been addressed by states or the United Nations to date. It is important in applying and enforcing the rights of persons with disabilities to not only recognise rights to self-determination and equality before the law, but to add in protection of culture and language, and to apply those rights in culturally appropriate ways in a manner that speaks to the connections indigenous people feel with their lands and communities.

Current Status of Supported Decision-Making in New Zealand

The Ministry of Social Development (MSD) provides the support required for persons with disabilities, and this includes advice on supported decision-making. They provide guidance on a 6-stage decision-making pathway that involves friends, family and other supporters under the general heading of *accessibility resources for disabled persons* (MSD, n.d.). The guidance

---

[10] Refers to a treasured item

[11] Refers to, variously, concepts of self-determination, sovereignty, autonomy, self-government, domination, rule, control, power (https://maoridictionary.co.nz/word/8124)

provided is largely in line with the supported decision-making process set out above in that the steps include provision of easy-to-understand information, exploration of options open to the decision-maker, confirmation of the decision-maker's preferred option, then ensuring the decisions are recorded and making them work. MSD advises reviewing earlier steps as implementation progresses to see whether there have been any changes or if new information has become available.

MSD links to the IHC Group (IHC), a disabled support group advocating for the rights of disabled persons in New Zealand and supporting them to live in the community. IHC provides the guide to supported decision-making linked as a resource by MSD. The IHC guide acknowledges the right of people to make decisions for themselves, in line with the provisions of the CRPD, the right to support in reaching those decisions, and the same rights before the law as any other person in New Zealand (IHC, n.d.).

Health service providers in New Zealand also provide additional guidance for people facing dementia. An example of this is the 2017 publication on the dementia patient's decision-making journey provided by Waitemata District Health Board (WDHB)(WDHB, 2017). This publication states that a person is able to make decisions for themselves until a doctor has assessed them as no longer possessing capacity to do so. At that point, the guidance says that decisions are assigned to another person via either a guardianship order or an enduring power of attorney, and the welfare guardian would have the final say in any decision on behalf of the patient, taking into account their best interests.

Searching through aged care providers' websites for New Zealand providers, it should be noted that a range of the providers are described and accredited by Alzheimers NZ as being "dementia friendly". Accreditation as dementia friendly means that the organisation or facility meets the seven standards set by Alzheimers NZ. None of the dementia friendly standards include active promotion or use of supported decision-making frameworks or provide training for staff to accommodate or provide for supported decision-making. The standards as published are:

> **1. Person-centred**
>
> We understand the needs of people living with dementia as they relate to our business or organisation from their perspective.

2. Leadership

We have the right structures in place to maintain a sustainable dementia friendly business or organisation.

3. Workforce

Staff and volunteers have an awareness and understanding of dementia.

4. Physical environments

We have a continuous improvement plan to make our physical environment(s) accessible to people with dementia.

5. Workplace

We respect and support employees affected by dementia (people living with dementia or people caring for someone with dementia).

6. Collateral and websites

Websites, communications and published information are accessible for people with dementia.

7. Review

Regular formal reviews of dementia friendly progress are planned for into the future.

(Azheimers NZ, 2020. Page 5)

It can only be considered disappointing that, despite New Zealand being an early adopter of the CRPD rights for disabled persons, supported decision-making is still difficult to find for people living with dementia. The above standards are well intentioned but there is no consideration for the promotion and adoption of supported decision-making for people who live in dementia residential care facilities. Nor is there any mention or acknowledgement of the obligations contained in the CRPD. As recently as 2023, the Aged Care Association in New Zealand was advocating for the increased use of substituted decision-making amongst people admitted to aged care facilities (NZACA, 2023). A search of dementia care providers in the aged care sector in New Zealand did not turn up any specific mentions of a supported decision-making programme being in place, but all made mention of secure dementia living, meaning the doors to dementia units are secured, denying the persons within freedom to move around, freedom to associate with others outside the unit and removing their inherent dignity. The exception to the rule is Rymans Healthcare which has adopted a programme of research-led dementia care in their *myRyman Life* care model to ensure the best possible outcomes for those in their care and as far as possible, the full realisation of their rights to informed decision-making and dignity (Ryman Healthcare, 2024).

New Zealand Law Commission Part B

The Law Commission in New Zealand was asked by the Minister of Justice in 2021 to commence a review of decision-making laws and to recommend changes required to current laws. Currently in New Zealand, as already briefly discussed, the primary legislation that relates to decision-making is the Protection of Personal and Property Rights Act (PPPR Act) which allows courts to appoint guardians when a person is deemed not to have sufficient decision-making capacity (NZLC, 2024).

From the initial issues survey undertaken in 2022, the NZLC second issues paper contains a more detailed analysis of current laws and provides some suggestions for reform of current legislation. It considers human rights obligations under the CRPD, with a focus on Article 12, Te Tiriti o Waitangi and obligations towards Māori, tikanga, as well as improvements that could be made to current systems.

It should be acknowledged that the New Zealand Law Commission (NZLC) review runs parallel with proposals to repeal, change or replace other pieces of New Zealand legislation that provide for the removal of decision-making capacity from people in various situations. These are the Mental Health (Compulsory Assessment and Treatment) Act 1992, the Health and Disability Commissioner Act 1994, the HDC Code of Rights and follows closely on the heels of a review undertaken recently of the Substance Addiction (Compulsory Assessment and Treatment) Act 2017. Final recommendations on the review of decision-making law from the Law Commission are due in 2025 after another round of public consultation.

In 2022, there were 6,649 applications for guardianship orders under the PPPR Act in New Zealand, almost doubling from 3,370 in 2013 (NZLC, 2024). This shows a marked increase over a ten-year period without consideration to use other decision-making supports such as supported decision-making, and decision-making accommodations outside of the narrow provisions of the PPPR Act. In the view of the Law Commission, it is preferable to replace the PPPR Act rather than try to amend it. The NZLC cite several reasons for this, including changes in how disability is viewed by society, shifting from a medical model (individual illness, condition, or impairment requiring intervention) to a more social-orientated one as reflected in the CRPD (equality, dignity of the individual and the removal of barriers to inclusion, which would include having full use of rights granted to non-disabled persons), and the inability of the PPPR Act to properly reflect the obligations under Te Tiriti o Waitangi to consider and recognise the needs and aspirations of Māori.

The Law Commission noted that from the first preliminary issues consultation, many submissions they received talked to the need to shift attitudes in New Zealand towards a more support-focused, holistic model (NZLC, 2024). Replacing the old Act, they explain, would be a trigger to assist the necessary attitude adjustment away from paternalistic practices where decisions are made for people towards a focus on providing support and accommodations to ensure equality, dignity and autonomy.

There is a long discussion in the second review paper that gives legal interpretations of what is required under Article 12 of the CRPD to realise equality, dignity and autonomy for people with disabilities, including acknowledging that at times, persons with disabilities may need to be treated differently to achieve equality and autonomy on an equal basis with others in society. Given that New Zealand adopted the CRPD in 2008, it is important that discussions amongst those who influence the making of laws in the country are acknowledging the requirements of the CRPD and turning their minds towards some robust definitions of its requirements to meet the needs of those whose rights are defined therein. An example used by the NZLC is that Article 12 does not allow restrictions on legal capacity that result in unjustified discrimination as this is a breach not only of the Convention, but also the New Zealand Bill of Rights Act 1990 if it results in a disadvantage to the person with a disability.

New legislation should consider obligations on Aotearoa New Zealand under the principles of Te Tiriti o Waitangi to allow Māori to live according to tikanga and to access communal decision-making to support those who live with cognitive impairments (NZLC, 2024). New legislation must therefore allow for a tikanga approach whenever it is considered relevant, and to recognise that decision-making support must be sourced from relevant social and cultural contexts, including individuals, groups and organisations. Tikanga also calls for out-of-court dispute resolution processes which might be more relevant for Māori, allowing a better connection to their culture and community instead of placing decisions in the hands of a Pākehā court system. Connection to land, culture and community is of primary importance to indigenous people on both sides of the Tasman, as has already been discussed. More culturally appropriate ways of dealing with Indigenous people, preserving their cultural connections and involving their own communities in decisions will improve their experience and interactions with the care system and health and social outcomes for their communities (Cowles, 2024; Keelan et al., 2024; Reweti, 2023; Royal Commission, 2023a)

The Law Commission, based on submissions, states that any legislation that claims to act in a person's 'best interests' for their welfare is unlikely to meet the requirements of Te Tiriti o Waitangi and Article 12 of the CRPD. Any new legislation would therefore have to consider what principles lie at its base, with the CRPD a central part of that as well as an attitudinal shift towards seeing disability from a social perspective, removing barriers and ensuring accommodations are made to protect legal capacity and ensuring equal ability to exercise rights. This would also require a more robust definition of what terms such as "'capacity', 'competence', 'legal capacity' and 'mental capacity'" (NZLC, 2024, page 97) mean as these terms, they claim, are used interchangeably and differentially, depending on context and the author. The Law Commission claims decision-making capacity as a legal concept and therefore proposes a functional test to determine capacity where failing to demonstrate decision-making capacity when tested would require a legal response to intervene on the affected person's behalf. The NZLC also proposes, in the same manner as the current PPPR Act, that any care orders under new legislation should be reviewed regularly to ensure they are in place for the shortest possible amount of time (NZLC, 2024). However, it is disappointing to see, considering the rights granted under the CRPD, that such representative orders are still being considered as necessary after pointing out that the rights granted by the CRPD should form the basis of any new legislation. Consultation continues under the NZLC review process. Results of the public consultation on the second issues paper closed in June 2024 and results of the review together with the final recommendations to the Minister are expected in 2025.

Conclusion

The Convention on the Rights of Persons with Disabilities came out of the United Nations 58 years after the initial Universal Declaration of Human Rights. The CRPD did not provide any new rights for disabled persons but did frame inalienable rights already exercised by other non-disabled people in the context of persons with disabilities, rights contained in documents such as the Universal Declaration on Human Rights, and subsequent treaties expanding and contextualising rights for different groups of people and situations. In doing so, it expanded and explained some of the obligations to respect, enforce and promote rights on States Parties who adopted the Convention and deliver on these rights for disabled persons. Since its inception, Article 12 has been the focus of much debate relating to how to define legal capacity and grant the right to autonomy, dignity, and equal rights before the law. States such as Ireland and some Australian States have been through extensive processes to change their legislation and allow supported decision-making frameworks to replace guardianships and other substitute decision-making frameworks.

The changes went as far as requiring a Royal Commission in Australia, where legislative changes are still underway, that supported decision-making should be adopted across all states, along with the recognition and protection of the needs of their First Nations' people. In Ireland, a more gradual legislative process has been adopted, including setting up new government funded agencies and providing information and tools to allow the adoption of supported decision-making.

In many ways, supported decision-making improves outcomes and experiences of persons with disabilities, including those with changeable or degenerative conditions such as dementia in being able to exercise their rights as a person with dignity and equality before the law and their ability to provide for informed consent to healthcare decisions. Aotearoa New Zealand has received recommendations from the Committee on the Rights of Persons with Disabilities since 2014 to adopt a supported decision-making framework to replace the guardianship model from the Protection of Personal and Property Rights Act. Despite the work being done by the Disabilities Office, progress has been very slow and it was not until 2021 that the Minister asked the Law Commission to undertake a review of the legislation and make recommendations on a new law to replace the PPPR Act.

Supported decision-making also allows indigenous people to retain connection to Country[12], community and culture in ways that improve both their experiences of the health and welfare systems. Any new legislation must take this into account when the Law Commission's final recommendations are presented to the Minister. Te Tiriti o Waitangi forms part of the unwritten constitution of New Zealand as a founding document, and the Cabinet Manual requires consideration of the principles of Te Tiriti o Waitangi when making decisions (Department of the Prime Minister and Cabinet, 2023). Māori have distinct needs and worldview from the pākehā-based system of laws, courts and healthcare. To address inequities in outcomes for Māori, we must introduce a system that also considers and addresses their unique needs and aspirations compared to those of the pakehā population and that fully considers their worldview and dignity.

Societal views of disability have shifted away from the individualistic view of disability as an impairment to one where we strive for equality and ways to overcome barriers to inclusion (NZLC, 2022). This is far more in line with the expanded definitions of the rights set out in the Convention. Recommendations such as those to abandon guardianships and to adopt supported decision-making as the best model to realise those rights should not be met with delays and apathy by states parties who have the very clear obligation to use all tools at their disposal, including legislative change, to provide and protect those rights for all people, equally, but in context acknowledging their culture, worldview and dignity.

---

[12] As used in the context of First Nations People in Australia.

References

Alzheimers NZ. (2020). Dementia Friendly Recognition Programme Ngā pou whirinaki mate wareware. Retrieved from: https://cdn.alzheimers.org.nz/wp-content/uploads/2021/04/Dementia-Friendly-Recognition-Programme-Toolkit-for-businesses-and-organisations.pdf

American Civil Liberties Union (ACLU). (2024). Supported Decision-Making: Frequently Asked Questions. Retrieved from: https://www.aclu.org/sites/default/files/field_document/faq_about_supported_decision_making.pdf

Atkin, B. (2013). The protection of personal and property rights act 1988 update and reflections. *Victoria University of Wellington Law Review, 44*(3/4).

Bedson L, Chesterman J, Woods M. The prevalence of elder abuse among adult guardianship clients. *MACQUARIE LAW JOURNAL*.18. https://search-ebscohost-com.ezproxy.aut.ac.nz/login.aspx?direct=true&db=edsapt&AN=rmitplus20190319007818&site=eds-live

Browning, M., Bigby, C., Douglas, J., (2021). A process of decision-making support: Exploring supported decision-making practice in Canada. *Journal of Intellectual & Developmental Disability. Vol 46*(2) 138-149. https://doi.org/10.3109/13668250.2020.1789269

Cahill, S. (2018). *Dementia and human rights*. Policy Press, UK.

Campbell, J., Brophy, L., Davidson, G., O'Brien, A. (2018). Legal capacity and the mental health social worker role: an international comparison. *Journal of Social Work Practice. Vol 32*(2). 139-152. https://doi.org/10.1080/02650533.2018.1439458

Davidson, G., Kelly, B., McDonald, G., Rizzo, M., Lombard, L., Abogunrin, O., Clift-Matthews, V., Martin, A. (2015). Supported Decision-Making: A review of the international literature. *International Journal of Law and Psychiatry, vol38*. https://doi.org/10.1016/j.ijlp.2015.01.008

Decision Support Service (n.d.). Welcome to the Decision Support Service website. https://decisionsupportservice.ie/

Decision Support Service, (2023). The Assisted Decision Making (Capacity) Act 2015: Easy Read Guide. Retrieved from: https://decisionsupportservice.ie/sites/default/files/2023-05/DSS%20Easy%20Read%20-%2026%20May%202023.pdf

Decision Support Service (2023a). Code of Practice for Supporting Decision-Making and Assessing Capacity. Retrieved from: https://decisionsupportservice.ie/sites/default/files/2023-03/1.%20COP_on_supporting_decision-making_and_assessing_capacity_0.pdf

Dementia Alliance International (DAI), (2021), Human Rights & Dementia as a Disability. Retrieved from: Human Rights & Dementia as a Disability | Dementia Alliance International

Department of the Prime Minister and Cabinet (2023). Cabinet Manual 2023. Retrieved from: https://www.dpmc.govt.nz/our-business-units/cabinet-office/supporting-work-cabinet/cabinet-manual

Earp, B.D., Demaree-Cotton, J., Savulescu, J. (2022). Against Externalism in Capacity Assessment—Why Apparently Harmful Treatment Refusals Should Not Be Decisive for Finding Patients Incompetent. *American Journal of Bioethics vol 22*(10). https://doi.org/10.10809/15265161.2022.2110973

Foster, C., Herring, J., Doron, I. (editors) (2014). The Law and Ethics of Dementia. Hart Publishing. Ebook retrieved from: https://portal-igpublish-com.ezproxy.aut.ac.nz/iglibrary/obj/HARTB0000958

Francis, C.J., Johnson, A. Wilson, R.L., (2023). Supported decision-making interventions in mental healthcare: A systematic review of current evidence and implementation barriers. *Health Expectations vol 27*. https://doi.org/10.1111/hex.14001

Health and Disability Commissioner (HDC). (2023). Code of Health and Disability Services Consumers' Rights. Retrieved from: https://www.hdc.org.nz/your-rights/about-the-code/code-of-health-and-disability-services-consumers-rights/

Huang, H., Shyu, Y. L., Weng, L., Chen, K., & Hsu, W. (2018). Predictors of advance directives among nursing home residents with dementia. *International Psychogeriatrics, 30*(3), 341-353. doi:10.1017/S1041610217001661

IHC Group (n.d.) Supported Decision-Making, A Guide for Supporters of People with an Intellectual Disability. Retrieved from: https://assets-global.website-files.com/628455c1cd53af649dec6493/63e5b3b5535a984457bb064c_SupportedDecisionMaking.pdf

Jones, C. (2023). Co-governance and the Case for Shared Decision Making. *Policy Quarterly vol 19*(2). https://doi.org/10.26686/pq.v19i2.8231

Jox, R.J., Denke, E., Hamann, J., Mendel, R., Förstl, H. & Borasio, G.D. (2011). Surrogate decision making for patients with end-stage dementia. *International Journal of Geriatric Psychiatry vol 27*(10). https://doi.org/10.1002/gps.2820

Karp, N., & Wood, E. (2008). Guardianship monitoring: Promising state and local court practices to protect incapacitated older adults. *Generations, 32*(3), 22-26. Retrieved from: Found Here

Kohn, N.A., (2021). Realizing Supported Decision-Making: What It Does – and Does Not- Require. *The American Journal Of Bioethics, Vol 21,* (11), 40–42. https://doi.org/10.1080/15265161.2021.1980148

Legal Dictionary (2015). Guardianship. https://legaldictionary.net/guardianship/

Mayo Clinic (2025). Dementia. Retrieved December 2024 from: https://www.mayoclinic.org/diseases-conditions/dementia/symptoms-causes/syc-20352013

McGee, A. (2014). Best Interests Determinations and Substituted Judgement: Personhood and Precedent Autonomy. In *The law and ethics of dementia: Edited by Charles Foster, Jonathan Herring and Israel Doron*. Hart Publishing. Ebook retrieved from: https://portal-igpublish-com.ezproxy.aut.ac.nz/iglibrary/obj/HARTB0000958

Ministry of Health (2024). Annual Update of Key Results 2023/24: New Zealand Health Survey. Retrieved from: https://www.health.govt.nz/publications/annual-update-of-key-results-202324-new-zealand-health-survey

Ministry of Social Development (n.d.). Supported Decision-making. https://www.msd.govt.nz/about-msd-and-our-work/work-programmes/accessibility/supported-decision-making.html

Miola, J. (2014). Proxy Decision-Making. In *The law and ethics of dementia: Edited by Charles Foster, Jonathan Herring and Israel Doron*. Hart Publishing. Ebook retrieved from: https://portal-igpublish-com.ezproxy.aut.ac.nz/iglibrary/obj/HARTB0000958

Näkki, K., Mäki-Petäjä-Leinonen, A., Ervasti, K., Halkoaho, A.,Nurmi, S., Solomon, A., Suhonen, N., Portaankorva, A.M., Krüger, J. & Solje, E. (2024). Diverging medical and legal perceptions of the need for legal guardianship in people with dementia: A qualitative study. *European Journal of Neurology 31*(8). https://doi.org/10.1111/ene.16334

Näkki, K., Mäki-Petäjä-Leinonen, A., Ervasti, K., Solje, E. (2024(a)). Evaluating the need for legal guardianship in people with dementia: gaining insight into professionals' assessment criteria. *INTERNATIONAL JOURNAL OF LAW POLICY AND THE FAMILY, 38*(1), https://doi.org/10.1093/lawfam/ebae005

New South Wales Council for Intellectual Disability. (2023). Supported Decision Making Framework. Retrieved from: https://cid.org.au/resource/sdm-framework/

New Zealand Aged Care Association. (2023). Submission to Te Aka Matua o te Ture | Law Commission on the Review of Adult Decision-Making Capacity Law: Preliminary Issues Paper. Retrieved from: https://nzaca.org.nz/wp-content/uploads/2023/02/NZACA-submission-on-the-review-of-adult-decision-making-capacity-law.pdf

New Zealand Law Commission (NZLC) (2022). He arotake i te ture mō ngā huarahi whakatau a ngā pakeke; Review of adult decision-making capacity law: Preliminary Issues Paper. Retrieved from: https://huarahi-whakatau.lawcom.govt.nz/wp-content/uploads/2022/11/LawCommission-ADC-PIP49-Standard.pdf

New Zealand Law Commission. (2024). He arotake i te ture mō ngā huarahi whakatau a ngā pakeke. Review of adult decision-making capacity law. Second Issues Paper. Retrieved from: https://www.lawcom.govt.nz/assets/Publications/IssuesPapers/NZLC-IP52.pdf

Nichols, E., Steinmetz, J. D., Vollset, S. E., Fukutaki, K., Chalek, J., Abd-Allah, F., . . . Vos, T. (2022). Estimation of the global prevalence of dementia in 2019 and forecasted prevalence in 2050: An analysis for the Global Burden of Disease Study 2019. *The Lancet Public Health, 7*(2), e105. https://doi.org/10.1016/S2468-2667(21)00249-8

O'Connor, D. (2010). Personhood and dementia: toward a relational framework for assessing decisional capacity. *The Journal of Mental Heath Training, Education and Practice vol5*(3). DOI: 10.5042/jmhtep.2010.0501

Office for Disability Issues (2014). Disability Action Plan 2014-2018: New Zealand's priorities to advance implementation of the United Nations Convention on the Rights of Persons with Disabilities and the New Zealand Disability Strategy. Retrieved from: https://www.odi.govt.nz/nz-disability-strategy/disability-action-plan/

Office for Disability Issues (2017). Summary of progress on improving disabled people's exercise of legal capacity. Retrieved from: https://www.odi.govt.nz/assets/Uploads/2017-08-24-Summary-progress-report-legal-capacity-PDF-issues3.pdf

Office for Disability Issues (2018). Actions for Implementation. Retrieved from: https://www.odi.govt.nz/nz-disability-strategy/disability-action-plan/actions-for-implementation/#ensure

Office for Disability Issues (2019). Disability Action Plan 2014-2018: Update 2015. Retrieved from: https://www.odi.govt.nz/nz-disability-strategy/disability-action-plan/disability-action-plan-2014-2018-update-2015/

Oregon Department of Human Services (n.d.) Supported Decision-Making**.** https://www.oregon.gov/odhs/supported-decision-making/Pages/default.aspx

Parliamentary Counsel Office. (1988). Protection of Personal and Property Rights Act 1988. Retrieved from: https://www.legislation.govt.nz/act/public/1988/0004/latest/whole.html?search=qs_act%40bill%40regulation%40deemedreg_property+protection_resel_25_h&p=1#DLM126576

Pathare, S., & Shields, L. S. (2012). Supported decision-making for persons with mental illness: A review. *Public Health Reviews*, *34*, 1-40. https://link.springer.com/article/10.1007/BF03391683

Penhale, B. (2014). Abuse, Safeguarding and Dementia. In *The law and ethics of dementia: Edited by Charles Foster, Jonathan Herring and Israel Doron*. Hart Publishing. Ebook retrieved from: https://portal-igpublish- com.ezproxy.aut.ac.nz/iglibrary/obj/HARTB0000958

Peterson, A., Karlawish, J., Largent, B. (2020). Supported decision making with people at the margins of autonomy. *The American Journal of Bioethics 21*(11) 4–18 https://doi.org/10.1080/15265161.2020.1863507

Pogach, D. (2020). Supported Decision-Making for Older Adults with Age-Related Cognitive Decline. *Journal of the American Society on Aging vol43* (4). Retrieved from: https://search-ebscohost-com.ezproxy.aut.ac.nz/login.aspx?direct=true&db=edsjsr&AN=edsjsr.26908298&site=eds-live

Reweti, A. (2023). Understanding how whānau-centred initiatives can improve Māori health in Aotearoa New Zealand. *Health Promotion International, vol. 38.* https://doi.org/10.1093/heapro/daad070

Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability (2023). Final Report. Retrieved from: https://disability.royalcommission.gov.au/publications/final-report

Ryman Healthcare (2024). myRyman Life. Our bespoke model of dementia care. https://www.rymanhealthcare.co.nz/living-and-care-options/myryman-life

Soken-Huberty, E., (n.d.). What is Human Dignity? Common Definitions. Retrieved from: https://www.humanrightscareers.com/issues/definitions-what-is-human-dignity/

Splaine, M. (2022). A demographic and community challenge: people living alone with dementia *in World Alzheimer Report 2022* (page 206-207). Alzheimer's Disease International.

Then, S., Bigby, C., (2024) Supported decision-making and the Disability Royal Commission, Research and Practice. *Intellectual and Developmental Disabilities, Vol11(*1), 86-106, DOI: 10.1080/23297018.2024.2330961

United Nations (2006). Convention on the Rights of Persons with Disabilities and Optional Protocol. Retrieved from: https://www.un.org/disabilities/documents/convention/convoptprot-e.pdf

United Nations Committee on the Rights of Persons with Disabilities, (2013). Implementation of the Convention on the Rights of Persons with Disabilities: Initial reports submitted by States parties under article 35 of the Convention: New Zealand. Retrieved from: https://digitallibrary.un.org/search?ln=en&cc=Committee+on+the+Rights+of+Persons+with+Disabilities&p=new+zealand&f=&action_search=Search&rm=&sf=&so=d&rg=50&c=Committee+on+the+Rights+of+Persons+with+Disabilities&c=&of=hb&fti=0&fti=0

United Nations Committee on the Rights of Persons with Disabilities, (2014). List of issues in relation to the initial report of New Zealand. Retrieved from: https://tbinternet.ohchr.org/_layouts/15/treatybodyexternal/Download.aspx?symbolno=CRPD%2FC%2FNZL%2FQ%2F1&Lang=en

United Nations Committee on the Rights of Persons with Disabilities, (2014(a)). Committee on the Rights of Persons with Disabilities. Twelfth session Summary record of the 143rd meeting. Retrieved from: https://digitallibrary.un.org/record/779783?ln=en

United Nations Committee on the Rights of Persons with Disabilities (2016) CRPD/C/3: Guidelines on periodic reporting to the Committee on the Rights of Persons with Disabilities, including under the simplified reporting procedure. United Nations. https://www.ohchr.org/en/treaty-bodies/crpd/reporting-guidelines

United Nations Committee on the Rights of Persons with Disabilities (2018). List of issues prior to submission of the combined 2nd and 3rd periodic reports of New Zealand : Committee on the Rights of Persons with Disabilities. Retrieved from: https://digitallibrary.un.org/record/1482028?ln=en&v=pdf

United Nations Committee on the Rights of Persons with Disabilities (2018(a)). Report of the Special Rapporteur on the rights of persons with disabilities. Retrieved from: https://documents.un.org/doc/undoc/gen/g17/360/32/pdf/g1736032.pdf

United Nations Committee on the Rights of Persons with Disabilities (2019). Combined second and third periodic reports submitted by New Zealand under article 35 of the Convention pursuant to the optional reporting procedure, due in 2019. Retrieved from: https://tbinternet.ohchr.org/_layouts/15/treatybodyexternal/Download.aspx?symbolno=CRPD%2FC%2FNZL%2F2-3&Lang=en

United Nations Committee on the Rights of Persons with Disabilities (2022). The New Zealand Government's additional report, 2019 – 2022, to the United Nations Committee on the Convention of the Rights of Persons with Disabilities (CRPD). Retrieved from: https://tbinternet.ohchr.org/_layouts/15/treatybodyexternal/Download.aspx?symbolno=INT%2FCRPD%2FAIS%2FNZL%2F48736&Lang=en

United Nations Committee on the Rights of Persons with Disabilities (2022(a)). Committee on the Rights of Persons with Disabilities Concluding observations on the combined second and third periodic reports of New Zealand. Retrieved from: https://tbinternet.ohchr.org/_layouts/15/treatybodyexternal/Download.aspx?symbolno=CRPD%2FC%2FNZL%2FCO%2F2-3&Lang=en

United Nations Committee on the Rights of Persons with Disabilities (n.d.). Digital Library. Committee on the Rights of Persons with Disabilities. https://digitallibrary.un.org/search?ln=en&cc=Committee+on+the+Rights+of+Persons+with+Disabilities&p=new+zealand&f=&action_search=Search&rm=&sf=&so=d&rg=50&c=Committee+on+the+Rights+of+Persons+with+Disabilities&c=&of=hb&fti=0&fti=0

United Nations (2024). Universal Periodic Review. https://www.ohchr.org/en/hr-bodies/upr/upr-home

United Nations (2024a). UN Declaration on the Rights of Indigenous Peoples. Retrieved from: https://www.ohchr.org/en/indigenous-peoples/un-declaration-rights-indigenous-peoples

Waitemata DHB (2017). Dementia Decision-making Journey. Retrieved from: https://www.waitematadhb.govt.nz/assets/Documents/health-professionals/DementiaDecisionMakingBookletFINALISED2014.pdf

World Health Organisation (WHO) (2015). Ensuring a Human Rights-Based Approach for People Living with Dementia. Geneva, Switzerland. Retrieved from: https://www.ohchr.org/sites/default/files/Documents/Issues/OlderPersons/Dementia/ThematicBrief.pdf

World Health Organization (WHO). (2021). Global Dementia Observatory. https://www.who.int/data/gho/data/themes/global-dementia-observatory-gdo

Wright, M.S. (2020). Dementia, Cognitive Transformation, and Supported Decision Making. *The American Journal of Bioethics vol20*(8). https://doi.org/10.1080/15265161.2020.1781959

Wright, M.S., (2021). Implementing Ethical and Legal Supported Decision Making: Some Unresolved Issues. *The American Journal of Bioethics vol21*(11). https://doi.org/10.1080/15265161.2021.1980150

Yuen-Sim, S., Higgins, S., McMillan, M. (2010). The essentials of Advance Care Planning for end-of-life care for older people. *Journal of Clinical Nursing vol19(*3-4). https://doi.org/10/111/j.1365-2702.2009.03001.x

Zhang, X., Yuen-Sim, S., Chan, S. (2021). Advance care planning for older people in mainland China: An integrative literature review. *International Journal of Older People Nursing Vol 16*(6). https://doi.org/10.111/opn.12409